



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

Melanie Chapman^{a,*}, Pam Iddon^b, Kathy Atkinson^c, Colin Brodie^{c,1}, Duncan Mitchell^d, Garry Parvin^e, Steve Willis^f

^a Manchester Learning Disability Partnership, Quality Research & Service Development Team, Mauldeth House, Mauldeth Road West, Manchester M21 7RL, United Kingdom

^b NHS Manchester, Specialist Nurses in Commissioning Team, Primary Care Commissioning, Ground Floor, Parkway 3, Parkway Business Centre, Princess Road, Manchester M14 7LU, United Kingdom

^c NHS Manchester, NHS Manchester Library, Mauldeth House, Mauldeth Road West, Manchester M21 7RL, United Kingdom

^d Manchester Metropolitan University, Elizabeth Gaskell Campus, Hathersage Road, Manchester M13 0JA, United Kingdom

^e Joint Commissioning Team: Learning Disability Services, Fenham, 5 Moorfield Road, West Didsbury, Manchester M21 8UA, United Kingdom

^f Manchester Learning Disability Partnership, South Community Learning Disability Team, Oakwood Resource Centre, 177 Longley Lane, Manchester M22 4HY, United Kingdom

ARTICLE INFO

Article history:

Received 10 September 2009

Received in revised form 5 October 2010

Accepted 25 October 2010

Keywords:

Intellectual disabilities

Learning disabilities

Epilepsy

Diagnosis

Misdiagnosis

Systematic review

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.

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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

* Corresponding author. Tel.: +44 0 161 958 4166; fax: +44 0 161 958 4149.

E-mail addresses: melanie.chapman@manchester.gov.uk (M. Chapman), pamela.iddon@manchester.nhs.uk (P. Iddon), kathy.atkinson@manchester.nhs.uk (K. Atkinson), Colin.Brodie@westminster-pct.nhs.uk (C. Brodie), D.Mitchell@mmu.ac.uk (D. Mitchell), garry.parvin@manchester.gov.uk (G. Parvin), steve.willis@manchester.gov.uk (S. Willis).

¹ Present address: Public Health Information & Resource Unit (PHIRU), NHS Westminster, 3rd Floor, 15 Marylebone Road, London NW1 5JD, United Kingdom.

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 under-diagnosis 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
Publication type	International and British studies English language publications only Published between January 1998 and August 2008	Systematic/literature review where included studies are outside the timeframe of this review
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

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