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Epidemiology of Epilepsy in Older Adults With an Intellectual Disability in Ireland: Associations and Service Implications

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Abstract

There are limited studies on the prevalence of epilepsy and co-morbid conditions in older adults with an ID. To begin to address this prevalence of epilepsy was estimated for participants in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. Associations with demographic variables and co morbid health conditions were examined. It was found that prevalence was high (30.7%); but declined as people aged. Those with epilepsy were less likely to live with family, independently or in community settings, rates of refractory epilepsy were high and, despite medication over half of those with epilepsy still reported experiencing seizures. Given these findings, people with ID and their careers have considerable needs for information about epilepsy management, and for support from specialist ID and epilepsy services.

Key Words: *Epilepsy; intellectual disability; epilepsy management*

The prevalence of epilepsy in people with intellectual disability (ID) is high, with estimates of 14%–44% (Beavis, Kerr, Marson, & Dojcinov, 2007; Bowley & Kerr 2000), greatly exceeding the 0.4%–1.0% reported for the general population (Picot, Baldy-Moulinier, Daurès, Dujols, & Crespel, 2008). Epilepsy has been reported to be associated with severity of ID, increasing from 6% in those with mild ID, to 24% in those with moderate ID, to 50% in those with profound ID (Lhatoo & Sander, 2001), a finding confirmed by McGrother et al. (2006). There have also been reports that high prevalence of associated morbidities and global skills deficits make epilepsy care in people with ID highly complex (Espie et al., 2003). Underlying etiology of ID appears related to risk of seizure activity; for example, in people with cerebral palsy or post-traumatic brain injury, prevalence rates as high as 75% have been reported (Goulden, Shinnar, Koller, Katz, & Richardson, 1991). The prevalence of epilepsy in children with Down syndrome (DS) has been reported as relatively low, ranging from 1.4% (Tatsuno, Hayashi, Iwamoto, Suzuki, & Kuroki et al., 1984) to 24% (Corbett, Harris, & Robinson, l975, Steffenburg, Hagberg, Viggedal, & Kyllerman, 1995), but perhaps of most interest are reports of a distinct increase in seizure activity in the fourth and fifth decades of life for people with DS, coincident with the onset of Alzheimer's disease with prevalence rates ranging from 78% to 98% (Evenhuis, 1990; McCarron, Gill, McCallion, & Begley, 2005; Tyrrell et al., 2001; Visser et al., 1997). Age has also been reported as associated with epilepsy, with rates highest in those age 25–49 years and lower in older age groups for the general population (Picot et al., 2008), but the association with age in people with ID and with DS requires further systematic investigation.

Increased prevalence of mental health problems has been reported to be associated with epilepsy both in the general population (Hoare, 1984); and in people with ID (Deb 1997; Deb et al., 1998). One recent study by Turky, Felce, Jones, and Kerr (2011) agreed, finding a 7-fold increase in psychopathology in people with

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epilepsy and ID compared to those with ID without epilepsy. However, Arshad et al. (2011) reported no association between epilepsy and psychopathology in people with ID, and Espie et al. (2003) concluded that epilepsy may be a risk factor for psychiatric concerns among only a minority of people with ID. Amid these conflicting findings, a recent *Cochrane Review* article concluded there was no consensus on whether people with both ID and epilepsy are at increased risk of psychiatric morbidity compared to their peers with either epilepsy or ID alone (Beavis et al., 2007).

There has also been recent concern about the risk of both diagnostic overshadowing and undershadowing of epilepsy diagnosis in people with ID, given communication difficulties; inadequate history and frequent staff turnover; a range of cognitive and behavior challenges; difficulties with compliance for routine tests such as electroencephalogram and brain imaging; and motor problems associated with specific syndromes, for example, Rett syndrome often misinterpreted as epileptic events (Chapman et al., 2011). In addition, polypharmacy is frequent in people with ID (McCarron et al., 2011); many have experienced long-term exposure to drug treatments for mental health and behavior problems, and adverse medication effects presenting as involuntary movements and twitching, gait disturbance, and tardive dyskinesia can be easily misinterpreted as seizure activity. The training of those making diagnoses appears to be of concern. Several case studies have documented how misdiagnosis was corrected when an ID team nurse visited and observed the event (John, 2008), or members of a pediatric team with syndrome-specific knowledge were able to distinguish motor activity associated with specific syndromes (example.g., Sandifer syndrome) from epilepsy (Somjit, Lee, Berkovic, & Harvey, 2004).

A review on epilepsy and ID research (Bowley & Kerr, 2000) highlighted a number of methodological concerns in prior reports of the prevalence of epilepsy in people with ID, including lack of definition on seizure type; lack of representative samples, with studies often confined to either institutional (Mariani, Ferini-Strambi, Sala, & Erminio, 1993) or community-based samples (Welsh Office, 1995); and inferences drawn from surveys conducted only with children (Corbett et al., 1975; Steffeburg et al., 1995) or younger adults (McGrother et al., 2006). The methodological issues identified, in particular the selection bias associated with studies confined to children, indicate that reported prevalence figures cannot be generalized to adults with ID. This article seeks to address this concern by estimating the prevalence of epilepsy in older adults with ID, and to further add to knowledge by estimating and considering the frequency of associated comorbid health conditions in people with and without epilepsy.

Methods

Data on epilepsy were drawn from the first wave of data collected as part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). IDS-TILDA is a multiwave longitudinal study of older adults with ID in Ireland. It was designed to explore their aging profile, physical and behavioral health, health services needs, psychological health, social networks, living situations, and community participation including employment.

Sample

The sample was randomly selected from Ireland's National Intellectual Disability Database (NIDD), a mandatory database monitored for completeness and accuracy, which collects information on all people with an ID who are eligible for or receive services. More than 26,000 people are registered, including those with all levels of ID and in the full range of residential and family and independent living circumstances (Kelly & Kelly, 2011). Inclusion criteria were (a) age $\geq$ 40 years with intellectual disability; (b) registered with NIDD; and (c) written consent to participate and/or family/guardian written agreement, where required (Figure 1). Age 40 years was selected to

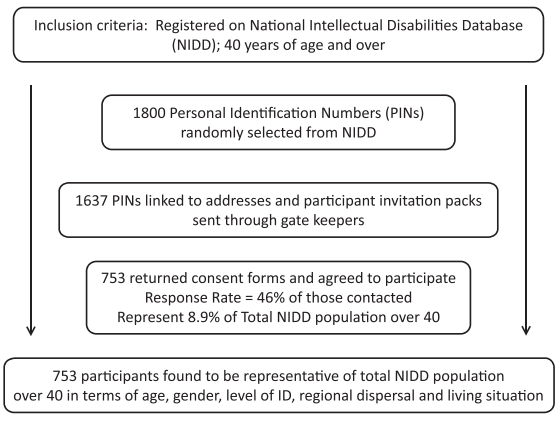

Figure 1. Sampling frame.

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reflect the lower longevity of people with ID and thus ensure that there would be sufficient subjects for future waves of data collection, and because this would provide opportunities to offer insight into aging for those who may age prematurely. From a 5% randomly selected sample, the recruited, consented, and protocols-completed sample was 753 people with an ID, age 40 and older, an overall response rate of 46% comprising people who represented 8.9% of the total population age 40 and over registered on the 2008 NIDD database. Comparison with the published demographics of the 2008 NIDD cohort confirmed that the IDS-TILDA random sample was also representative of the larger sample (McCarron et al., 2011).

Measures

A preinterview questionnaire (PIQ) was sent to each participant before the interview. This questionnaire covers demographical information including age; level of ID; etiology of ID: DS or ID from other etiology; physical and mental health status (including physician-confirmed diagnoses of physical and mental health concerns); health care utilization and medication usage. The purpose of this preliminary questionnaire was to give respondents time to locate the information required, thereby increasing reliability of data. Specifically, each participant/caregiver respondent reported (a) whether the individual with ID was ever diagnosed with epilepsy by a doctor or other relevant health professional; (b) seizure types, for example; tonic-clonic, atonic, myoclonic, absence, simple partial or complex partial; (c) attendance at an epilepsy clinic or a specialist; (d) who reviewed their epilepsy for example, general practitioner, psychiatrist, neurologist; (e) when they had their epilepsy reviewed: within the last 12 months, last 2 years, more than 2 years or never; (f) whether they kept a record of seizure events; and (g) how often they had a seizure in the past 2 years, reported as more than 2 years ago, daily, weekly, or more than once a month. Data were also collected on related medication use. A PIQ was completed for all 753 participants. The reported presence of a diagnosis of epilepsy identified in the PIQ was then confirmed at a subsequent face-to-face interview with the participant and with their key worker.

Ethical Approval

The IDS- TILDA study received ethics approval from the Faculty of Health Sciences Ethics Committee at Trinity College Dublin and all of the participating services providers (*N=138*).

Data Analyses

Prevalence, age-standardized prevalence based on the WHO standard population 2000–2025 (Ahmad et al., 2001), and the corresponding 95% confidence interval were calculated by counting the number of individuals reporting any of the possible components of seizure activity.

To describe associations specific to epilepsy, relative risk was calculated using age, gender, level of ID, and comorbid physical and mental health for those with and without DS. Possible associations with epilepsy were then explored using a binary logistic regression to calculate odds ratios (OR), 95% confidence intervals, and levels of significance (p values). The amount of variance explained by the resulting models was also examined.

Results

Of the 753 participants in the randomly selected cohort, 45% were male and 55% were female. The mean age of the group was 54.75 years (SD = 9.56), with 36% age 40–49 years, 46% age 50–64 years, and 18% age 65 years and over. Overall, 24% were classified as having a mild ID, 46% a moderate ID, 24% a severe ID, and 5% a profound ID; 5% were ID unverified. For the purpose of analyses, participants classified as having mild and moderate ID were grouped together as were those with severe to profound ID. Those with an unverified level of ID were excluded from the subsequent analyses.

Among the study group, 229 individuals with an ID had epilepsy; a prevalence rate of 30.7%. As can be seen in Table 1, prevalence was higher in females than males (32.9% and 27.8%, respectively); however, the difference was not statistically significant (p = .13). Prevalence of epilepsy was significantly higher in those with severe or profound ID compared to those with mild or moderate ID (43.4% and 26.9%, respectively), $\chi^2(1, n = 692) = 18.147$, $p < .0001$. The prevalence of epilepsy was also significantly higher among those living in residential facilities at 60.3%, compared with 39.7% among those in community settings or living independently or with family, $\chi^2(1, n = 747) = 22.97$, $p < .0001$. Controlling for dementia, prevalence of epilepsy in those with DS was significantly lower than

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Table 1
Prevalence (%) of Epilepsy Among Adults With an Intellectual Disability in Ireland

	Male		Female		All persons	
Age group	% w/ Epilepsy	*Frequency*	% w/ Epilepsy	*Frequency*	% w/ Epilepsy	*Frequency*
40–49 (n=274)	28.3	38/134	36.4	51/140	32.5	89/274
50–64 (n=344)	27.6	40/145	32.7	65/199	30.8	105/340
65+ (n=134)	25.9	15/58	26.3	20/76	26.3	35/133
All Ages	27.8	93/334	32.9	136/413	30.7	229/747

reported for adults with ID from other etiologies (13.4% and 34.1%, respectively), $\chi^2(1, n = 726) = 19.95$, $p < .0001$. However, epilepsy was significantly associated with dementia in those with DS, with 12 out of 23 people with DS and dementia (52.2%) reporting a diagnosis of epilepsy $\chi^2(1, n = 142) = 18.26$, $p < .0001$.

In terms of seizure activity, 73.8% of those with epilepsy experienced generalized seizures, 22.3% had seizures of unknown type, and 23.1% experienced multiple types of seizures activity. Types of seizure activity reported were tonic clonic (53.5%), unknown (22.9%), absence (22%), tonic (11.9%), myoclonic (7.9%), simple partial seizures (7.9%), atonic (4.8%), complex partial seizures (4.8%), and clonic (3.5%). Generalized seizures were significantly more prevalent in those with severe or profound ID than in those with mild or moderate ID (91.9% and 68%, respectively), $\chi^2(1, n = 221) = 16.754$, $p < .0001$. In terms of epilepsy management, 62.7% of participants reported having had their epilepsy reviewed at a specialist epilepsy clinic, and the majority (81.5%) kept a record of their seizures.

Within the group, 89.5% ($n = 205$) of those with epilepsy were taking antiepileptic medication. Despite taking antiepileptic medication, 56.1% ($n = 102$) reported that they had experienced seizures within the last 2 years, with 25.3% ($n = 46$) of those experiencing a seizure more than once a month. There was no difference between people with severe or profound and mild or moderate ID in use of antiepileptic medication (91% and 88.5%, respectively) or in rates of seizures being experienced more than once a month at (28.2% and 21.8%, respectively).

Of those with epilepsy who were not taking medication ($n = 24$), nine (37.5%) had not had a seizure in the past 2 years, three (12.5%) had had a seizure more than once a month, and three (12.5%) had had a seizure less than once a month but within the past 2 years. Nine (37.5%) of those with epilepsy who were not taking medication did not answer the question on seizure frequency. A chi-squared test of independence showed a significant relationship between age and frequency of seizures, $\chi^2(4, n = 197) = 15.39$, $p = .004$.

Overall, participants reported having had their epilepsy reviewed on a regular basis, with 80.8% having had a review within the past 12 months and 5.1% within the past 2 years. An additional 11.6% had not had their epilepsy reviewed in over 2 years, and 2.5% had never had their epilepsy reviewed. In relation to the question about who reviewed your epilepsy, 51% reported that a general practitioner reviewed their epilepsy, 40% a psychiatrist, and 42% a neurologist. In addition, 34.7% had epilepsy reviewed by more than one group/professional.

The majority of respondents (83.1%) kept a record of their seizures, with those living in residential care (92.7%) more likely to have such a record than those living independently, (43.5%) or in the community (77.8%). Those with epilepsy were significantly more likely to have problems with activities of daily living (ADL) such as washing, dressing, toileting, and mobility than those without epilepsy. However, epilepsy did not appear associated with instrumental activities of daily living (IADL) such as preparing hot food or controlling their own money.

In terms of comorbid health concerns, data in Table 2 indicate that significant bivariate associations were found between epilepsy and joint disease, gastrointestinal disease, and stroke; however, there was no association between epilepsy and mental health concerns, with 46.7% of those with epilepsy reporting mental health problems compared with 48.1% of those without epilepsy.

In the investigation of differences between those with and without DS and the predictors of epilepsy, Table 3 indicates that for people with DS age (negative) dementia diagnosis, and endocrine

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Table 2
Physical and Mental Health Comorbidities Associated With Epilepsy

	Prevalence		Unadjusted			Adjusted		
Comorbidities	Individuals with epilepsy (%)	Individuals without epilepsy (%)	Odds ratio	95% Confidence interval	p-Value	Odds ratio	95% Confidence interval	p-Value
Hypertension	13.5	16.2	1.236	.52–1.26	0.350	1.193	.76–1.88	.448
Eye Disease	52.4	51	1.059	.78–1.45	0.717	1.054	.77–1.45	.747
Heart Disease	14	10.8	1.34	.84–2.13	0.217	1.379	.86–2.2	.179
Endocrine	18.3	23.4	1.357	.50–1.09	0.127	1.427	.96–2.13	.080
Joint Disease	29.3	16.8	2.049	1.42–3.96	<0.0001	2.10	1.45–3.06	<0.0001
Lung Disease	6.6	7.5	1.162	.47–1.60	0.634	1.126	.61–2.09	.708
Gastrointestinal	34.5	23.4	1.728	1.23–2.43	0.002	1.775	1.26–2.5	0.001
Mental Health	46.7	48.1	1.055	.70–1.30	0.734	1.04	.76–1.43	.810
Stroke	5.2	1.9	2.809	1.20–1.6	0.018	3.345	1.38–8.96	.007
Cancer	4.4	4.2	1.029	.48–2.21	0.941	1.096	.51–2.38	.818
Liver	.9	.4	2.273	.32–16.24	0.413	2.348	.33–16.88	.396

disease were the significant predictors of epilepsy. Among those with DS, individuals with diagnosed dementia were 12.98 times more likely to have epilepsy. As can also be seen in Table 3, for those without DS, mild and moderate levels of ID, higher ADL needs, lower IADL needs, endocrine disease, and joint disease were the significant predictors. Participants with mild and moderate levels of ID were 1.79 times more likely to have epilepsy, and those with joint disease were 1.60 time more likely.

Discussion

The high prevalence rates of epilepsy reported among people with ID were confirmed (30.7%) in this study. Differences in prevalence of epilepsy among genders were present but not statistically significant. Consistent with other reports, (McDermot et al., 2005; McGrother et al., 2006), prevalence was highest in the younger age groups (40–49 years) and declined with age. Epilepsy, also consistent with prior reports

Table 3
Predictors of Epilepsy in Persons With ID With and Without Down Syndrome

	With Down syndrome (n=28)					Without Down syndrome (n=170)				
Variable	B	S.E.	Sig.	Exp(B)	95% C.I. EXP(B)	B	S.E.	Sig.	Exp(B)	95% C.I. EXP(B)
Gender	−.223	.49	.65	.08	.31–2.08	.202	.21	.34	1.22	.81–1.85
Age	−.072	.03	.19	.93	.88–.99	−.010	.01	.38	.99	.97–1.01
Mild/Moderate ID	.225	.89	.80	1.25	.22–7.26	.584	.31	.05	1.79	.99–3.27
Severe/Profound ID	.424	.99	.67	1.53	.22–10.78	.526	.40	.19	1.69	.77–3.68
Dementia	2.56	.55	.00	12.98	4.39–38.39	−.937	.48	.05	.39	.15–1.0
Cardiovascular Disease	.105	.43	.81	1.11	.48–2.58	.274	.18	.12	1.32	.93–1.87
ADL	−.002	.05	.96	.99	.91–1.09	.120	.02	.000	1.13	1.08–1.18
IADL	.174	.10	.09	1.19	.98–1.46	−.088	.03	.006	.92	.86–.98
Endocrine	1.099	.48	.02	3.00	1.19–7.57	−.668	.27	.012	.50	.30–.86
Joint Disease	.298	.53	.57	1.34	.48–3.79	.467	.24	.050	1.60	1.00–2.55
Gastrointestinal Disease	−.526	.52	.31	.59	.21–1.63	.151	.23	.51	1.16	.74–1.83

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(McGrother et al., 2006; see review Bowley & Kerr, 2000), was found to be significantly more prevalent in those with severe or profound ID than in those with mild or moderate ID. Those with epilepsy and ID were less likely to live with family, independently, or in community-based accommodation. Rates of refractory epilepsy were high, and despite taking antiepileptic medication, more than half of those with epilepsy reported experiencing seizures within the last 2 years, with more than a quarter experiencing a seizure more than once a month (Espie et al., 2003; McGrother et al., 2006). Findings from this study also support those of previous reports (see Beavis et al., 2007) of low lifetime risk of seizure activity in people with DS compared with ID from other aetiology but also confirm the association in later years between seizure activity in people with DS and the onset of Alzheimer-type dementia. The additional regression finding in a population age 40 years and older of a negative association with age is not surprising given the well-reported early onset of dementia among people with DS (McCallion & McCarron, 2004). Clearly, greater vigilance for both epilepsy and dementia as people with DS advance beyond their 40th year is supported by the present data.

This study also identified a significant bivariate association (upheld for those without DS) between epilepsy and joint disease such as arthritis and osteoporosis (not previously reported). In the regression analyses, this association appeared particularly significant for those with ID without DS, further highlighting concerns found in the general population (Pack & Morrell, 2001) that antiepileptic medication may be an additional factor in disorders of bone metabolism in people with ID. In Wave II of IDS-TILDA, objective measures on bone density are planned to further investigate these concerns.

The significant bivariate association between gastrointestinal disease and epilepsy in people with ID has also not previously been reported, although an adverse relationship between use of antiepileptic medication and adverse effects such as chronic constipation in the elderly is well established (Carpay, Aldenkemp, & vanDonselaar, 2005; Gallagher, O'Mahony, & Quigely, 2008; Jahromi & Tosha, 2011; Perucca & Meador, 2005). Nevertheless, the association was not supported when the population was divided into those with DS and those without DS. This division may allow other variables to become more prominent, but this finding will require further follow-up. The finding of no association between mental health problems and epilepsy adds to the literature questioning other reports of such an association (Beavis et al., 2007; Espie et al., 2003). Finally, the overall finding that IADL needs were not associated with epilepsy, but did appear associated for those without DS, again raises an issue that perhaps something different in the association with epilepsy is occurring for people with and without DS, and this also deserves further investigation.

Another important finding was a number of people who reported a history of seizure activity but were not taking medication despite experiencing seizures. This group tended to be those with mild or moderate ID who lived in community or independently. It was not possible to ascertain whether medications were prescribed or discontinued and, if so, what the reasons were; additional information on these issues will also be pursued in Wave II using recent guidelines from the International League against Epilepsy (Kwan, Schachter, & Brodie, 2011).

The data reported here confirm prior findings about epilepsy among people with ID but are limited by the self-report, records review, and cross-sectional nature of the data collection. It was not possible or planned to independently confirm a diagnosis of epilepsy. Having developed a profile of the epilepsy status of the sample, subsequent waves of the IDS-TILDA will offer an important opportunity to gather more detailed information and to track actual incidence of later onset epilepsy, particularly among people with DS.

In Ireland, as elsewhere, there is continued movement of people with ID, including people with epilepsy, from residential-type settings with dedicated health care resources to more community-based settings. This will only increase needs among people with ID and epilepsy, their caregivers, and families for information about epilepsy and its management, access to specialized epilepsy centers, and support from specialist ID and epilepsy services. The planned waves of IDS-TILDA data collection will also offer an opportunity to understand how well community resources respond to the challenges faced by people with ID and epilepsy. These challenges are confounded by high prevalence of refractory epilepsy, and by communication and tolerance issues that often preclude investigation by electroencephalogram,

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magnetic resonance imaging, and computed tomography. Many people with ID may require a general anesthetic for these tests, and consent issues and associated risk may result in many people not receiving a standardized diagnostic work-up. Lack of experience among general health care professionals in communicating effectively with this population and little training in ID issues, the presentation of epilepsy, diagnosis, treatment and management, comorbidities, and risk of premature death for this population further compound these concerns. The findings of the current study should encourage high vigilance and competent and skilled support for people with ID and epilepsy.

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