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The misdiagnosis of epilepsy in people with intellectual disabilities: A systematic review

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ABSTRACT

Purpose: Epilepsy is common in people with intellectual disabilities. Epilepsy can be difficult to diagnose and may be misdiagnosed in around 25% of cases. A systematic review was conducted to explore:

(i) How common the misdiagnosis of epilepsy is amongst people with intellectual disabilities.
(ii) Reasons for misdiagnosis of epilepsy.
(iii) Implications of misdiagnosis.
(iv) Improving diagnosis.

Methods: Primary studies and systematic reviews published in the English language between 1998 and 2008 were identified from electronic databases, experts, the Internet, grey literature, and citation tracking. Included studies were critically appraised by team members using the appraisal tools produced by the Critical Appraisal Skills Programme (CASP) at the Public Health Resource Unit, Oxford.
Results: Eight studies were included in the review and critically appraised: six cohort studies and two case studies. Where data was provided in the cohort studies between 32% and 38% of people with intellectual disabilities were diagnosed as not having epilepsy or as having nonepileptic events. The main reason for misdiagnosis was the misinterpretation of behavioural, physiological, syndrome related, medication related or psychological events by parents, paid carers and health professionals.
Conclusions: Those working in epilepsy and intellectual disability services and families must be made more aware of the possibility of misdiagnosis. Future research is needed about the misdiagnosis of epilepsy amongst people with intellectual disabilities and carer knowledge.

1. Introduction

Epilepsy affects 0.5–1% of the British population and up to a quarter of people with epilepsy are believed to have intellectual disabilities.[1] Epilepsy is more common in people with intellectual disabilities than the general population and seems to increase with the severity of disability.[2] Prevalence rates rise from 15% in people with moderate intellectual disabilities to 30% in people with severe and profound intellectual disabilities.[1] In England, National Institute for Clinical Excellence (NICE) clinical guidelines state that diagnosis of epilepsy should be established by a specialist medical practitioner with training and expertise in epilepsy.[3] Diagnosis is based upon a detailed history and (where possible) eyewitness reports of events usually supplemented with EEG. Where diagnosis cannot be clearly established, further investigations (e.g., blood tests, sleep EEG, neuro-imaging and 12-lead ECG) and/or referral to a tertiary centre and cardiologist should be considered.[3]

It is difficult to diagnose epilepsy and epilepsy may be misdiagnosed in around 25% of cases.[3] Conditions such as syncope, paroxysmal disorders or conversion disorder may be misdiagnosed

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as epilepsy,[4] leading to potential over-diagnosis of epilepsy. Alternatively, the symptoms of epileptic seizures may be misdiagnosed as resulting from psychiatric or associated disorders, leading to potential under-diagnosis of epilepsy.[3] The adequacy of epilepsy service provision and resourcing may also have implications for diagnosis; e.g., the misdiagnosis or mistreatment for childhood epilepsy by a Paediatrician Consultant working at Leicester Royal Infirmary in the 1990s drew attention to the potential for misdiagnosis and raised a number of questions about the provision of epilepsy services in the United Kingdom.[5–8]

The misdiagnosis of epilepsy may lead to human costs such as distress to patients and carers, unnecessary lifestyle changes, social stigma, social and financial deprivation.[9,10] People may receive inappropriate treatment for a condition they do not have, whilst their true condition is not being treated. Seizure activity may continue when epilepsy is not diagnosed and treated and very occasionally, an incorrect diagnosis of epilepsy can result in death if a serious condition remains undiagnosed or untreated.[3] In addition, the misdiagnosis of epilepsy has economic costs, placing an unnecessary burden on the NHS.[3] Taking into account unnecessary treatment costs, the economic costs of lost work and payment of disability living allowance, the estimated annual cost of epilepsy misdiagnosis in England is around £189 million.[10]

The recently published 'Consensus guidelines in the management of epilepsy in adults with intellectual disability' identified both the misdiagnosis of non-epileptic events as epilepsy and the underdiagnosis of particular seizure types as particular problems in people with intellectual disabilities.[11] Two literature reviews suggest that people with intellectual disabilities are at additional risk of misdiagnosis for a number of reasons including stereotypical behaviours, drug induced involuntary body movement disorders such as tardive dyskinesia, communication difficulties, dependence on the observations of carers and difficulties gaining an EEG.[2,12]

The systematic literature review reported here was carried out because a group of intellectual disability and epilepsy health practitioners wanted up-to-date evidence about the misdiagnosis of epilepsy amongst people with intellectual disabilities. The review team consisted of health practitioners and commissioners working in epilepsy and intellectual disability services, researchers and health information specialists. The review aimed to examine evidence on the following questions:

(i) How common is the misdiagnosis of epilepsy amongst people with intellectual disabilities?
(ii) What are the reasons for misdiagnosis of epilepsy amongst people with intellectual disabilities?
(iii) What are the implications of misdiagnosis of epilepsy amongst people with intellectual disabilities?
(iv) How can the process of diagnosis be improved for people with intellectual disabilities?
(v) How can misdiagnosis of epilepsy with people with intellectual disabilities best be addressed?

2. Methods

2.1. Identification of studies

Relevant published and unpublished studies were identified by searching the following electronic databases: AMED, British Nursing Index (BNI), CINAHL, MEDLINE, EMBASE, HMIC, PsychInfo, Cochrane Library, and Social Care Online. In all cases the results were restricted to the previous 10 years (January 1998–August 2008). The following search terms were used as free text or subject headings as appropriate for each database: learning disabilities, intellectual disabilities, mental retardation, developmental disabilities, learning disorders, mental handicap, mentally disabled persons, mental deficiency, intellectual impairment, developmental disorder, epilepsy, misdiagnosis, underdiagnosis, overdiagnosis, incorrect diagnosis, missed diagnosis, diagnostic errors and seizure.

Key websites in epilepsy and intellectual disabilities were also searched to identify further published and unpublished work. Researchers and experts in the field were contacted via the Learning Disability Health Network, the Epilepsy Action Network and the Epilepsy Nurse Specialist Network. Further literature was sought through the citation trails from identified references.

Table 1 gives details of the inclusion and exclusion criteria for the review.

A total of 105 references were identified by the searching process. Titles and abstracts of all references found by the searches were screened to identify references which might be relevant to the review. Full text versions of potentially relevant articles and studies were examined by the group in order to determine whether they met the inclusion criteria. Two members of the review team decided independently whether each paper should be included and if there was any doubt about whether a paper should be included the paper was discussed by the group until consensus was reached. This resulted in eight publications being considered

Table 1
Inclusion and exclusion criteria for the review.

	Inclusion criteria	Exclusion criteria
Study design	Systematic review or primary research study (e.g., RCTs, case studies, observational studies, interviews, cohort studies, surveys, audits)	Discussion papers, opinion pieces, editorials, letters, and commentaries Systematic/literature review where included studies are outside the timeframe of this review
Publication type	International and British studies English language publications only Published between January 1998 and August 2008	
Population	People with intellectual disabilities (adults and children) who are misdiagnosed as having epilepsy, or where epilepsy is not diagnosed	People with intellectual disabilities form part of the sample but there is no separate analysis of data for people with intellectual disabilities
Study focus	The diagnosis or misdiagnosis of epilepsy: (1) Level of misdiagnosis (2) Reason for misdiagnosis (3) Implication of misdiagnosis (4) Improving diagnosis (5) Reducing diagnostic overshadowing (6) Addressing misdiagnosis	Studies on: (1) The cause of epilepsy (2) Prognosis (3) Management and treatment of epilepsy (4) Where a diagnosis of epilepsy has occurred, but there has been a misdiagnosis of the specific type of epilepsy (5) The association of epilepsy with problem behaviours (6) The diagnosis (or misdiagnosis) of a learning disability syndrome of which epilepsy is a symptom

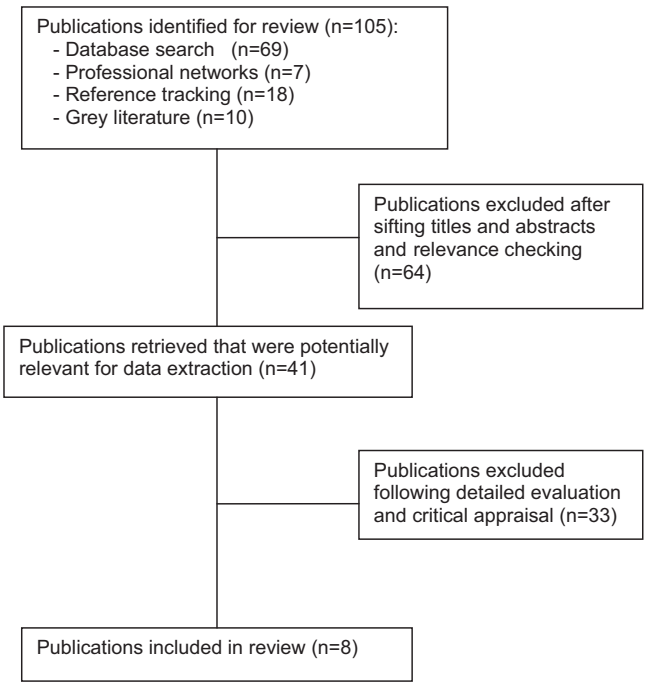

Fig. 1. Quality of reporting of meta-analyses (QUORUM) flow diagram.

relevant and included in the review. For full results of the screening process see the QUORUM flowchart in Fig. 1.[13]

2.2. Critical appraisal and data extraction

Each study which met the criteria for inclusion was allocated to two members of the review group for independent critical appraisal using tools produced and provided by CASP at the Public Health Resource Unit, Oxford.[14] Reviewers considered study population, methodology, data collection, findings and follow-up. The findings and any issues arising from the critical appraisal were discussed as a group.

3. Findings

3.1. Included studies

Of the eight published studies which were included in the review, six were cohort studies[15–20] and two were case studies.[21,22] The studies are summarised in Table 2. The majority of participants in the studies were children or adolescents with only one cohort study[15] and two case studies[21,22] focusing on adults.

3.2. How common is the misdiagnosis of epilepsy?

Table 3 summarises the key findings relating to the levels of epileptic and non-epileptic events recorded in the cohort studies. Between 15 and 43% of the cohorts with and without intellectual disabilities had non-epileptic events recorded.[16,17,20] It was difficult to determine whether levels of non-epileptic events recorded were higher in those with intellectual disabilities due to the lack of information on total numbers of those with intellectual disabilities in some studies. Where this information was provided, 32–38% of those with intellectual disabilities were diagnosed as not having epilepsy or having non epileptic events.[17,20] Behavioural events were more frequently diagnosed and psychogenic events less frequently diagnosed in children with intellectual disabilities.[20]

3.3. Reasons for misdiagnosis

Throughout the studies a common reason for misdiagnosis was the misinterpretation of epileptic or non-epileptic events by parents, paid carers and health professionals. Parents were often

Table 2
Studies included in the review.

Study	Country	Aims	Study type	Sample
Glaze et al.[18]	United States	To explore whether many events classified as syndromes in Rett Syndrome are paroxysmal non-epileptic events	Prospective cohort study	82 females with Rett Syndrome (aged 2–30 years; mean 7–8 years) (clinical stages II, III, and IV). 55 had a history of seizures and 43 were receiving anticonvulsants
Bye et al.[19]	Australia	To determine the frequency, nature and clinical characteristics of paroxysmal non-epileptic events (NEEs) in children referred to a tertiary clinic	Retrospective cohort study	666 children (aged 2 weeks to 17 years) referred by a neurologist or paediatrician to a tertiary centre for video-EEG diagnostic monitoring of paroxysmal events over a 10 year period (1988–1999)
Thirumalai et al.[20]	United States	To evaluate the usefulness of video-EEG in the evaluation of paroxysmal events of unclear etiology To identify differences in children with and without 'mental retardation' in the diagnosis of recorded seizures	Prospective cohort study	193 children, 70 (36%) of whom had 'mental retardation', referred to a University Medical Centre between 1990 and 1993 for video-EEG study to evaluate paroxysmal events of unclear etiology Children were aged under 18 (mean age 9.6 years, SD 5.7)
DeToledo et al.[15]	United States	To evaluate new seizure types identified by care staff	Cohort study	63 adults (aged 19–67) with 'multiple disabilities' and epilepsy living in an institution for whom there had been a request to evaluate 'new seizure types'
Kotagal et al.[16]	United States	To provide information on relative frequency of various types of paroxysmal non-epileptic events (PNEs) encountered in children and adolescents	Cohort study	134 children and adolescents with PNEs (aged 2 months–18 years) identified from 883 who underwent video-EEG monitoring in a Paediatric Epilepsy Monitoring Unit between January 1989 and December 1995
Somjit et al.[21]	Australia	Not stated. To describe example of a man who had Sandifer Syndrome but was misdiagnosed with epilepsy	Case study	27 year old man with mild-moderate intellectual disability
Uldall et al.[17]	Denmark	To determine the proportion of children admitted to a tertiary epilepsy centre with difficult to treat paroxysmal events who did not have epilepsy	Observational retrospective cohort study	223 children admitted to a tertiary epilepsy centre in 1997. Median age was 8 years and 6 months (range 8 months–17 years and 8 months)
John[22]	United Kingdom	To critically analyse a clinical incident To discuss and identify training needs of learning disability nurses	Case study Discussion with nurses	Young man who had recently moved to adult services and his family in the United Kingdom Learning disability team colleagues

Table 3
Levels of epileptic and non-epileptic events recorded in cohort studies.

Study	Total sample	Subsample with intellectual disabilities
Bye et al.[19]	40% had epileptic events recorded 18% had no events recorded 43% had non-epileptic events recorded	43% of those with non-epileptic events recorded were 'developmentally delayed', and 25% were 'neurologically impaired'
Thirumalai et al.[20]	33% diagnosed as epileptic 26% diagnosed as non-epileptic 3% diagnosed as epileptic and non-epileptic 38% no diagnosis 3 children without intellectual disabilities had behavioural events diagnosed 25 children without intellectual disabilities had psychogenic events diagnosed	39% diagnosed as epileptic 32% diagnosed as non-epileptic 7% epileptic and non-epileptic 23% no diagnosis 17 children with intellectual disabilities had behavioural events diagnosed 2 children with intellectual disabilities had psychogenic events diagnosed
Kotagal et al.[16]	15% of children and adolescents monitored had paroxysmal non-epileptic events	11% of children with paroxysmal non-epileptic events had developmental delay 5% had developmental delay and epilepsy
Uldall et al.[17]	39% did not have epilepsy 30% of those referred with no doubts about diagnosis had diagnosis disproved 47% of those presenting for the first time discharged with diagnosis of non-epileptic seizures	38% of those with intellectual disabilities were diagnosed as not having epilepsy

confused by non-epileptic events such as complex self stimulatory tics[19] and behaviours (e.g., a young man going quiet, turning his head to one side, and counting to himself repeatedly whilst tapping his leg with his hand), even when a person may not appear confused or disorientated.[22] Non-epileptic events were incorrectly reported as being epileptic seizures by 82% of parents of females with Rett Syndrome reporting an event. However, other parents did not recognise events associated with discharges as being epileptic: whilst 13 females with Rett Syndrome had EEG seizure discharges associated with a clinical event, only 5 parents identified these as an epileptic seizure.[18]

In a sample of adults with multiple disabilities and a diagnosis of epilepsy, 94% of new seizure types reported by staff working in an institution were non-epileptic events. The 6% of new seizure types which were confirmed as epileptic occurred where staff had identified the clinical progression of existing seizures, probably due to medication change. Reasons suggested for the incorrect diagnosis by care staff included poor training and communication and lack of continuity and consistency of staff.[15]

Table 4
Events which have the potential to be misinterpreted as epileptic events.

Behavioural[a]
Stereotypic repeated blinking or swallowing[15]
Self stimulatory tics or behaviours[15,19,20,22]
Spontaneous smiling or grimacing, laughing episodes[15,20]
Staring spells[16,17,19,20]
Inattention, unresponsiveness, going quiet, apparent psychomotor arrest[15,16,21,22]
Simulation of convulsions[15]
Physiological[a]
Head and/or eye turning[21,22]
Buccolingual movements[15]
Hypnic jerks[16]
Dystonic and tonic posturing, stiffening of limbs[15,20]
Ataxia with falls[15]
Syndrome related[a]
Behaviours, motor abnormalities or EEG abnormalities associated with Rett Syndrome (e.g., breath-holding, abnormal hand movements, and unresponsiveness)[18,20]
Symptoms of Sandifer Syndrome[16,21]
Medication related
Personality changes due to reduction of antiepileptic medication[15]
Decreased daytime alertness because of side effects of antiepileptic medication or disturbed sleep[15]
Psychological
Conversion disorder[16]

[a] Some events could be in more than one category (e.g., head turning and stereotypic blinking could be behavioural or physiological).

Hospital staff may be unaware of symptoms of relatively rare syndromes such as Sandifer Syndrome and misdiagnose these as epilepsy, especially if occurring in adults with intellectual disabilities.[21] Community learning disability team staff may have little awareness of the subject of differential diagnosis and common disorders that could be mistaken for seizures, and different levels of knowledge of non-epileptic events and diagnostic tests. They generally accepted information given by families and were unlikely to challenge a diagnosis.[22]

Table 4 summarises non-epileptic events which have the potential to be mistaken for epileptic events identified within the studies. On clinical grounds alone it can be difficult to distinguish epileptic events from normal phenomena that appear in a person's repertoire of behaviours or physiological or syndrome-related occurrences. Whilst the signs described in Table 4 could be features of a seizure they may indicate events requiring further investigation to determine whether they are epileptic or not.

3.4. The implications of misdiagnosis

The studies demonstrate that people may receive the incorrect treatment due to misdiagnosis. If non-epileptic events are misdiagnosed as epileptic events people may be prescribed unnecessary antiepileptic medication. 48% of those with Rett Syndrome whose seizures were not associated with EEG seizure discharges were receiving antiepileptic medication.[18] In one study 35% of patients with paroxysmal non-epileptic events had been started on antiepileptic medications unnecessarily[16]; in another study 35 of the 87 children without epilepsy had been treated with antiepileptic medications at admission and a further 22% had been treated with antiepileptic medications which had been tapered off prior to admission.[17]

Conversely, if a diagnosis of epilepsy is missed people may not be prescribed antiepileptic medication which might control epileptic events; 30% of the females with Rett Syndrome with recorded EEG seizure discharges were not receiving antiepileptic medications.[18] Finally, other health conditions, such as Sandifer Syndrome, may not be correctly treated if misdiagnosed as epilepsy.[21]

4. Discussion

This review had a number of strengths. It was carried out by a multidisciplinary team whose members brought a range of skills and knowledge to the review. Many aspects of the review process

were robust; e.g., a wide range of databases were searched and decisions about inclusion/exclusion and critical appraisal were carried out by two or more team members to help ensure quality and avoid bias. However, few studies were identified and those included were not as focused on the review questions as the team initially expected. The majority of study participants were children, therefore the findings may not be applicable to adults with intellectual disabilities. Most of the cohort studies were carried out in the United States, with one study in Australia and one in Denmark; there are no large scale studies to determine the size of the issue in other countries.

The review findings have to be interpreted bearing in mind a number of methodological concerns relating to the studies. It is not clear how generalisable the case studies' findings are.[21,22] Many cohort studies provided incomplete data about the number of people with intellectual disabilities included in the sample and/or the number diagnosed with epileptic events. Different terminologies relating to intellectual disabilities were used (e.g., 'developmental delay', 'mental retardation', 'multiple disabilities' and 'neurological impairment') and the criteria for defining these categories were rarely described. It is therefore difficult to draw conclusions from studies and make comparisons across studies.

The levels of non-epileptic events found in some studies may be affected by referral or selection bias. People are more likely to be referred for monitoring if there is uncertainty over the appropriate diagnosis, leading to overestimation of the true level of non-epileptic events in the wider population. Common events such as syncope and breath-holding spells are likely to be under-represented within inpatient studies, leading to underestimation of events. Most papers do not describe whether people were referred by specialist intellectual disability services; if not, people with intellectual disabilities may be under-represented in samples.

There are a number of ways in which the method of collecting information or making the diagnosis may have led to further potential for bias. Generally, in the cohort studies the diagnosis was made by only one person.[19,20] EEG monitoring was not always carried out for all participants[17] or of consistent quality[18]; therefore, it is not possible in these cases to determine whether events were associated with epileptic discharges or not. There are also issues about whether monitoring was long enough to detect epileptic events and the lack of long term follow up in the majority of studies adds to this concern.[15,16–19]

However, the studies do indicate high levels of non-epileptic events which have the potential to be misdiagnosed as epileptic events in people with and without intellectual disabilities. The studies also show that the occurrence of seizures may be both over-estimated and under-recognised. People may experience a combination of epileptic and non-epileptic events and in some cases it may not be possible to reach a diagnosis. The knowledge of family members, support workers and a range of health staff also affects whether events are correctly diagnosed as epileptic or not.

These issues are not unique to people with intellectual disabilities. However, the findings do suggest that people with intellectual disabilities are likely to face additional barriers to receiving an accurate diagnosis. The review corroborates earlier findings that cognitive, behavioural, affective, communication and motor problems and side effects of medication experienced by people with intellectual disabilities may be misinterpreted as epileptic events.[2,12,24–31] Other studies have found that diagnosis of epilepsy may be complicated by communication barriers and the consequent dependence on paid and family carers to provide a history.[12,19,32] A recent study found that people with intellectual disabilities and psychogenic non-epileptic seizures were markedly more likely than those without intellectual disabilities to have documented past episodes of prolonged or repeated non-epileptic seizures that were misidentified or treated as epilepsy in hospital. The authors suggested that an increased readiness by hospital doctors to diagnose epilepsy in patients with intellectual disabilities or the response of carers to psychogenic non-epileptic events might explain this.[23]

In line with NICE guidelines all people presenting with a first seizure should be assessed by clinicians with expertise in epilepsy because of potential high rates of diagnostic inaccuracy.[3] Non-epileptic events should be considered as a matter of course, particularly in people with intellectual disabilities. However, a recent study found that only about half of epilepsy diagnoses for people with intellectual disabilities had been made by a seizure expert and that in parts of England less than half of people with a diagnosis of epilepsy and intellectual disabilities may have had EEG investigations and even fewer brain imaging.[33] Whilst it has been suggested that it may be more difficult to get EEG readings for people with intellectual disabilities,[34] this review indicates that video-EEG monitoring is valuable in reaching correct diagnosis, particularly with people with intellectual disabilities, and that short-term monitoring may be sufficient to classify frequent events.[15,20]

It is worrying that in the case studies misdiagnoses were only detected by chance: e.g., someone having an event whilst an intellectual disability team nurse visited,[22] and because paediatric members of an epilepsy team had experience of Sandifer Syndrome.[21] Learning disability team members may not question a diagnosis or may be unwilling to challenge an existing diagnosis of epilepsy.[22] Given the potential for misdiagnosis, it is important to review the diagnoses of epilepsy amongst adults with intellectual disabilities, and better education of GPs, primary care staff and learning disability team members is needed on the potential for misdiagnosis and the importance of reviewing diagnosis within annual reviews. Awareness-raising is also needed amongst hospital staff, direct care workers, and family members.

The review highlighted a clear lack of research focusing on the diagnosis and misdiagnosis of epilepsy amongst people with intellectual disabilities. Whilst cohort studies have been carried out in the United Kingdom on the diagnosis and misdiagnosis of epilepsy,[35,36] they do not include details of the number of people with intellectual disabilities. Conversely, recent studies focusing on epilepsy and people with intellectual disabilities have not investigated the potential level of misdiagnosis.[33,34] Whilst the review shows that misdiagnosis may lead to inappropriate treatment and medication, the included studies did not explore the wider implications of misdiagnosis on the lives of people with epilepsy and carers (e.g., lifestyle, social and financial impacts).

Future research could usefully explore the diagnosis and potential levels of misdiagnosis of epilepsy amongst children and adults with intellectual disabilities; the impact of reviewing epilepsy diagnoses with people with intellectual disabilities; means of improving staff and family knowledge of epilepsy and the diagnosis and management of epilepsy; and the attitudes and experiences of people with intellectual disabilities who have a diagnosis of epilepsy and their families.

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References

1. Lhatoo SD, Sander JWAS. The epidemiology of epilepsy and learning disability. *Epilepsia* 2001;**42**(s1):6–9.
2. Bowley C, Kerr M. Epilepsy and intellectual disability: a review. *Journal of Intellectual Disability Research* 2000;**44**:529–43.
3. Stokes T, Shaw EJ, Juarez-Garcia A, Camosso-Stefinovic J, Baker R. *Clinical guidelines and evidence review for the epilepsies: diagnosis and management in adults and children in primary and secondary care*. London: Royal College of General Practitioners; 2004.
4. Zaidi A, Fitzpatrick AP. Misdiagnosis of convulsive syncope as epilepsy. *Cardiovascular Reviews & Reports* 2000;**21**:359–64.
5. Follis R. Seven up for Leicester epilepsy settlement. *irwinmitchell* http://www.irwinmitchell.com/PressOffice/PressReleases/epilepsy-misdiagnosis.htm; 2006 [accessed 27.07.06].
6. Chadwick D, Smith D. The misdiagnosis of epilepsy. *British Medical Journal* 2002;**324**:495–6.
7. White C. Doctor referred to GMC after inquiry into epilepsy diagnoses. *British Medical Journal* 2001;**323**:1323.
8. Morton R, Appleton RE. Misdiagnosis of epilepsy. *British Medical Journal* 2002;**324**:1219.
9. Smith D, Defalla BA, Chadwick DW. The misdiagnosis of epilepsy and the management of refractory epilepsy in a specialist clinic. *Quarterly Journal of Medicine* 1999;**92**:15–23.
10. All-Party Parliamentary Group on Epilepsy. *The human and economic cost of epilepsy in England: wasted money, wasted lives*. London: APPG on Epilepsy; 2007.
11. Kerr M, Scheepers M, Arvio M, Beavis J, Brandt C, Brown S, et al. Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *Journal of Intellectual Disability Research* 2009;**53**:687–94.
12. Alvarez N, Besag F, Iivanainen M. Use of antiepileptic drugs in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998;**42**(S1):1–15.
13. Moher D, Cook DJ, Eastwood S, Olkin I, Rennie D, Stroup DF, et al. Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement. *The Lancet* 1999;**354**:1896–900.
14. CASP at the Public Health Resource Unit. *Appraisal tools*. Oxford: Public Health Resource Unit; 2007.
15. DeToledo JC, Lowe MR, Haddad H. Behaviors mimicking seizures in institutionalized individuals with multiple disabilities and epilepsy: a video-EEG study. *Epilepsy & Behavior* 2002;**3**:242–4.
16. Kotagal P, Costa M, Wyllie E, Wolgamuth B. Paroxysmal nonepileptic events in children and adolescents. *Pediatrics* 2002;**110**:e46.
17. Uldall P, Alving J, Hansen LK, Kibaek M, Buchholt J. The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events. *Archives of Disease in Childhood* 2006;**91**:219–21.
18. Glaze DG, Schultz RJ, Frost JD. Rett syndrome: characterization of seizures versus non-seizures. *Electroencephalography and Clinical Neurophysiology* 1998;**106**:79–83.
19. Bye AME, Kok DJM, Ferenschild FTJ, Vles JSH. Paroxysmal non-epileptic events in children: a retrospective study over a period of 10 years. *Journal of Paediatrics and Child Health* 2000;**36**:244–8.
20. Thirumalai S, Abou-Khalil B, Fakhoury T, Suresh G. Video-EEG in the diagnosis of paroxysmal events in children with mental retardation and in children with normal intelligence. *Developmental Medicine & Child Neurology* 2001;**43**:731–4.
21. Somjit S, Lee Y, Berkovic SF, Harvey AS. Sandifer syndrome misdiagnosed as refractory partial seizures in an adult: video case report. *Epileptic Disorders* 2004;**6**:49–50.
22. John K. *Differential diagnosis in epilepsy*. Leeds: Leeds Metropolitan University; 2008.
23. Duncan R, Oto M. Psychogenic nonepileptic seizures in patients with learning disability: comparison with patients with no learning disability. *Epilepsy & Behavior* 2008;**12**:183–6.
24. Paul A. Epilepsy or stereotypy? Diagnostic issues in learning disabilities. *Seizure* 1997;**6**:111–20.
25. Kaufman ME, Levitt H. A study of three stereotyped behaviors in institutionalized mental defectives. *American Journal of Mental Deficiency* 1965;**69**:467–73.
26. Berkson G, Davenport Jr RK. Stereotyped movements of mental defectives. I. Initial survey. *American Journal of Mental Deficiency* 1962;**66**:849–52.
27. Holmes GL, McKeever M, Russman BS. Abnormal behavior or epilepsy? Use of long-term EEG and video monitoring with severely to profoundly mentally retarded patients with seizures. *American Journal of Mental Deficiency* 1983;**87**:456–8.
28. Branford D. A study of the prescribing for people with learning disabilities living in the community and in National Health Service Care. *Journal of Intellectual Disability Research* 1994;**38**:577–86.
29. Clarke DJ, Kelley S, Thinn K, Corbett JA. Psychotropic drugs and mental retardation: 1. Disabilities and the prescription of drugs for behaviour and for epilepsy in three residential settings. *Journal of Mental Deficiency Research* 1990;**34**:385–95.
30. Jacobson J. Problem behaviour and psychiatric impairment with a developmentally disabled population. III: psychotropic medication. *Research in Developmental Disabilities* 1988;**9**:23–38.
31. Aman M, Singh N. Pharmacological intervention. In: Matson J, Mulick J, editors. *Handbook of mental retardation*. Oxford: Pergamon Press; 1983. p. 317–37.
32. Jenkins LK, Brown SW. Some issues in the assessment of epilepsy occurring in the context of learning disability in adults. *Seizure* 1992;**1**:49–55.
33. Reuber M, Gore J, Wolstenhome J, Jonas P, Frankson C, Murray C, et al. Examining a community model of epilepsy care for people with learning disabilities. *Seizure* 2008;**17**:84–91.
34. Ring H, Zia A, Bateman N, Williams E, Lindeman S, Himlok K. How is epilepsy treated in people with a learning disability? A retrospective observational study of 183 individuals. *Seizure* 2009;**18**:264–8.
35. Angus-Leppan H. Diagnosing epilepsy in neurology clinics: a prospective study. *Seizure* 2008;**17**:431–6.
36. Leach JP, Lauder R, Nicolson A, Smith DF. Epilepsy in the UK: misdiagnosis, mistreatment, and undertreatment? The Wrexham area epilepsy project. *Seizure* 2005;**14**:514–20.