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Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications

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Summary

Statement of the problem: The prevalence of epilepsy in people with an intellectual disability (ID) is apparently higher than in the general population. The outlook for individuals with both epilepsy and ID depends on the presence of any associated conditions. However, there have been few epidemiological studies of the prevalence of epilepsy and associated problems within a representative adult ID population to inform the development of policy.
Method: This was a population-based prevalence study using the Leicestershire Learning Disability Register. Prevalence was estimated from the number of individuals with reported epilepsy identified from structured home interviews with carers. Associations with epilepsy were investigated for a range of defined physical, mental and skill attributes. Logistic regression was done with and without adjustment for age, sex and level of understanding to identify specific and holistic links respectively.
Results: The prevalence of epilepsy was 26%. Among those with epilepsy, 68% experienced seizures despite anti-epileptic medication. Epilepsy showed a significant association with low levels of understanding. Specific morbid associations included wetting (adjusted odds ratio 2.7), soiling (2.2), walking (2.5), daily living skills (1.6), poor speech (2.2), lack of empathy (1.5), mood swings (1.5), being uncooperative (1.6), seeking attention (1.7) and disturbing others at night (1.9). Holistic associations included a wider range of physical and mental problems and global skills deficits.

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Conclusions: The high prevalence, associated morbidities and global skills deficits make epilepsy care for adults with ID important and complex. Specialist epilepsy services for this population need a multidisciplinary skills mix.

Introduction

The prevalence of epilepsy in people with an intellectual disability (ID) appears to be much higher than in the general population.[1–11] However, most of the previous studies have been confined to children with ID and cannot be generalised to adults with ID because of potential developments in later life. Community-based studies of epilepsy in adults with ID show a prevalence of 16–26%.[1,5,10,11] A review of existing studies highlighted the methodological problems, particularly case ascertainment and selection bias.[12] It is important to establish the extent of inequality in the prevalence of epilepsy between a representative group of adults with ID and the general population as a basis for providing equitable services for the socially neglected ID population.

Clinical studies of adults with ID have identified higher rates of behaviour and psychological problems in those who also have epilepsy compared with those without epilepsy.[13–15] However, there have been few epidemiological studies of morbidity associated with epilepsy in the adult ID population as a whole. Knowledge of physical and mental health problems specifically associated with epilepsy in adults with ID may improve understanding of co-morbid connections and help to focus therapeutic efforts.

Both epilepsy and ID may be caused by a range of genetic, congenital, traumatic and other pathological processes.[1,2,5] The risk of epilepsy is greater in those with additional neurological impairments as well as ID.[6] It is generally accepted that epilepsy arises secondarily to brain damage or abnormality, which is the presumed cause of ID, but the precise relationship between ID and epilepsy is not always clear.[1,8] It is important to identify factors related to the individual as a whole, incorporating both epilepsy and ID, as a basis for planning and delivering services.

The outlook for people with both epilepsy and ID varies according to the underlying and associated conditions.[5,6,16,17] The latter include adaptive behaviour problems, which manifest as a lack of skills essential for living in our complex society.[15] These have implications both for the management of individual patients and for planning services for those with multiple disabilities.

A key principle of the government's white paper *Valuing People*[18] is to enable people with ID to access mainstream services. However, professionals in primary care may have limited knowledge and experience of managing people with ID or epilepsy.[19] Services for epilepsy in the UK are highly variable and few are orientated towards the needs of individuals with ID.[20] Psychiatrists in specialist ID services often lack experience of diagnosing and managing epilepsy. An epidemiological perspective on the extent of epilepsy in adults with ID and factors specifically and holistically associated with it may inform the debate about the mix of appropriate service provision for this group.

The aims of the study were to estimate the prevalence of epilepsy in adults with ID; and, among adults with ID, to compare the frequency of overall and specific physical disabilities, deficits in daily living skills, autistic traits, psychological symptoms and behaviour problems in those with and without epilepsy.

Method

This was a population-based prevalence study. The Leicestershire Learning Disability Register was used to identify adults with ID resident within the unitary authorities of Leicester City, Leicestershire and Rutland. The register was set up in 1987 to provide a sampling frame for research and a range of high quality epidemiological information to assist service planning and delivery.[21] ID is defined as a moderate, severe or profound developmental intellectual impairment[22] with associated adaptive behaviour problems[23] and a likely need for long-term support. Adults aged 19 and over with ID who are known to specialist health or social services are continually notified to the register by a comprehensive network of service providers using methods similar to earlier UK registers.[24] Ascertainment for the register using capture–recapture methodology is estimated to be 95%.[25]

Detailed information is collected by specially trained interviewers in a 5-year rolling programme of structured home interviews with carers.[26] This includes the Disability Assessment Schedule,[27] which covers physical disabilities, daily living skills, level of understanding, behaviour problems and autistic traits based on the characteristics proposed by Wing.[28] Psychological symptoms were incorporated into the questionnaire before any validated instruments had been developed and were based on the clinical experience of psychiatrists at the time.

Adults on the register are followed up for life. The uptake of interviews is 95% for first interviews, 96% for second ones and 98% for third.[21]

Reported epilepsy (i.e. any epilepsy) was identified from a question with three components: the condition of epilepsy; the experience of seizures; and the use of medication to control epileptic seizures. Details of this and other relevant definitions used in the structured questionnaire are given in the box.

Reported epilepsy	a positive response to the question 'Does s/he suffer from epilepsy?' *or* reported experience of seizures occasionally or more often *or* reported taking of medication to prevent or control epileptic seizures
Level of understanding	three hierarchical levels of understanding were used as a indicator of the level of ID: 1 (lowest level) understands a few simple commands at most 2 (middle level) understands comments, questions and instructions related to personal needs and experiences 3 (highest level) understands information about things outside his/her immediate experience eg major items of current news
Residential status	independent/ with family - living alone or with spouse/partner, parents, other relatives, guardian, foster carers or friends residential care - hospital or staffed home or hostel (NHS, Social Services, private or voluntary sector)
Physical disabilities	poor vision - blind, almost blind or poor/partially sighted poor hearing - deaf or poor hearing difficulty with walking - unable to walk half a mile unaided wetting - occurring at least once a week soiling - occurring at least once a week
Skills deficits	cannot manage the following without help: • washing him/herself • dressing him/herself • toileting • feeding and drinking • preparing simple foods • reading • writing • using money • understanding time • finding way around residence
Autistic traits	poor speech - little, nothing or meaningless echolalia social interaction - aloof, passive, odd or 'unwarm' lack of empathy - limited awareness and concern about people's feelings obsessive behaviour - elaborate routines of the kind and intensity found in early childhood autism simple stereotypies - constant marked repetitive activities
Psychological symptoms	recent major or minor presence of: • frustration • unhappiness, upset or crying • withdrawal • anxiety, phobias or irrational fears • imagining voices or images • mood swings or intermittent confusion • lethargy • feels things always against him/her
Behaviour problems	severe and/or frequent (occurring more than three times a week): • physically aggressive to others • destructive behaviour • excessive activity • seeks attention • self-injury • wanders or runs away • screams or makes disturbing noises • tantrums or verbal abuse • disturbs others at night • scatters or throws objects • antisocial or delinquent behaviour • untruthful • inappropriate sexual behaviour • uncooperative • difficult or offensive personal habits • other

The study sample comprised all the adults on the register who had had an interview in the 5-year period from 1997 to 2001 and were aged 20 or over at the time. Individuals were excluded from the study if any of the key study variables — age, sex, level of understanding, reported diagnosis of epilepsy, reported experience of seizures, reported taking of anti-epileptic medication and the variables required to estimate the level of intelligence — were missing.

Measures of prevalence were derived by counting the numbers of individuals with each and any of the three components of reported epilepsy. Possible associations with epilepsy were explored using logistic regression to calculate odds ratios (OR), 95% confidence intervals (CI) and levels of significance (p-values). This was done initially on the unadjusted data to describe holistic associations with components of each domain between people with and without epilepsy. Secondly, to describe associations specific to epilepsy, adjustment was made for age, sex and level of understanding. For associations within the overall domains of interest (such as *any* physical disability), results with a value of $p < 0.05$ were accepted as significant. However, for individual components of each domain, the Bonferroni adjustment for multiple comparisons was made to the level of significance. For example, for *each* of the five autistic traits, a value of $p < 0.01$ (0.05/5) was accepted as being significant.

Results

Between 1987 and 2001, 2688 individuals aged 20 or over who had been notified to the register had had an interview. The key study data were complete for 2393 (89%) of these individuals, who were included in the study. There were no significant differences between the sampling and study populations in relation to age, sex or residence. Fewer South Asians (10/223 = 4.3%) were excluded than those of white or other ethnicity (285/2170 = 11.6%, $p = 0.0006$).

Prevalence and patterns of epilepsy

Among the study group, 620 (25.9%) adults with ID had epilepsy (Table 1). The prevalence was similar in men (25.6%) and women (26.3%). In both sexes, the prevalence was highest in younger adults (20—39 years), dipping in early middle-age (40—49 years) and rising slightly thereafter before declining in old age. The prevalence of epilepsy was not significantly different in South Asians (29.6%) from the rest of the study group (25.5%) (OR 1.2, CI 0.9—1.7, $p = 0.19$) even after adjustment (OR 1.1, CI 0.8—1.5, $p = 0.53$). The prevalence of epilepsy was similar in those living with their families or independently (25.2%) and those living in residential care (27.0%) (OR 0.9, CI 0.8—1.1, $p = 0.3$) even after adjustment (OR 0.9, CI 0.7—1.1, $p = 0.2$).

Within the group with epilepsy, 67.7% experienced seizures despite taking anti-epileptic drugs (Table 2). 3.7% appeared to have quiescent epilepsy, experiencing no seizures in the absence of treatment. 19.5% of individuals were seizure-free on anti-epileptic medication. This pattern was very similar in men and women.

Associated disabilities and problems

The prevalence of any epilepsy showed a significant inverse relationship with the level of understanding (Figure 1). The association held for each component of epilepsy, viz. reported diagnosis of epilepsy, reported experience of seizures and reported taking of anti-epileptic medication. Individuals with the lowest level of understanding (10% of the study group) were significantly more likely to have any reported epilepsy than those with the highest level of understanding (46% of the study group) (OR 4.85,

Table 1 Prevalence (%) of epilepsy among adults on the Leicestershire Learning Disability Register

Age group	Number of adults with an intellectual disability	Percentage (number) of adults with epilepsy					
		Males		Females		Persons	
		%	*n*	%	*n*	%	*n*
20—29	917	29.4	157	29.8	114	29.6	271
30—39	572	28.4	86	30.9	83	29.6	169
40—49	436	18.2	47	19.1	34	18.6	81
50—59	251	25.9	38	19.2	20	23.1	58
60—69	143	22.1	17	22.7	15	22.4	32
70+	74	5.4	2	18.9	7	9.5	9
All ages	**2393**	**25.6**	**347**	**26.3**	**273**	**25.9**	**620**

Table 2 Treatment and outcome by age group among adults with epilepsy on the Leicestershire Learning Disability Register

Age group	On anti-epileptic medication				Not on anti-epileptic medication			
	Seizures		No seizures		Seizures		No seizures	
	%	*n*	%	*n*	%	*n*	%	*n*
20–29	64.9	176	21.8	59	8.9	24	4.4	12
30–39	72.8	123	16.0	27	8.3	14	3.0	5
40–49	79.0	64	13.6	11	3.7	3	3.7	3
50–59	55.2	32	25.9	15	17.2	10	1.7	1
60–69	62.5	20	25.0	8	9.4	3	3.1	1
70+	55.6	5	11.1	1	22.2	2	11.1	1
All ages	**67.7**	**420**	**19.5**	**121**	**3.7**	**56**	**3.7**	**23**

CI 3.60–6.54, $p < 0.0001$). Individuals with the middle level of understanding (44% of the study group) were at intermediate risk of any reported epilepsy (compared with those with the highest level of understanding OR 1.62, CI 1.32–1.98, $p < 0.0001$). There was also a significant trend through the three levels of understanding (OR 2.03, CI 1.76–2.33, $p < 0.0001$).

The level of understanding was also associated with physical disabilities, skills deficits, autistic traits, psychological symptoms and behaviour problems.

Those with epilepsy were significantly more likely to have a range of physical disabilities than those without epilepsy (adjusted overall OR 1.8, CI 1.5–2.2, $p < 0.05$). Associations of epilepsy with poor vision and with poor hearing became non-significant after adjustment, suggesting that these were not specifically related. However, people with epilepsy remained significantly more likely to have problems with wetting (OR 2.7, CI 2.1–3.4, $p < 0.0001$), soiling (OR 2.2, CI 1.6–3.1, $p < 0.0001$) and walking (OR 2.5, CI 2.0–3.2, $p < 0.0001$).

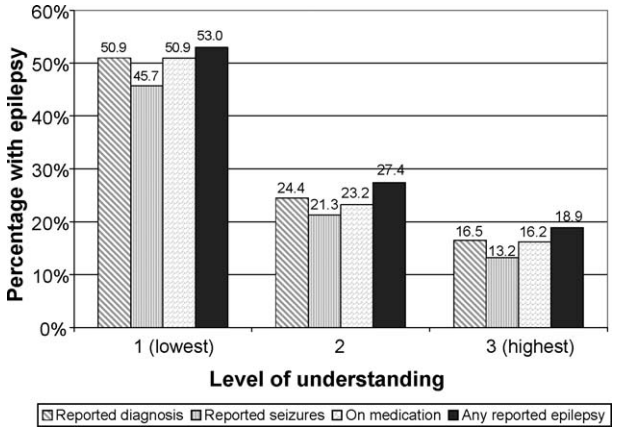

Figure 1 Association between epilepsy and level of understanding.

Those with epilepsy were significantly more likely to have problems with daily living skills than those without epilepsy (OR 2.0, CI 1.6–2.4, $p < 0.0001$). Epilepsy remained specifically associated with global skills deficits (adjusted OR 1.6, CI 1.3–2.1, $p < 0.0001$) and with deficits of each individual skill (Table 3).

Overall, the presence of one or more autistic trait was associated with epilepsy (OR 1.9) (Table 4). After adjustment, the association remained for poor speech and lack of empathy but not for simple stereotypies, obsessional behaviour or poor social interaction. Even where individuals had four or five autistic traits, they were not at increased risk of having epilepsy (adjusted OR 1.4, CI 0.8–2.4, $p > 0.05$).

Overall, psychological symptoms were associated with epilepsy (OR 1.3) (Table 4). Following adjustment, the overall association remained significant but mood swings was the only specifically associated symptom.

Those with epilepsy were significantly more likely to have severe or frequent behaviour problems than those without epilepsy (overall OR 1.6) (Table 5). Associations with destructive behaviour, self-injury, tantrums or verbal abuse, and scattering or throwing objects became non-significant following adjustment. Only problems with disturbing others at night, seeking attention and being uncooperative remained specifically associated with epilepsy.

The subgroup of individuals taking anti-epileptic drugs had no increase in psychological symptoms, behaviour problems or other disabilities compared with the subgroup not on anti-epileptic drugs. However, there was a significant association between taking anti-epileptic drugs and a low level of understanding (OR 4.1, CI 1.6–10.4, $p < 0.003$). Within the subgroup of people taking anti-epileptic drugs, those with frequent seizures (monthly or more) had significantly more problems with wetting and feeling that things were always set against them

Table 3 Skills deficits associated with epilepsy

Deficit of daily living skill[a]	Prevalence		Unadjusted data			Adjusted data[b]		
	Individuals with epilepsy (%)	Individuals without epilepsy (%)	Odds ratio	95% confidence interval	*p*-value	Odds ratio	95% confidence interval	*p*-value
Washing	47.3	22.7	3.06	2.52–3.71	<0.0001	2.44	1.96–3.04	<0.0001
Dressing	35.9	13.3	3.66	2.95–4.53	<0.0001	2.90	2.24–3.72	<0.0001
Toileting	30.7	9.0	4.48	3.54–5.68	<0.0001	3.62	2.66–4.65	<0.0001
Feeding and drinking	8.1	1.2	6.99	4.19–11.63	<0.0001	3.64	1.94–5.99	<0.0001
Preparing simple foods	40.6	20.1	2.72	2.23–3.31	<0.0001	2.18	1.73–2.76	<0.0001
Reading	46.4	27.3	2.31	1.91–2.97	<0.0001	1.77	1.47–2.28	<0.0001
Writing	50.2	29.9	2.36	1.96–2.85	<0.0001	1.85	1.54–2.34	<0.0001
Using money	72.7	59.0	1.86	1.52–2.27	<0.0001	1.47	1.23–1.87	<0.0001
Understanding time	37.1	18.7	2.56	2.09–3.13	<0.0001	1.44	1.48–2.36	<0.0001
Finding way around residence	25.7	9.9	3.13	2.47–3.97	<0.0001	2.32	1.76–3.18	<0.0001
Any of the above[c]	**78.6**	**65.1**	**1.96**	**1.58–2.43**	**<0.0001**	**1.59**	**1.33–2.07**	**<0.0001**

[a] As defined in the box of definitions in the methods section.
[b] Adjusted for age, sex and level of understanding.
[c] Level of significance: $p < 0.05$ for *any* skills deficit and $p < 0.005$ (0.05/10) for each *individual* skills deficit because of the Bonferroni adjustment for multiple comparisons.

compared with those with occasional or no seizures (OR 1.8, CI 1.2–2.8, $p < 0.005$ and OR 2.7, CI 1.6–4.4, $p < 0.0001$ respectively). They had no more behaviour problems than those with less frequent seizures or none.

Discussion

Prevalence and patterns of epilepsy

The prevalence of 26% found in our study is comparable with or slightly higher than that found in other population-based studies of the adult ID population.[1,5,10,11] Within the general population, most studies of relatively unselected populations have reported the prevalence of chronic epilepsy as 0.4–1% and lifetime prevalence 1.5–5%.[12]

There was no significant difference in the prevalence of epilepsy between men and women with ID at any age. Within the ID population, Forsgren et al.[5] found a slightly higher prevalence of epilepsy in men than women between the ages of 20 and 39 and no difference in those aged over 40. Richardson et al.[4] found no sex difference in the prevalence of epilepsy in individuals under 22 with severe ID. In the general population, most published studies have reported higher rates of epilepsy in men,[12] which is attributed to boys being more vulnerable to brain damage and hence to seizures.[3]

Overall, the pattern of prevalence with age was similar in adults with ID to that in the general adult population. The proportion of adults with epilepsy decreased after the age of 60. Branford et al.[29] found a similar decline after the age of 50 and McDermott et al.[11] a steady decline throughout the adult years. This may be due to the increased risk of early mortality associated with epilepsy and ID.[29] Those with profound ID have both the highest rates of epilepsy and the highest mortality rates from all causes.[5]

There was no significant difference in the prevalence of epilepsy in South Asians and whites. Studies in the general population have reported a higher prevalence of epilepsy in blacks compared with whites[12] and in lower socio-economic groups.[12] Most adults with ID have restricted opportunities for paid employment or car ownership and derive their income from state benefits, making it difficult to use indicators of socio-economic group in a meaningful way for internal comparisons. Unlike earlier studies, we did not find a significantly higher prevalence of epilepsy in those living in residential care, which may in part reflect the changing provision of care in the community.

Table 4 Autistic traits and psychological symptoms associated with epilepsy

Autistic traits and psychological symptoms[a]	Prevalence		Unadjusted data			Adjusted data[b]		
	Individuals with epilepsy (%)	Individuals without epilepsy (%)	Odds ratio	95% confidence interval	*p*-value	Odds ratio	95% confidence interval	*p*-value
Poor speech	20.7	6.7	3.61	2.76–4.73	<0.0001	2.21	1.53–3.19	<0.0001
Social interaction	13.9	8.2	1.81	1.36–2.41	<0.0001	1.21	0.88–1.66	0.232
Lack of empathy	52.8	36.8	1.92	1.60–2.31	<0.0001	1.49	1.22–1.83	<0.0001
Obsessive behaviour	4.2	3.1	1.36	0.85–2.19	0.203	1.21	0.74–1.98	0.449
Simple stereotypies	18.2	9.9	1.36	1.58–2.64	<0.0001	1.39	1.05–1.84	0.021
Any autistic trait[c]	**57.1**	**41.6**	**1.87**	**1.55–2.25**	<0.0001	**1.45**	**1.18–1.77**	**<0.0001**
Frustration	53.9	46.7	1.34	1.11–1.61	0.002	1.22	1.00–1.48	0.047
Unhappiness	37.3	33.2	1.20	0.99–1.45	0.066	1.10	0.90–1.34	0.340
Withdrawal	26.4	25.8	1.03	0.82–1.30	0.784	0.98	0.78–1.25	0.897
Anxiety/phobias/fears	34.4	38.0	0.86	0.69–1.06	0.157	0.92	0.74–1.15	0.459
Voices/images	7.5	7.9	0.95	0.66–1.37	0.787	1.06	0.73–1.52	0.771
Mood swings	43.6	35.0	1.43	1.19–1.73	<0.0001	1.46	1.21–1.77	<0.0001
Lethargy	24.9	20.1	1.32	1.01–1.74	0.045	1.34	1.01–1.78	0.042
Feels things always set against him/her	16.7	18.5	0.89	0.69–1.13	0.336	0.99	0.77–1.28	0.945
Any psychological symptom[d]	**79.4**	**74.2**	**1.34**	**1.07–1.67**	**0.011**	**1.28**	**1.02–1.61**	**0.034**

[a] As defined in the box of definitions in the methods section.
[b] Adjusted for age, sex and level of understanding.
[c] Level of significance: $p < 0.05$ for *any* autistic trait and $p < 0.01$ (0.05/5) for each *individual* autistic trait because of the Bonferroni adjustment for multiple comparisons.
[d] Level of significance: $p < 0.05$ for *any* psychological symptom and $p < 0.00625$ (0.05/8) for each *individual* psychological symptom because of the Bonferroni adjustment for multiple comparisons.

Table 5 Behaviour problems associated with epilepsy

Behaviour problems[a]	Prevalence		Unadjusted data			Adjusted data[b]		
	Individuals with epilepsy (%)	Individuals without epilepsy (%)	Odds ratio	95% confidence interval	*p*-value	Odds ratio	95% confidence interval	*p*-value
Physically aggressive	15.3	11.7	1.37	1.05–1.78	0.021	1.26	0.96–1.65	0.099
Destructive behaviour	13.5	9.1	1.55	1.17–2.06	0.002	1.37	1.02–1.84	0.112
Excessive activity	6.7	4.3	1.59	1.07– 2.36	0.021	1.39	0.93–2.10	0.112
Seeks attention	16.1	10.6	1.62	1.24–2.10	<0.0001	1.65	1.26–2.16	<0.0001
Self-injury	11.7	7.3	1.68	1.23–2.27	0.001	1.22	0.88–1.69	0.235
Wanders or runs away	6.5	4.2	1.57	1.06–2.33	0.026	1.25	0.82–1.90	0.292
Disturbing noises	10.4	6.8	1.59	1.16–2.20	0.004	1.18	0.84–1.66	0.348
Tantrums or verbal abuse	20.5	15.1	1.45	1.14–1.83	0.002	1.42	1.11–1.81	0.005
Disturbs others at night	12.2	5.9	2.20	1.61–3.01	<0.0001	1.85	1.33–2.57	<0.0001
Scatters or throws objects	6.7	3.1	2.25	1.48–3.42	<0.0001	1.86	1.20–2.87	0.006
Antisocial behaviour	4.2	6.1	0.68	0.44–1.06	0.091	0.74	0.48–1.16	0.194
Untruthful	2.1	3.7	0.57	0.31–1.04	0.067	0.64	0.35–1.18	0.151
Inappropriate sexual behaviour	1.6	2.0	0.80	0.39–1.62	0.527	0.87	0.42–1.78	0.702
Uncooperative	20.0	12.6	1.74	1.36–2.21	<0.0001	1.60	1.25–2.06	<0.0001
Difficult personal habits	13.0	11.9	1.10	0.83–1.45	0.497	0.86	0.64–1.15	0.313
Other	10.9	10.4	1.05	0.78–1.41	0.760	0.99	0.73–1.35	0.948
Any of the above[c]	**54.2**	**42.0**	**1.64**	**1.36–1.97**	**<0.0001**	**1.42**	**1.17–1.72**	**<0.0001**

[a] As defined in the box of definitions in methods section.
[b] Adjusted for age, sex and level of understanding.
[c] Level of significance: $p < 0.05$ for *any* behaviour problem and $p < 0.0031$ (0.05/16) for each *individual* behaviour problem because of the Bonferroni adjustment for multiple comparisons.

7Associated disabilities

The prevalence of epilepsy was significantly associated with low levels of understanding. This association has been described in previous studies in children with ID[3,4,6–8] and adults with ID.[5,29] The marked increase in the prevalence of epilepsy in those with severe ID is understandable as most have overt signs of brain damage.[3] Low levels of understanding may be due to a significant cognitive impairment or to other causes such as anti-epileptic medication.

The association of low levels of understanding with a range of disabilities underlines the importance of adjusting for the level of understanding in the analyses so that associations specific to epilepsy can be identified. Earlier studies described the effect of coexisting disabilities on the prevalence of epilepsy without always making this adjustment.

Our study showed that epilepsy was associated with specific physical disabilities, notably problems with continence and walking. Forsgren et al.[5] and McDermott et al.[11] found an association with cerebral palsy and Eyman et al.[30] with difficulties in arm-hand coordination. Problems with mobility and coordination may compound the difficulties in learning and maintaining daily living skills.

A link between autistic spectrum disorder and epilepsy has been described in a number of other studies.[4,31–33] However, we found no association with the best indicator of autistic spectrum disorder (i.e. four or five autistic traits). Specific associations were confined to poor speech and lack of empathy.

Our population-based study showed an overall association of epilepsy with psychological symptoms, largely reflecting a specific problem with mood swings. A clinical study of psychopathology in adults with ID and epilepsy found that the group with epilepsy had less psychiatric illness than those without epilepsy; and that changeable mood was common in both groups and more common than in the general population.[14]

The overall association of epilepsy with a range of behaviour problems was attenuated on adjusting for level of understanding. The specific associations remaining after adjustment included disturbing others at night but not overtly aggressive behaviour. Individuals with ID often experience sleep deprivation and other sleep disturbances, which may precipitate seizures.[8] Anti-epileptic drugs may also predispose to sleep disturbance.[1,8,34] The increase in feeling that things are set against them found in the subgroup with frequent seizures and taking anti-epileptic drugs has not been described clinically.

The literature on an association between epilepsy and behaviour problems in the ID population is complex, some studies finding an overall association[30,33] and others not.[13,15] The only association Epsie's study[15] found was in a small subgroup whose epilepsy was resistant to pharmacological control. Deb and Hunter[13] found an association in subgroups where epileptic factors were strong (multiple types of seizures, frequent seizures or generalised epileptiform activity on electroencephalogram) and the underlying brain damage was less severe (mild ID). Some anti-epileptic drugs may worsen behaviour problems,[35,36] though monopharmacy, particularly carbamazepine, may have a protective effect.[13]

Service issues

Sixty-eight per cent of those with epilepsy experienced seizures despite taking anti-epileptic drugs. Clinically, this does not equate with refractory epilepsy as some individuals may have had a significant reduction in the frequency of their seizures with medication. However, Forsgren et al.[5] and Branford et al.[29] reported high rates of refractory epilepsy, with only 32% and 25% being seizure-free respectively. The main goals of anti-epileptic medication in the ID population are to achieve control of or, ideally, freedom from seizures; and to maintain a quality of life that allows an individual to participate meaningfully in day-to-day activities.[37] These two goals need to be balanced as full control of seizures is not always possible. In addition, anti-epileptic drugs commonly cause drowsiness, dizziness, ataxia, gastrointestinal disturbances, behaviour problems and other side effects, which may further impair the quality of life.[37]

Epilepsy was associated with global deficits in daily living skills. This is consistent with Epsie's[15] finding that adults with ID and epilepsy have consistently poorer life skills than their matched peers without epilepsy. Epilepsy potentially constrains learning potential and learning outcome by interrupting consciousness during and probably also between seizures; and by anti-epileptic drugs reducing arousal and selective attention.[38] Daytime drowsiness associated with epilepsy[37] may or may not be related to anti-epileptic drugs.[38] People with ID and, to a lesser extent, those with epilepsy may be overprotected and lack opportunities for learning compared with their peers, particularly if living in residential accommodation. Lower skills levels in South Asians with ID may result from different ethnic or cultural perceptions of the importance of these skills.[39] Skills deficits may compound the difficulties in monitoring neuropsychological functioning and day-to-day management of epilepsy.

In adults with ID, the association of epilepsy with low levels of understanding, global skills deficits and

problems of detachment, mood swings and behaviour problems makes epilepsy care particularly difficult. The aims of high quality care for this population are the same as for anyone with epilepsy: more quality-of-life-adjusted years and more effective, efficient use of resources.[40] Professionals providing specialist services need a range of skills to deal with both epilepsy and the associated disabilities, including ID. There are frequently issues of limited resources. In Leicestershire, learning disability psychiatrists generally manage adults with ID and active epilepsy although some patients, particularly those with refractory epilepsy, access neurology services. Joint clinics are being discussed for those with challenging behaviour and/or psychological problems in addition to epilepsy.

The long-term management of epilepsy in adults with ID involves families and carers, health professionals, social services, the voluntary sector and employment and educational agencies.[20] For optimum care, it is important to develop close links between all of these groups.[41]

Methodology of the study

Identifying individuals with ID from a long-standing population-based register with high ascertainment of ID and high interview uptake plus an interview schedule that includes standardised questions about epilepsy is likely to provide less selection bias and better case ascertainment of epilepsy than other methods.[1,5,12] The register does not collect data on the clinical definition of epilepsy, the type of seizure, aetiology or age of onset, but these have been reported in adults with ID in Leicestershire in another study.[29] Clinicians see individuals referred to them with problems. The unadjusted analyses present a picture analogous to impressions gained from clinical practice. The strength of this study lies in the large, more representative study group and analyses adjusted for ID, which enable specific associations with epilepsy to be identified.

Conclusions

The prevalence of epilepsy reported from the Leicestershire Learning Disability Register was at least 26 times higher than in the general adult population. There was no particular concentration of epilepsy in any gender, ethnic or residential subgroups. Morbidities specifically associated with epilepsy included low level of understanding, incontinence (urinary and faecal), difficulty in walking, poor speech, lack of empathy, mood swings, uncooperativeness, seeking attention and disturbing others at night. Holistically, accompanying problems included a wider range of physical, autistic, psychological and behavioural problems, probably linked to the associated low level of understanding. These problems and the attendant skills deficits make epilepsy care more difficult for people with ID and suggest the need for a multidisciplinary skills mix.

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