# Epilepsy and challenging behaviour in adults with intellectual disability: a systematic review

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## Author note

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## Key Words

Challenging Behaviour, Epilepsy, Intellectual Disability, Learning Disability, Aggression, Self-Injurious Behaviour

**Abstract**

*Background* Epilepsy and challenging behaviour are both highly prevalent in the intellectual disability population and it is thus crucial to understand any possible associations between the two.

*Method* PsycINFO, MEDLINE, Embase, CINAHL and Web of Science were searched for quantitative data about epilepsy and any forms of challenging behaviour in adults with intellectual disability.

*Results* A total of 25 articles were included in the review. Overall the evidence suggests that while epilepsy is not a good explanatory variable for presence of challenging behaviour, the relationship is complex. A link between certain types of challenging behaviour and seizure types may exist.

*Conclusions* Given the possible link between epilepsy related factors such as seizure type and specific subgroups of challenging behaviour, investigating these relationships further and particularly exploring how to best measure challenging behaviour in people with epilepsy could be of great clinical benefit.

# Introduction

## Challenging Behaviour

Challenging Behaviour is a significant problem in people with intellectual disabilities (ID) and their carers or family. Challenging behaviour refers to a range of behaviours from mannerisms or rituals to sexually inappropriate behaviour or physical aggression towards self, other people or objects (Banks, Bush, & Baker, 2007). Such behaviour may threaten not only the quality of life but also potentially the safety of the person with challenging behaviour and others. Challenging behaviour can have serious consequences such as the individual being excluded or subjected to restrictive practices (Banks et al., 2007). There is a reported prevalence ranging from 10-15% for any type of challenging behaviour in people with ID (Emerson et al., 2001) to 45% for destructive or aggressive behaviour and 82% for stereotypical or self-injurious behaviour in people with multiple disabilities and profound ID (Poppes, Van der Putten, & Vlaskamp, 2010). Male gender, level of ID, communication difficulties and autism are associated with various forms of challenging behaviour (McClintock, Hall, & Oliver, 2003).

## Epilepsy

Epilepsy is the most common serious neurological condition and it can have a direct impact on life expectancy, cognitive ability and general physical health for individuals (Bowley & Kerr, 2000). A recent meta-analysis reported a 0.58% lifetime prevalence of epilepsy in the general population in developed high-income countries (Bell, Neligan, & Sander, 2014). However, in people with ID, the prevalence of epilepsy is reported to be much higher with a pooled estimate, which included data from 38 studies, being reported as 22.2%, with higher rates in people with severe ID (Robertson, Hatton, Emerson, & Baines, 2015).

Not surprisingly, the question of whether epilepsy is a possible marker for challenging behaviour has been explored over the years. There have only been two systematic reviews

to date exploring the relationship between challenging behaviour and epilepsy. De Winter, Jansen, and Evenhuis (2011) investigated the relationship between physical health conditions (including epilepsy) and challenging behaviour, and van Ool et al. (2016) examined the relationship between challenging behaviour and neuropsychiatric comorbidities in epilepsy and ID. However De Winter et al. (2011) reported on only one study which focussed on a subtype of challenging behaviour (Mendez, Doss, & Taylor, 1993), while van Ool et al. (2016) included two studies focusing on adults with ID, which examined challenging behaviour subtypes (McGrother et al., 2006; Tyrer et al., 2006) as well as two considering the impact of epilepsy related factors on ID (Andrews, Everitt, & Sander, 1999; C. Espie et al., 2003). The present systematic review provides an update and includes all relevant studies that have considered whether specific subtypes of challenging behaviour are associated with epilepsy and whether there are certain aspects of epilepsy, e.g. seizure type or severity, which are related to challenging behaviour. The purpose of this review is thus to provide a comprehensive and nuanced picture of epilepsy and challenging behaviour in ID in order to inform clinical practice and future research.

## Objective

The aim of this systematic review is to determine whether there is evidence for an association between epilepsy (including epilepsy related factors) and challenging behaviour and its different subtypes. Therefore, we examined the available evidence regarding the following questions:

- Is there an association between presence of epilepsy and presence or severity of challenging behaviour?
- Is there an association between presence of epilepsy and presence or severity of subtypes of challenging behaviour?
- Is there an association between epilepsy related factors and presence or severity of challenging behaviour or subtypes of challenging behaviour?

## Methods

### Literature search strategy

PsycINFO, MEDLINE, Embase, CINAHL and Web of Science were searched combining terms for ID, epilepsy and all common forms of challenging behaviour as outlined in Table 1. Where indicated, Medical Subject Heading (MEsH) terms or the respective equivalents for the listed databases were used. The search was carried out in January 2015 with a further top up search in August 2016. No language restrictions were applied and foreign language papers that were identified were screened by a native speaker.

To ensure sensitivity in identifying all relevant studies, MeSH terms or equivalents were exploded. The bibliographies of key studies were hand-searched to identify any papers which may have been missed by the initial search of the electronic databases.

*TABLE 1*

### Study selection criteria

We considered studies for inclusion if they were reporting primary research; were published between January 1985 and August 2016; had a minimum sample size of five participants; focussed on adults with any level of ID; and used quantitative methods.

Papers were excluded if they only reported results combining data of adults and children (i.e. younger than 18 years old) or if they included both people with and without ID where less than 50% of the sample had ID.

### Methods of the review

The initial literature search identified 2420 papers following the removal of duplicates; the top up search returned a further 226. Studies were selected using the strategy outlined in a flow diagram in Fig. 1.

FIGURE 1

The principal review author (JB) initially screened all titles and abstracts of identified articles to exclude any studies, which were clearly not relevant. The remaining 82 references were screened independently by two reviewers (J.B. and A.A.). Following this, the manuscripts of 41 studies were independently assessed for eligibility by the reviewers. Discrepancies were resolved by discussion and consensus was reached for all studies. Seventeen articles were excluded at this stage. One reviewer (J.B.) then extracted data on the study design; participants, including demographic and clinical characteristics; how ID and epilepsy were evaluated; outcome, i.e. challenging behaviour type and how it was measured.

The Scottish Intercollegiate Guidelines Network's SIGN-50 Methodology checklist tools (2008) were used to assess quality and risk of bias of the included studies. SIGN-50 allocates a level of evidence (LE) of 2++ for high quality case control studies with low risk of bias and high probability of causal relationship, 2+ for well conducted studies with low risk of bias and moderate probability of causality and 2- for case control or cohort studies with a high risk of confounding, bias and risk of non-causal relationship. Both checklist tools for case-control and cohort studies were used as appropriate. As SIGN-50 does not provide a tool for cross-sectional studies, in line with previous reviews (De Winter et al., 2011; van Ool et al., 2016) these were considered using the cohort study checklist and allocated LE2 unless they did not carry out a statistical analysis in which case they scored LE3 which marks non-analytic studies according to the SIGN criteria. The majority of identified studies scored as having a low LE according to SIGN-50. However due to the paucity of studies that have investigated our research questions, low LE studies will be considered in our results and discussion. The five studies we assessed to be well-conducted and of low risk of bias (Andrews et al., 1999; C. Espie et al., 2003; Matthews, Weston, Baxter, Felce, & Kerr, 2008; McGrother et al., 2006; Tyrer et al., 2006) are marked with * in the results tables for ease of identification. Both quality and bias are considered in the discussion of our results.

## Results

Twenty-five studies were included and allocated according to which of our three research questions they addressed. Study particulars, assessment of exposure and outcome and statistical results are presented in three corresponding tables (see tables 3-5).

### Is there an association between presence of epilepsy and presence or severity of challenging behaviour?

For epilepsy and presence/severity of challenging behaviour, eleven studies were identified (see table 3), with a total of 5,653 participants, including 2,032 participants with epilepsy. The studies were published between 1985 and 2008. Nine studies were based in the UK, while the remaining two were carried out in the US (Matson, Bamburg, Mayville, & Khan, 1999) and Denmark (Lund, 1985) respectively. Only two of the included studies (Matthews et al., 2008; McGrother et al., 2006) were assessed as providing a satisfactory LE.

Four studies investigated the prevalence or rate of challenging behaviour within their study population. The studies focused on samples based on an ID register (Lund, 1985), social services records (Deb, Thomas, & Bright, 2001) an inpatient population (Turkistani, 2004) and a community ID team (Pawar & Akuffo, 2008). Only two of the studies (Deb et al., 2001; Lund, 1985) used validated outcome measures while the remaining studies relied on case notes. While Lund (1985) reported significantly higher prevalence of challenging behaviour, Turkistani (2004) and Deb et al. (2001) found no significant differences in overall rates of challenging behaviour between their groups of participants with epilepsy (EP) and those without (NEP). Pawar and Akuffo (2008) reported descriptive statistics only, with a lower percentage of participants with epilepsy recorded as having challenging behaviour than control group participants.

Overall levels of challenging behaviour were reported by five studies (Deb & Hunter, 1991; C. Espie et al., 2003; C. A. Espie, Pashley, Bonham, Sourindhrin, & O'Donovan, 1989;

Matson et al., 1999; Matthews et al., 2008). Reporting levels of challenging behaviour measured by the Aberrant Behaviour Checklist (ABC), neither the satisfactory LE study (Matthews et al., 2008) nor Deb and Hunter (1991) reported a significant difference in overall challenging behaviour scores between EP and NEP. Similarly (C. A. Espie et al., 1989) did not find EP and NEP to differ on the prevalence of overall challenging behaviour using the Adaptive Behaviour Scale (ABS). In a study with no NEP control group, C. Espie et al. (2003) reported challenging behaviour scores within their epilepsy sample which were consistently lower than ID population norms, while the remaining study (Matson et al., 1999) actually found significantly higher overall challenging behaviour in the NEP group in a residential sample of participants with mostly profound ID.

Finally differences in rates of severe or frequent challenging behaviour were investigated by five studies (Deb, 1997; Deb & Hunter, 1991; Deb et al., 2001; Matthews et al., 2008; McGrother et al., 2006).The two high LE studies reported conflicting results. One found no significant difference in severe challenging behaviour, defined as overall ABC scores of 45+ (Matthews et al., 2008), which was also reflected in two studies by (1997); Deb and Hunter (1991) reporting only non-significantly higher rates of severe challenging behaviour as measured by the Profile of Abilities and Adjustment Schedule (PAAS). Conversely, the other high LE study did find significantly more severe and frequent challenging behaviour as measured by the Disability Assessment Schedule (DAS) within their EP group (McGrother et al., 2006), a finding also observed by Deb et al. (2001) using the same outcome measure.

TABLE 3

**Is there an association between presence of epilepsy and prevalence or severity of challenging behaviour subtypes?**

**Self-Injurious Behaviour (SIB)**

Eight of the included studies investigated the association between epilepsy and SIB (Collacott, Cooper, Branford, & McGrother, 1998; S. A. Cooper, Smiley, Allan, et al., 2009; Deb et al., 2001; C. A. Espie et al., 1989; Fitzgerald, Matson, & Barker, 2011; Lundqvist, 2013; McGrother et al., 2006; Smith & Matson, 2010a). The well-conducted low-bias study (McGrother et al., 2006) found no association between epilepsy and SIB following adjustment for age, sex and level of understanding and this finding was echoed in virtually all included papers. The only study finding a significant association (C. A. Espie et al., 1989), in fact saw EP scoring significantly lower on SIB than their NEP control group.

**Aggressive/Destructive Behaviour (ADB)**

ADB was explored by seven studies, including two with low risk of bias (McGrother et al., 2006; Tyrer et al., 2006). No significant difference in presence, frequency or severity of ADP was found (S. A. Cooper, Smiley, Jackson, et al., 2009; Creaby, Warner, Jamil, & Jawad, 1993; Deb et al., 2001; Lundqvist, 2013; McGrother et al., 2006; Smith & Matson, 2010a; Tyrer et al., 2006), however, Creaby et al. (1993) further analysed different types of ADP as reported by carers and in case notes and while no overall difference on frequency of ADP was found, they did observe EP to be significantly more likely to show unprovoked aggression, and aggression directed against objects.

**Stereotyped Behaviour (SB)**

Only four of the included studies investigated SB. While EP initially appeared more likely to exhibit SB, this did not remain significant following adjustment for other factors (Lundqvist, 2013). This finding is consistent with that of the remaining three studies (Chung & Cassidy, 2001; Fitzgerald et al., 2011; Smith & Matson, 2010a) which also found no such association.

**Other Reported Behaviour Problems**

Six studies considered other behaviour problems.

EP were found to be significantly more irritable than NEP, but no difference was found for lethargy, hyperactivity or inappropriate speech (Chung & Cassidy, 2001).

One study (Smith & Matson, 2010b) which employed a case-control design between four groups: EP; Autism Spectrum Disorder (ASD); combined epilepsy and ASD; and control, found no difference between the EP and ID control group in their outcomes. However, they found significantly higher scores in the combined epilepsy and ASD group for Irritability/Behavioural Excess and Attention/Hyperactivity. Another study (Smith & Matson, 2010a) employing the same cohort and study design found that challenging behaviour scores did not differ between the EP and control groups for SB, SIB or ADB. Epilepsy contributed significantly more to disruptive behaviour ratings than ASD within their combined EP and ASD group.

McGrother et al. (2006), using the DAS showed epilepsy to have a significant association with disturbing others at night, being uncooperative and seeking attention.

C. A. Espie et al. (1989) also reported EP to have significantly more 'inappropriate interpersonal manners' as recorded by the ABS than NEP.

Finally Deb et al. (2001) found no association between epilepsy and 'temper tantrums'.

TABLE 4

**Is there an association between epilepsy related factors and prevalence or severity of challenging behaviour or challenging behaviour subtypes?**

**Active vs. Controlled Epilepsy**

One study found that having seizures within the past year was associated with being less co-operative and exhibiting more echolalia compared with participants with greater seizure control (Deb & Hunter, 1991). Reporting descriptive statistics only (Ring, Zia, Lindeman, & Himlok, 2007), SIB, based on case notes and clinician reports, was reported to have occurred at comparable rates in participants with and without seizures over the past three months.

### Seizure Frequency

Five studies considered seizure frequency as a potential marker for challenging behaviour. While no association between overall challenging behaviour (Deb & Joyce, 1999; C. Espie et al., 2003; Turkistani, 2004), ADP (Creaby et al., 1993) or aggressive behaviour (Mendez et al., 1993) and seizure frequency was seen, inappropriate speech (Chung & Cassidy, 2001), anti-social behaviour and social dysfunction (C. A. Espie et al., 1989) were correlated.

SIB, was shown to be significantly higher in community EP experiencing frequent seizures (Deb & Hunter, 1991), though a further study with a higher potential for bias found no differences in seizure frequency between individuals with and without SIB (Collacott et al., 1998).

### Seizure Type

In a well-conducted study, C. Espie et al. (2003) found seizure type was not a strong explanatory variable for challenging behaviour, with general disability factors such as level of intellectual, sensory or motor disability being more closely associated. Conversely one study reported that experiencing generalised tonic-clonic seizures was related to higher rates of challenging behaviour (Deb & Joyce, 1999). Another high quality study also found more hyperactivity/non-compliance in generalised versus localised-related epilepsy (Andrews et al., 1999).

Two studies considered seizure type in participants with ADB with conflicting results, one did not find an association with aggressive behaviour (Mendez et al., 1993), while the other found EP with ADB to be significantly more likely to have generalised seizures than EP without ADB (Creaby et al., 1993).

Finally, Chung and Cassidy (2001) found an association between inappropriate speech and experiencing simple partial seizures.

### Seizure Severity

One included study (C. Espie et al., 2003) explored seizure severity, which was measured with the Epilepsy Quality of Life scale sub-scales. They found that general disability factors provided a better marker for challenging behaviour scores than seizure severity in their sample.

### EEG and Imaging

No difference in type of EEG focus was found between aggressive and non-aggressive participants (Mendez et al., 1993). However, inpatients with generalised epileptiform activity exhibited significantly more irritability and temper tantrums (Deb & Hunter, 1991) than matched NEP participants.

Those without focal lesions on MRI showed significantly more hyperactivity/non-compliance (Andrews et al., 1999).

### Other Epilepsy Related Factors

No difference in age of epilepsy onset was discovered between aggressive and non-aggressive participants (Mendez et al., 1993), while significantly more ADP, SIB and irritability was reported for those with a more recent epilepsy onset (duration<20 years) (Deb & Hunter, 1991).

A history of febrile convulsions was found to be significantly associated with irritability, agitation and crying (Andrews et al., 1999).

TABLE 5

# Discussion

## Discussion of results

Our included studies were rated as LE 2+, which indicates well-conducted studies with low risk of bias or lower, i.e. were of poorer quality with a significant risk of bias. We found a few studies with a rating of LE 2+ but most were of poorer quality with a significant risk of bias.

The evidence suggests that variables other than epilepsy better explain the presence or rate of severity of challenging behaviour mirroring the findings of two earlier reviews (De Winter et al., 2011; van Ool et al., 2016). However, when considering the broader scope applied in this review, it appears that there is still conflicting evidence about epilepsy and challenging behaviour in individuals with ID.

Four, including two relatively robust studies, report conflicting results about whether there is a significant association between severe/frequent challenging behaviour and the presence of epilepsy. Interestingly all studies which did observe such an association used the DAS to evaluate challenging behaviour rather than the perhaps most popular measure, the ABC.

There is very limited evidence that some specific subtypes of challenging behaviour may be associated with epilepsy, but no relationship between SIB, ADB, SB and epilepsy was found in this review. Again all but one study Chung and Cassidy (2001) which reported a significant association for any subtype of challenging behaviour did not utilise the ABC.

A high seizure frequency appeared to be associated with SIB (Deb & Hunter, 1991) and other challenging behaviour subtypes (Chung & Cassidy, 2001; C. A. Espie et al., 1989). Active epilepsy, i.e. having seizures within the past year, a factor only explored by one methodologically satisfactory study, was also potentially indicative of specific challenging behaviour subtypes when compared to people with greater seizure control. This highlights the importance of achieving optimum seizure control. There is limited evidence that

generalised seizures may be related to higher rates of challenging behaviour (Andrews et al., 1999; Creaby et al., 1993; Deb & Hunter, 1991). It is important to note where epilepsy subgroups were studied, the sample size was often small and thus caution needs to be applied in interpreting the results. There is a definite case for future research focusing on a large, representative epilepsy population to further investigate these findings.

Due to the heterogeneity of both epilepsy and challenging behaviour, it is difficult to establish how epilepsy related factors may affect challenging behaviour. Individuals may experience very different ictal and post-ictal effects. For example, high seizure frequency could mean frequent focal seizures for one individual. This could perhaps be accompanied by automatisms or agitated behaviour which may be reported as challenging behaviour. Other individuals with epilepsy may experience daily tonic-clonic seizures, resulting in fatigue, potentially reducing challenging behaviour or could causing distress or confusion with resulting behaviour potentially misinterpreted as evidence of challenging behaviour. Such diverse effects may to some extent explain why the ABC, a robust instrument to measure challenging behaviour, may not detect differences which may be observed anecdotally in clinical practice.

Both epilepsy and ID may share common aetiological factors and processes, which, without careful observation and history-taking, may pose difficulties in distinguishing between challenging behaviours and post-ictal behaviours especially in people with severe ID who may be non-verbal. This again may provide a source of bias for many of the available studies due to reliance on proxy reports of observations and interpretations of behaviour.

**Strengths and limitations of the review**

While the review was conducted in a systematic way, the review methodology could potentially have been improved by having both reviewers complete the initial screen and data extraction. No language restrictions were applied to the search and one foreign

language paper was identified, the full text screened and ultimately excluded. Further non-English articles may have been missed as all search terms were common English/American terminology and non-English papers may have utilised different keywords. The review could have been further enhanced by including a 'grey literature' search to identify conference reports and PhD theses. Nonetheless, as the strategy employed was very comprehensive, overall it is unlikely that any key research has been missed. Finally, the variety of instruments used to measure challenging behaviour between studies added to the heterogeneity of the finding and precluded a meta-analysis.

**Conclusions**

This review highlights that while no clear and consistent relationship between epilepsy and overall rates of challenging behaviour were found, there is an argument for the need for further research in specific sub-groups. Considering how to best measure challenging behaviour to capture the complexities of epilepsy, e.g. ictal and post-ictal effects on behaviour or medication side effects is crucial to allow for true associations to emerge. Such an approach is also likely to impact clinical practice in terms of improved ascertainment of seizures and challenging behaviour and therefore, better and targeted management.

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# Appendix

## Excluded papers and reasons

Table 2 **Excluded papers and reasons**

| | |
|---|---|
| York and Kerr (2014) | Small sample size (n=3). |
| Turygin, Matson, and Adams (2014) | Data reported focuses on psychiatric disorder with no separate data for challenging behaviour |
| Crocker, Prokić, Morin, and Reyes (2014) | Data reported is for 'neurological conditions'. No separate data for epilepsy. |
| Buono et al. (2012) | Data presented includes children. No separate data for adults. |
| Piazzini et al. (2012) | Data presented includes both people with and without ID. |
| Arshad et al. (2011) | Data reported focuses on psychiatric disorder with no separate data for CB. |
| Poppes et al. (2010) | Data presented includes children. No separate data for adults. |
| Hove and Havik (2010) | Data reported groups Epilepsy and Cerebral Palsy. No separate data available for epilepsy only. |
| S.-A. Cooper, Smiley, Morrison, Williamson, and Allan (2007) | Data reported only for 'mental ill-health of any type'. No separate analysis available for challenging behaviour. |
| Emerson et al. (2001) | Data presented includes children. No separate data for adults. |
| Bogdanovic, Mead, and Duncan (2000) | Data presented includes both people with and without ID. |
| O'Dwyer and Friedman (1995) | Primary focus is on menstruation. |
| Steinert (1994) | Data presented includes both people with and without ID and includes children. |
| Davidson, Cain, Sloane-Reeves, and Van Speybroech (1994) | Data presented includes children. No separate data for adults. |
| Walshe et al. (1993) | Data presented includes children. No separate data for adults. |
| Gedye (1989a) | Description of case studies only. |
| Gedye (1989b) | Description of case studies only. |

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# Tables and Figures

Table 1 **Search Terms**

| Epilepsy Terms | ID Terms | CB Terms |
|---|---|---|
| Epilepsy (MeSH) | Learning Disorder (MeSH) | Aggression (MeSH) |
| Seizure (MeSH) | Intellectual Disability (MeSH) | Self-injurious behaviour (MeSH) |
| Epilep* | Learning Disab* | Psychopathology (MeSH) |
| Seizure* | Learning Difficult* | Challeng* Behavio* |
| | Learning Disorder* | Complex Behavio* |
| | Intellectual* Disab* | Problem* Behavio* |
| | Intellectual* Impair* | Disrupt* Behavio* |
| | Mental* Disab* | Self-stimula* Behavio* |
| | Mental* Deficien* | Stereotyp* |
| | Mental* Handicap* | Self Injur* |
| | Retard* | Anger |
| | | Aggress* |
| | | Violen* |

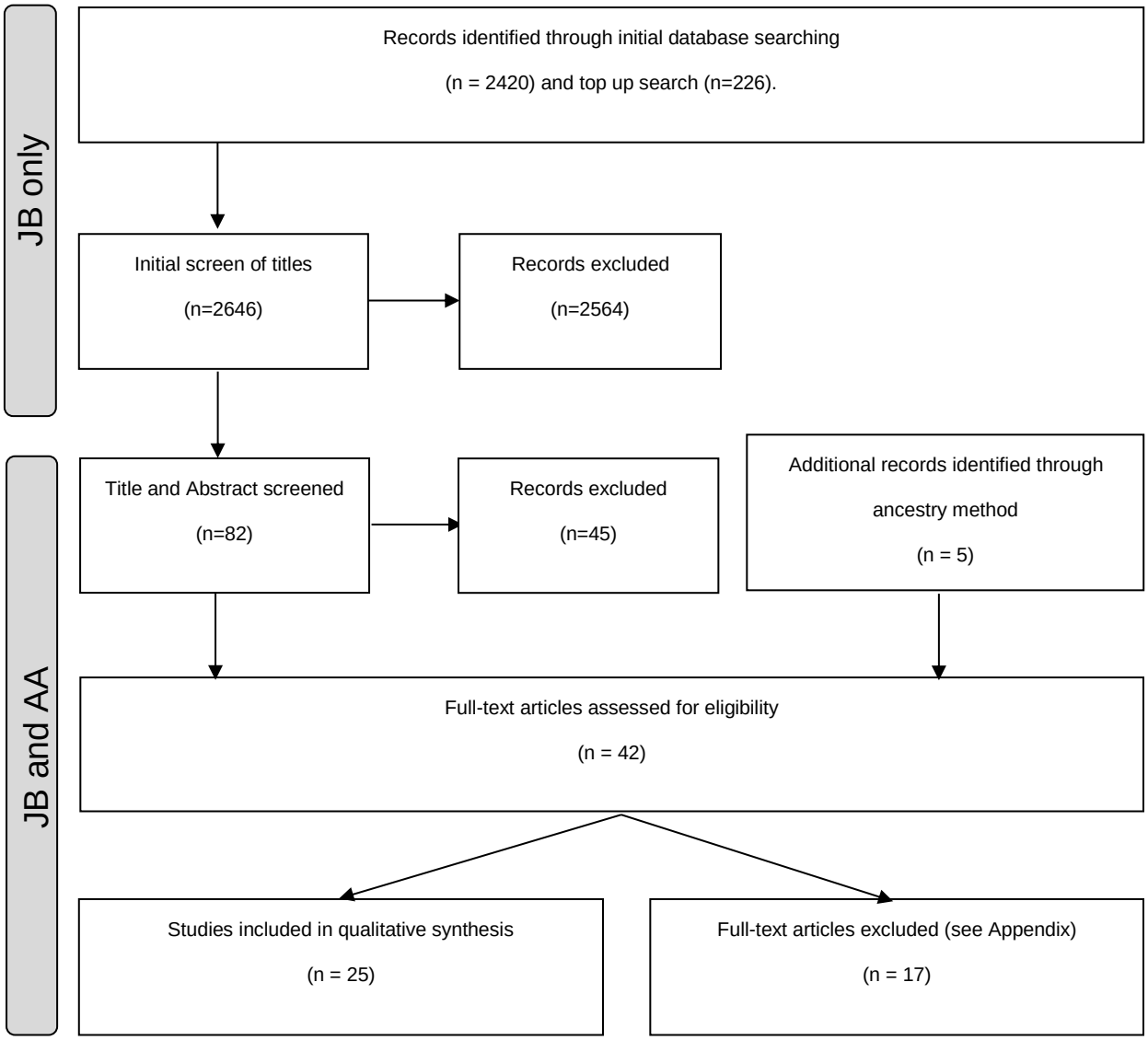
JB only
Records identified through initial database searching
(n = 2420) and top up search (n=226).
Initial screen of titles
(n=2646)
Records excluded
(n=2564)
JB and AA
Title and Abstract screened
(n=82)
Records excluded
(n=45)
Additional records identified through
ancestry method
(n = 5)
Full-text articles assessed for eligibility
(n = 42)
Studies included in qualitative synthesis
(n = 25)
Full-text articles excluded (see Appendix)
(n = 17)

Figure 1

## Table 3: Epilepsy and presence or severity of CB

EP = People with Epilepsy, NEP = People who do not have epilepsy

| Study, Country, Design | Sample | ID Level/ ID Identification | Epilepsy Criteria/ Epilepsy Identification | CB Outcome Measure | Analysis and Results |
|---|---|---|---|---|---|
| * Matthews et al. (2008)<br>UK (Wales)<br>Case-control study | Primary Care records; n=318 (EP n=55, NEP n=55); age 17-86 | Not reported/ Not specified | None/ Epilepsy research nurse, Neuropsychiatrist | Aberrant Behaviour Checklist | Mann-Whitney U.<br>No significant difference overall CB and in severe CB (Aberrant Behaviour Checklist scores 45+) between EP and NEP. |
| Pawar and Akuffo (2008)<br>UK (England)<br>Cross-sectional | Community ID Team; n=177 (EP n=53), age 17+ | Mild-severe and unspecified/ Medical records | None/ Case notes | Case notes | Descriptive statistics only.<br>70% of NEP and 59% of EP were recorded as having any kind of CB. |
| * McGrother et al. (2006)<br>UK (England)<br>Population-based prevalence study | Leicestershire ID Register; n=2993 (EP n=620); age 20+ | Moderate - profound/ Disability Assessment Schedule – estimate based on Developmental Quotient | None/ Carer report: has epilepsy, has seizures or takes medication to prevent seizures | Disability Assessment Schedule | Multivariate logistic regression.<br>EP significantly more likely to have 'severe or frequent behaviour problems' (OR=1.6; p=<0.0001). |
| Turkistani (2004)<br>UK (England)<br>Cross-sectional | ID inpatient service; n=240 (EP n=108); 'adult and elderly', mean age EP 40.3, NEP 43.5 | All/ Case notes | Seizure in last two yrevents/ Case notes | Case notes | Chi-square.<br>No significant difference in 'behavioural disturbance' found between EP and NEP. |

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| | C. Espie et al. (2003)<br>UK (Scotland)<br>Cross-sectional | Hospital-based epilepsy clinics, community ID teams, specialist teams for people with ID and epilepsy; EP n=186; age 18-60 | All/ Vineland Adaptive Behaviour Scale used to estimate level of ID in conjunction with medical and psychometric records | 1+ seizure per month on average/ Epilepsy confirmed by clinical history, seizure diaries, seizure classification by epileptologist based on descriptions of seizure presentation | Aberrant Behaviour Checklist | No control group within sample.<br>CB scores of study population consistently lower than ID population norms (by 0.5 SD on Aberrant Behaviour Checklist). |
| | Deb et al. (2001)<br>UK (Wales)<br>Cross-sectional | Population-based, i.e. known to Social Services ; n=101 (EP n=25); age 16-64 | Mild-severe/ Carer and patient report | None/ Carer and patient report | Disability Assessment Schedule, Psychiatrist | Chi-square.<br>Epilepsy significantly associated with 'severe behavioural disorders' ($X^2$= 4.83, p=0.02). No association with overall rate of CB. |
| | Matson et al. (1999)<br>USA<br>Case-control | Residential; n=706 (EP n=353); adults, mean age EP 37.85 ±14.15, NEP 41.19 ±11.18 | All (mostly profound)/ Case notes, diagnosis based on DSM-IV criteria | None/ Epilepsy diagnosed by neurologist | Aberrant Behaviour Checklist | ANOVA.<br>NEP had significantly higher CB scores than EP (*F*=19.1; p=<0.001). |
| | Deb (1997)<br>UK<br>Case–control | Institutions and community; n= 300 (EP n=150); age 20-77 | Mild to severe/ 'defined and classified according to ICD-9 | 3+ seizures in last two years or treated with AEDs/ Seizure classification according to International Classification of | Profile of Abilities and Adjustment Schedule | Wilcoxon.<br>Non-significantly higher rate of 'severe' CB in EP than NEP. |

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| | | | | Epileptic Seizures based on eye witness accounts | | |
| | Deb and Hunter (1991)<br>UK<br>Case–control | Inpatient and community; n= 300 (EP n=150); age 20-77 | Mild-Severe/ Case notes, diagnosis by psychologist using WAIS, WAIS-R, Raven's progressive matrices, Peabody Picture Vocabulary Test or Vineland Social Maturity Scale | 3+ seizures in last two years or currently treated with AEDs/ Seizure classification based on eye witness accounts; 'behaviour checklist during seizure', EEG in past 12 months or for study | Profile of Abilities and Adjustment Schedule | Wilcoxon.<br>No significant difference in CB scores between EP and NEP. Non-significantly more severe CB in EP than NEP. |
| | C. A. Espie et al. (1989)<br>UK<br>Case–control | Inpatient; n=30 (EP n=15); age 20-46 | All/ None described | Seizure in last year, current AED treatment/ 'Independent physician with expertise in epilepsy' | Adaptive Behaviour Scale, Psychosocial Behaviour Scale | Wilcoxon.<br>No significant difference in overall CB between EP and NEP. |
| | Lund (1985)<br>Denmark<br>Cross-sectional | ID Register; n=302 (EP n=55); age 20+ | All/ WHO ICD 8 criteria | None/ Case notes, EEGs, carer and medical personnel reports according to ILAE criteria | Medical Research Council schedule of Handicaps, Behaviour and Skills | Chi-square.<br>Significantly higher prevalence of 'behaviour disorder' in EP than in NEP (p=<0.05). |

## Table 4: Epilepsy and prevalence or severity of CB subtypes

EP = People with Epilepsy, NEP = People who do not have epilepsy, SIB = Self-Injurious Behaviour, SB = Stereotyped Behaviour, ADB = Aggressive/Destructive Behaviour

| Study, Country, Design | Sample | ID Level/ ID Identification | Epilepsy Criteria/ Epilepsy Identification | CB Outcome Measure | Analysis and Results |
|---|---|---|---|---|---|
| Lundqvist (2013)<br>Sweden<br>Cross-sectional | Community day centres and sheltered accommodation; n=915 (EP n=124); age 18-87 | All/ Carer report | None/ Carer report | Behaviour Problems Inventory | Univariate and multivariate logistic regression.<br>EP more likely to exhibit SB (OR=1.50; p<0.05) and SIB (OR=2.05; p<0.001) than NEP. Neither remained significant when influences of other variables were controlled for in multivariate analysis. There was also no significant difference in ADP between the groups. |
| Fitzgerald et al. (2011)<br>United States<br>Cross-sectional | Two developmental centres, n=321 (EP n=115), age 20-88 | Profound and severe/ Case notes | None/ Not specified | Diagnostic Assessment for the Severely Handicapped – 2nd Ed. | MANCOVA, ANCOVA.<br>No significant difference in SB and SIB between EP and NEP. |
| Smith and Matson (2010b)<br>United States<br>Case-control | Residential, n=100 (EP n=25, ASD n=25, ASD and EP n=25, control = 25); age 29-72 | Profound (n=96) and unspecified ID (n=4)/ Diagnosis by psychologist based on DSM-IV-TR criteria | Seizure in last two years/ Epilepsy diagnosed by neurologist based on ILAE criteria | Autism Spectrum Disorder Comorbidity Adult Version Battery | MANOVA, ANOVA.<br>EP, ASD only, EP and ASD and control group comparisons. No statistical significance between EP and control group for any subscales, but significant differences between the combined EP and ASD group compared the control group for 'Irritability/ Behavioural Excess' (p=<0.01) and' Attention/ Hyperactivity '(p<0.01) subscales. |

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| Smith and Matson (2010a)<br>United States<br>Case-control | See Smith and Matson, 2010a. | | | Autism Spectrum Disorders Behaviour Problem Adult Version Battery | MANOVA, ANOVA.<br>EP, ASD only, EP and ASD and control group comparisons. No statistical significance between EP and control group for any subscales (SB, SIB and ADB), but 'epilepsy contributed more to disruptive behaviour ratings than ASD'. |
| S. A. Cooper, Smiley, Allan, et al. (2009)<br>UK (Scotland)<br>Cohort | GP and social services, specialist ID health services record; n=1023 (EP n=349); age 16+ | All/ Medical and psychology case notes, where not available C21st Health Check and Vineland Scale | None/ Not specified | C21st Health Check screen, psychiatrist administered PAS-ADD checklist and Present Psychiatric State for Adults with Learning Disabilities schedule | Univariate and multivariate logistic regression.<br>Initial univariate analysis showed a possible association (p=0.009), but epilepsy did not remain associated with SIB at the second stage of analysis. |
| S. A. Cooper, Smiley, Jackson, et al. (2009)<br>UK (Scotland)<br>Cohort | See Cooper et al., 2009a. | | | | Univariate and multivariate logistic regression.<br>Epilepsy was not associated with ADP. |
| * McGrother et al. (2006)<br>UK (England)<br>Population-based prevalence study | Leicestershire ID Register; n=2993 (EP n=620); age 20+ | Moderate - profound/ Disability Assessment Schedule – estimate based on Developmental Quotient | None/ Carer report: has epilepsy, has seizures or takes medication to prevent seizures | Disability Assessment Schedule | Univariate and multivariate logistic regression.<br>CB subgroups of ADB and SIB were non-significant following adjustment. Attention seeking (OR=1.65; p=<0.0001), being uncooperative (OR=1.60; p=<0.0001) and disturbing others at night (OR=1.85; |

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| | | | | | p=<0.0001) remained significantly associated with epilepsy. |
| * Tyrer et al. (2006)<br>UK (England)<br>Cross-sectional | Leicestershire ID Register; n=3065 (EP n=812); age 19-92 | All/ Disability Assessment Schedule – estimate based on Developmental Quotient | None/ Carer report: 'has epilepsy, has seizures (once per month), takes AEDs' | Disability Assessment Schedule | Univariate and multivariate logistic regression.<br>Epilepsy associated with aggression (OR=1.55; p = 0.001) in univariate analysis, but did not remain significant in multivariate analysis. |
| Chung and Cassidy (2001)<br>UK (England) Case-control | Residential; EP n=14, NEP n=14); age 21+ | Not reported/ Not specified | None/ Six year profile of epilepsy from medical records | Aberrant Behaviour Checklist | T-test.<br>EP significantly more irritable than NEP (t=2.99; p<0.01). No differences between EP and NEP in lethargy, SB, hyperactivity or inappropriate speech. |
| Deb et al. (2001)<br>UK (Wales)<br>Cross-sectional | Population-based, i.e. known to Social Services; n=101 (EP n=25); age 16-64 | Mild-severe/ Carer and patient report | None/ Carer and patient report | Disability Assessment Schedule, Psychiatrist | Epilepsy was not associated with overall rates of SIB, physical aggression or temper tantrums. |
| Collacott et al. (1998)<br>UK (England)<br>Cross-sectional | Leicestershire ID Register; n=2277 (EP n=not reported); age 20+ | All/ Not specified | None/ Not specified | Disability Assessment Schedule | Chi-square and Mann-Whitney U.<br>No comparison between EP and NEP. No difference in prevalence of epilepsy between SIB and no SIB. |
| Creaby et al. (1993)<br>Ireland<br>Case-control | Residential; 230 (EP no ADB n=82, EP with ADB n=49, NEP with | Severe-profound/ Not specified | None/ Medical and nursing case notes, carer report | Medical and nursing case notes, carer report | Chi-Square test.<br>EP and NEP with ADB did not differ significantly on frequency of ADB. EP significantly more likely to show 'unprovoked aggression' ($X^2$=6.52; p=0.038), |

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| | ADB n=99); mean age 37.7, 38.8 and 40.3 respectively | | | | and aggression directed against objects ($X^2$=4.27; p=0.039). |
| C. A. Espie et al. (1989) UK Case–control | Inpatient; n=30 (EP n=15); age 20-46 | All/ None described | Seizure in last year, current AED treatment/ 'Independent physician with expertise in epilepsy' | Adaptive Behaviour Scale , Psychosocial Behaviour Scale | Wilcoxon. EP had significantly more 'inappropriate interpersonal manners' (Z=-2.29; p = 0.011) than NEP, but scored significantly lower on SIB (Z=-2.49; p = 0.006) than controls. |

**Table 5: Epilepsy related factors and prevalence or severity of CB or CB subtypes**

EP = People with Epilepsy, NEP = People who do not have epilepsy, SIB = Self-Injurious Behaviour, SB = Stereotyped Behaviour, ADB = Aggressive/Destructive Behaviour

| Study, Country, Design | Sample | ID Level/ ID Identification | Epilepsy Criteria/ Epilepsy Identification | CB Outcome Measure | Analysis and Results |
|---|---|---|---|---|---|
| Ring et al. (2007)<br>UK (England)<br>Cross-sectional | Community ID Team; EP n=175; age 16-72 | All/ ID team records reporting Wechsler Adult Intelligence Scale | None/ Case notes, clinician reports, EEG and imaging data; seizure frequency determined by carer report | Case notes checked against clinician reports | Descriptive statistics only.<br>SIB and CB occurred 'at similar rates' in EP who experienced seizures in the past three months and those who had been seizure free. |
| Turkistani (2004)<br>UK (England)<br>Cross-sectional | ID inpatient service; n=240 (EP n=108); 'adult and elderly', mean age EP 40.3, NEP 43.5 | All/ Case notes | Seizure in last two years/ Case notes | Case notes | Chi-square.<br>No significant difference in 'behavioural disturbance' between individuals with frequent (>1/mth) and infrequent (<1/mth) seizures. |
| * C. Espie et al. (2003)<br>UK (Scotland)<br>Cross-sectional | Hospital-based epilepsy clinics, community ID teams, specialist teams for people with ID and | All/ Vineland Adaptive Behaviour Scale used to estimate level of ID in conjunction with medical and psychometric records | 1+ seizure per month on average/ Epilepsy confirmed by clinical history, seizure diaries, seizure classification by epileptologist based on | Aberrant Behaviour Checklist | Bivariate analysis, logistic and linear regression.<br>General disability factors provide a better explanation for CB scores than epilepsy phenomena, i.e. seizure severity, seizure frequency, seizure type. |

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| | epilepsy; EP n=186; age 18-60 | | descriptions of seizure presentation | | |
| Chung and Cassidy (2001) UK (England) Case-control | Residential; EP n=14, NEP n=14); age 21+ | Not reported/ Not specified | None/ Six year profile of epilepsy from medical records | Aberrant Behaviour Checklist | Pearson correlation coefficient. Inappropriate speech correlated with simple partial seizures (r=0.5121; p=<0.025) and frequency of epilepsy (r=0.6524; p<0.002). |
| * Andrews et al. (1999) UK (England) Cross-sectional | Residential; EP n=255 ; age 18-93 | All/ Neuropsychological evaluation and clinical notes | Resident at specialist epilepsy centre, admitting those with 'severe' epilepsy/ Case notes, incl. previous EEG and CT | Aberrant Behaviour Checklist | Mann Whitney U. Significantly more hyperactivity/non-compliance in generalised versus localised-related epilepsy (p<0.05) and on MRI in those without focal lesions (Z=-2.18, p=0.29). Irritability, agitation and crying significantly associated with a history of febrile convulsions in EP (Z=2.49, p=0.013). |
| Collacott et al. (1998) UK (England) Cross-sectional | Leicestershire ID Register; n=2277 (EP n=not reported); age 20+ | All/ Not specified | None/ Not specified | Disability Assessment Schedule | Chi-square and Mann-Whitney U. No difference in seizure frequency (1+ per month, occasionally, none) between SIB and no SIB. |
| Deb and Joyce (1999) UK (Wales) Cross-sectional | Community ID Services, specialist hospital clinics, inpatient services; EP n=143; age 20-83 | Mild-Severe/ Case notes, observer information and direct examination | None/ Diagnosis and seizure classification based on clinical history and EEG according to International | Purpose-designed questionnaire | Chi-square. Tonic-clonic seizures were significantly associated with rate of CB ($X^2$=5.9; p = 0.01). No significant difference in level of CB associated with any other seizure type or seizure frequency. |

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| | | | Classification of Epileptic Seizures | | |
| Creaby et al. (1993)<br>Ireland<br>Case-control | Residential; 230 (EP no ADB n=82, EP with ADB n=49, NEP with ADB n=99); mean age 37.7, 38.8 and 40.3 respectively | Severe-profound/ Not specified | None/ Medical and nursing case notes, carer report | Medical and nursing case notes, carer report | Chi-Square test.<br>No significant difference in seizure frequency between EP with ADB and EP with no ADB. EP with ADB were significantly more likely to have generalised seizures than EP with no ADB ($X^2$=4.74; p = 0.029). |
| Mendez et al. (1993)<br>USA<br>Case–control | University-affiliated neurology clinic; EP n=132 (ADP n=44, no ADP n=88); adults | Mild-Moderate/ Psychological and psychometric records | None/ Neurologist assessed seizure variables | Referred for psychiatric evaluation due to violent behaviour, Overt Aggression Scale | McNemar $x^2$ and paired t-test.<br>Comparison between 'violent' and 'non-violent' participants. No association found between groups for age of epilepsy onset, frequency of seizures, seizure type or EEG focus. |
| * Deb and Hunter (1991)<br>UK<br>Case–control | Inpatient and community; n= 300 (EP n=150); age 20-77 | Mild-Severe/ Case notes, diagnosis by psychologist using WAIS, WAIS-R, Raven's progressive matrices, Peabody Picture Vocabulary Test or Vineland Social Maturity Scale | 3+ seizures in last two years or currently treated with AEDs/ Seizure classification based on eye witness accounts; 'behaviour checklist during seizure', EEG in past 12 months or for study | Profile of Abilities and Adjustment Schedule | Wilcoxon.<br>Active EP (seizures in past 12mths) were significantly less cooperative (Z=-2.21; p = 0.027) and displayed significantly more echolalia (Z=-2.36p = 0.018). Inpatient EP with EEG showing generalised epileptiform activity showed significantly more irritability (Z=-2.42; p = 0.016) and temper tantrums (Z=-2.47; p = 0.013) than matched NEP. Community EP had significantly more SIB in those experiencing |

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| | | | | | multiple and more frequent seizures (>1/mth) as well as significantly more ADP, SIB and irritability in those with an epilepsy duration of <20 years (no p values specified). |
| C. A. Espie et al. (1989)<br>UK<br>Case–control | Inpatient; n=30 (EP n=15); age 20-46 | All/ None described | Seizure in last year, current AED treatment/ 'Independent physician with expertise in epilepsy' | Adaptive Behaviour Scale , Psychosocial Behaviour Scale | ANCOVA.<br>Significantly more 'Antisocial behaviour' (F=3.38; p=0.045) and 'Social adaption/dysfunction' (F=5.87, p=0.016) in EP with frequent seizures (12+ seizures per year) than in EP with infrequent seizures (<12 seizures per year).<br>EP with frequent seizures had non-significantly higher 'Physical Aggression', 'Passivity/dominance' and 'Attention seeking'. |