Seizure: European Journal of Epilepsy 81 (2020) 111–116

Contents lists available at ScienceDirect

Seizure: European Journal of Epilepsy

journal homepage: www.elsevier.com/locate/seizure

Epilepsy, anti-seizure medication, intellectual disability and challenging behaviour – Everyone's business, no one's priority

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ARTICLE INFO

Keywords:
Learning disability
Anti-seizure medication
epilepsy

ABSTRACT

Purpose: People with Intellectual Disability (ID) and epilepsy are more likely to experience psychiatric conditions, challenging behaviour (CB), treatment resistance and adverse effects of anti-seizure medications (ASM) than those without. This population receives care from various professionals, depending on local care pathways. This study evaluates the training status, confidence, reported assessment and management practices of different professional groups involved in caring for people with ID, epilepsy and CB.

Methods: A cross sectional survey using a questionnaire developed by expert consensus which measured self-reported training status, confidence, and approaches to assessment and management of CB in people with ID and epilepsy was distributed to practitioners involved in epilepsy and/or ID.

Results: Of the 83 respondents, the majority had either a psychiatry/ID ($n = 39$), or Neurology/epileptology background ($n = 31$). Psychiatry/ID and Neurology/epileptology had similar confidence in assessing CB in ID-epilepsy cases, but Psychiatry/ID exhibited higher self-rated confidence in the management of these cases. While assessing and managing CB, Psychiatry/ID appeared more likely to consider mental health aspects, while Neurology/epileptology typically focused on ASM.

Conclusion: Psychiatry/ID and Neurology/epileptology professionals had varying training levels in epilepsy, ID and CB, had differing confidence levels in managing this patient population, and considered different factors

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Abbreviations: ID, Intellectual Disability; CB, Challenging Behaviour; MDT, Multi Disciplinary Team; ASD, autistic spectrum disorder; ADHD, attention deficit hyperactivity disorder

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https://doi.org/10.1016/j.seizure.2020.07.018
Received 18 May 2020; Received in revised form 9 July 2020; Accepted 20 July 2020

when approaching assessment and management. As such, training opportunities in ID should be offered to neurology professionals, and vice versa. Based on the findings, a best practice checklist is presented, which aims to provide clinicians with a structured framework to consider causal explanations for CB in this population.

1. Introduction

Epilepsy is a chronic neurological disorder characterised by an enduring predisposition to recurrent seizures, with social, biological and psychological consequences [1]. Epilepsy is more prevalent in persons with intellectual disability (ID) [2], compared to the general population [3]. In a cross-sectional study of 14,751 patients with ID, 18.5% had epilepsy compared to 0.7% of controls (Prevalence ratio 25) [4].

There are challenges to effectively managing epilepsy in people with ID, including communication issues [5], increased risks of detrimental effects of antiepileptic treatment [6], a lack of evidence of the effectiveness of anti-seizure medications (ASMs) [7], neuropsychiatric comorbidity [8] and complexities assessing and managing challenging behaviour [9] [10]. These are difficult to individually quantify as they depend on the specific population and study methodology.

Challenging behaviour is defined as culturally abnormal behaviours of an intensity, frequency or duration which jeopardise the safety of the individual or others, with possible resultant restricted access to the community [11]. Challenging behaviour is highly prevalent, with estimates suggesting 10% of ID patients having serious challenging behaviours Challenging behaviours have a complex relationship to epilepsy which can be affected by seizure type and medication related factors as well as other issues [10,12–16].

Comorbidities of epilepsy and ID include autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). A meta-analysis has shown a pooled prevalence of epilepsy of 21.5% in persons with autism and intellectual disability v. 8% in autism without intellectual disability [17].

Care pathways for people with ID and epilepsy are fragmented, poorly defined, regulated and governed [18], with marked heterogeneity in service provision between different UK regions. The professional discipline with treatment responsibility (e.g. neurology vs. psychiatry led) [18], and the context care is provided can vary widely, e.g. the general neurology outpatient clinic (with or without input from an ID psychiatrist) [18] or primary care).Relatedly, the training of ID psychiatrists in epilepsy and that of neurologists in ID is non-standardised. In the UK, psychiatric training includes the option to specialise in the Psychiatry of ID, qualifying the specialist as an ID psychiatrist. There is a lack of clarity on training standards, competency pathways and expected roles [18] and variability in the level of specialism. ID psychiatrists are offered training in epilepsy due to its increased prevalence in this patient group, yet may lack specialist knowledge pertaining to the diagnostic, investigation, and management aspects of seizures and the effects of ASMs [19,20]. Similarly, neurologists/epileptologists may have no training in the ID-specific elements of epilepsy, such as communication needs, environmental, risk, or mental capacity assessments, or an understanding of mental health and challenging behaviour [21].

It is hypothesised that different professional groups could have different priorities, insights, approaches, experiences, and biases regarding challenging behaviours. This has not been well explored in the ID and epilepsy context. The aims of this study were:

1 To identify the level of training of healthcare professionals in the assessment/management of challenging behaviour in patients with ID and epilepsy.
2 To assess confidence in assessment/management of challenging behaviour in patients with ID (without epilepsy) and epilepsy (without ID).
3 To assess approaches in the assessment/management of challenging behaviour in patients with ID and co-occurring epilepsy.
4 To develop a best practice checklist to guide professionals dealing with challenging behaviour in patients with ID and epilepsy.

2. Method and Materials

2.1. Measures and Survey Development

The study employed a mixed methodology, including qualitative and quantitative elements. A 12-item questionnaire (see supplementary information) was developed by RS, VC and MK alongside a consultation panel (comprising 11 national experts of 16 invited in either: epileptology, neurology, neuropsychiatry or ID; RTA, HA-L, MB, CC, JD, AH, MM, MR, HR, AR, MS). The survey was designed to take approximately 15 minutes to complete to facilitate a balance between ease of use and detailed information [22].

Initially, six vignettes were developed, then evaluated by the expert panel of clinicians and an expert by experience. After considering the qualitative feedback, on level of comprehension and clinical utility, two vignettes were taken forward for this present survey. Two final clinical vignettes (supplementary material) were presented within the survey. These vignettes were selected following development work with the expert panel.

Participants were asked to indicate their confidence in the assessment and management of each scenario on a five-point Likert scale from 1 - Not at all confident, to 5 - Very confident. Respondents entered free text (qualitative) replies to indicate factors they would consider in their approach to assessment and management.

2.2. Participants and Recruitment

The survey was accessible via SurveyMonkey®, with a link distributed by email to the professional networks and bodies which represent the occupational groups involved in the care of people with ID, epilepsy and challenging behaviour, and representatives from these networks and bodies were asked to forward the survey to their membership. The sample population was therefore drawn from the membership of the International League against Epilepsy British Chapter (ILAE, approximately 800 members), Royal College of Psychiatrists Faculty of ID (n = 332), Epilepsy Nurses Association (n = 340), and the Association of British Neurologists (n = 800). As potential respondents could be members of more than one organization the survey specified at the start that only one response is needed. Characteristics of non-responders were not available.

2.3. Data Analysis

Respondents (n = 70) were separated into two groups for quantitative analysis; neurology/epilepsy background, and psychiatry/ID background. Both quantitative (categorical and ordinal) and qualitative data were collected in this survey. Descriptive statistics and Chi-squared analysis were employed. Regarding Aim 1 and 2, descriptive statistics and Chi-squared analysis was used to compare the psychiatry and neurology groups. Where the Likert scale (1-5) was analysed using Chi-square approach, the responses were divided into two groups. The two Likert points indicating confidence (very confident and partially confident) were grouped, and compared to the two Likert points indicating low confidence (very unconfident and partially unconfident). The 2 × 2 analysis incorporated psychiatry and neurology groups and compared confident and low confidence groups.

P value significance was initially set at < 0.05, but with 11 hypotheses being tested, multiple comparisons were corrected with a Bonferroni correction and the newly determined significance level was set at P < 0.0045.

Aim three and aim four were approached using framework analysis, its methodology is appropriate for research that has specific questions, limited timeframe, pre-designed sample and a priori issues [23]. All respondents were included. Once key themes were assembled into a thematic framework, a checklist to provide a structured approach to causal explanations for challenging behaviour in this population was developed. The frequency of identified themes for different professional groups is presented.

2.4. Ethics and Governance

This project met the UK policy framework for health and social care research criteria for service evaluation, thus not requiring approval from a NHS Research Ethics Committee [24]. The survey was reviewed by each disseminating organization's chair prior dissemination to their membership. The survey was anonymous, and did not record or store personal data. Consent was presumed by the return of a questionnaire by a participant.

3. Results

Eighty three responses were received, mainly from medical and nursing professionals (Table 1). 95% were from the UK. Respondents were predominantly from a psychiatry/ID (n = 39) or a neurology/epilepsy background (n = 31) to include both medical and nursing disciplines. Respondents who did not indicate their specialism, and were classified as "unspecified" group (n = 13).

3.1. Training of healthcare professionals in ID and epilepsy

The majority of the respondents reported that they were fully qualified (e.g. Consultant Psychiatrist or Registered Learning Disability Nurse) (n = 65, 78%), with 10 (12%) currently in training and 8 (10%) did not specify their level of training. The cohort had 57 (69%) respondents with > 10 years clinical experience.

Sixty two (75%) respondents reported training/specialist interest/expertise in epilepsy and 44 (53%) in challenging behaviour. Eleven (13%) stated that they had no specialist knowledge of either. Of the respondents, 20/39 (51%) Psychiatry/ID professionals considered themselves to have expertise in both epilepsy and challenging behaviour, in contrast to 5/31 (16%) Neurology/epileptology (Chi squared; two-tailed P value, 0.0005*) (Table 1).

3.2. Healthcare professionals confidence in the assessment and management of challenging behaviour in patients with ID and epilepsy

3.2.1. Background confidence

Psychiatry and neurology professionals did not differ significantly in their confidence in the assessment [28 (74%) v 25 (81%) respectively] or management [30 (77%) v 18 (58%) respectively] of epilepsy associated with challenging behaviours (without co-occurring ID).

For challenging behaviour in ID (without epilepsy) psychiatrist professionals when compared to neurology professionals rated themselves as more confident in the assessment [35 (90%) v 16 (51%) P = 0.002*)] and management [13 (42%) of the Neurology/epileptology group (P = 0.0001*)], the result was significantly different (see supplementary table).

In their baseline confidence rating, psychiatry and neurology groups did show trends towards differences in their confidence in the assessment (28 v 19 respectively, P 0.051) and management (26 v 14 respectively, P, 0.016) of behavioural issues in epilepsy and co-occurring ID. With psychiatry groups showing greater confidence which after Bonferroni correction did not show significance.

3.3. The factors and approaches healthcare professionals consider when assessing and managing challenging behaviour in patients with ID and epilepsy (Vignettes)

The framework analysis indicated four overarching themes, biological, psychological/psychiatric/behavioural (mental health factors), social and medication-related factors (Table 2). Numerical results from summated themes per professional grouping are included in Table 3. Biological and social factors were considered equally between psychiatry and neurology groups, mental health factors were considered more frequently by psychiatry group and ASM related factors more frequently by neurology group (Table 3). Detailed statistical analysis for this aspect was not considered appropriate.

4. Discussion

This is the first UK based evaluation of healthcare professional's approaches to those with epilepsy/ID and challenging behaviours. The findings highlight differences in training, levels of confidence, and in assessment and management of the same vignettes. Neurology/epileptology professionals report less training in ID or challenging behaviour, were less confident in this area and didn't consider CB part of their skill set. They appeared more likely to attribute challenging behaviour to medication factors, in comparison to psychiatry colleagues who considered a broader range of factors, such as behavioural and psychiatric factors. Both groups considered biological and social factors to a similar extent. These findings are aligned with previous research which call for epileptologists to have enhanced psychiatric/behavioural neurology training [21,25]. An ILAE survey of 211 participants from 35 countries found > 60% of adult neurologists self-rated their knowledge of neurodevelopmental disabilities (Attention Deficit Hyperactivity

Table 1
Professional disciplines of respondents.

Professional discipline				N
Nursing (n = 28)		ID specialist		9
		Nurse with expertise in epilepsy		10
		Unspecified		8
		ID and epilepsy nurse (included within psychiatry/ID group)		1
Medical/affiliated (n = 55)	**Neurology based**	Neurology		14
		Epileptology		2
		Neurology/epileptology		5
	Psychiatry based	ID psychiatry Gold [15]		8
		ID psychiatry Silver [15]		3
		ID psychiatry Bronze [15]		11
		ID psychiatry (other)		3
		Neuropsychiatry		2
		Neuropsychiatry/general psychiatry		1
		General psychiatry		1
	Others	Clinical psychology		1
		General paediatrician		1
		General practitioner		1
		General practitioner with specialist interest in epilepsy		2
Self-reported expertise in epilepsy and/or behavioural assessment	Dual skilled (epilepsy and behavioural assessment) n (%)	Behaviour alone n (%)	Epilepsy alone n (%)	No specialist training in either n (%)
Psychiatry/ID (n = 39)	20 (51%)	9 (23%)	2 (5%)	8 (21%)
Neurology/epilepsy (n = 31)	5 (16%)	0 (0%)	24 (77%)	2 (7%)

Table 2
Assessing and managing challenging behaviour in a person with ID and epilepsy: framework analysis and checklist

Theme	
Biological factors - history taking, clinical examination and physical investigations	● Explore the history of the presenting complaint (with a focus on antecedent factors, seizure severity, including brain injuries, cognitive changes). ● Work out chronology of cause and effect. ● Explore possible underlying physical aetiologies (general medical issues such as; infections, metabolic upset, speech and language assessment of swallow, gut health check including stool chart evaluation, gastrointestinal symptoms, feeding regime/appetite (including relationship to meals), pain assessment, dental assessment, sleep evaluation, neurodegenerative disease, review other co-morbidities, including a review for possible trauma/injury). ● Complete biological investigations; blood testing (anti-seizure medication levels to assess compliance or toxicity), electroencephalography with comparison to previous electroencephalography results, video-telemetry, neuroimaging, lumbar puncture results, and video of any events/seizure diary. ● Complete bowel charts and urine dipstick. ● Measure weight (weight could be altering pharmacokinetics). ● Assess analgesia needs. ● Measure vital signs.
Mental health/psychological/psychiatric/ behavioural factors	● Complete a mental state examination/clinical psychology/ neuropsychiatry/neuropsychology assessment to explore for underlying/new psychiatric disorders such as depression, anxiety, autistic spectrum disorder, obsessive compulsive disorder). ● Consider other factors, such as the patient's insight into their behaviours and the impact it has on others, ● Boredom/engagement/occupational therapy needs, forced normalisation, bereavement, sensory issues. ● Complete a detailed behavioural assessment (e.g. positive behavioural support/functional analysis) with intellectual disability team. ● Consider the need for positive behavioural support plan amendments, de-escalation strategies, anger management strategies and cognitive behavioural therapy. ● Consider communication factors and refer for speech and language support if relevant.
Social factors	● Consider issues within social network, e.g. difficulties with friends or family. This will required detailed collateral history from other professionals and carers, particularly if the patient has communication difficulties. ● Consider environmental or life circumstances changes, e.g. /routine/social situation/carers), quality of life, levels of independence, sexual issues, trauma, vocational and recreational needs, whether the current care package is adequate, evaluate the living situation, e.g. whether others in the residential environment are affecting the patient's mental health. ● Impact assessment of seizures on family and behaviour and provide family training/support to work with patient. ● Consider the need for services such as outreach support or respite. ● Consider the need for social worker involvement, as well as other professionals, such as buddying, assisted living, or key workers, etc.
Medication factors	● Consider relevance of any recent changes in the anti-seizure medication, or other medications. Trial small dose reductions in cases of possible forced normalisation. ● Consider adverse effects including neuropsychiatric effects of medications. ● Consider patient compliance with medication, factors such as medication brand change, polypharmacy, drug errors, interactions and contraindications. ● Have rescue medications available. ● Consider the patient's level of understanding the risks and benefit analysis between drug side effects and the risk of having seizures. ● Consider the efficacy of past therapeutic approaches.

Table 3
Themes endorsed by healthcare professionals in each vignette scenario

	Vignette 1				Vignette 2			
	Assessment		Treatment		Assessment		Treatment	
	Neurology N (%)	Psychiatry N (%)	Neurology N (%)	Psychiatry N (%)	Neurology N (%)	Psychiatry N (%)	Neurology N (%)	Psychiatry N (%)
Biological	8 (26)	17 (44)	10 (32)	16 (41)	28 (90)	36 (92)	24 (77)	28 (72)
Mental health	16 (52)	28 (72)	16 (52)	26 (67)	9 (29)	14 (36)	8 (26)	15 (38)
Social	18 (58)	17 (44)	7 (23)	14 (36)	15 (48)	17 (44)	8 (26)	11 (28)
Medication	29 (94)	24 (62)	18 (58)	12 (31)	10 (32)	14 (36)	8 (26)	8 (21)

NB. For each vignette only one mention of a domain (such as biological) would be counted, giving a maximum of 31 for Neurology/epileptology and 39 for Psychiatry/ID. Two examples within the same domain were still only counted once. Note the absolute differences in Vignettes is not as relevant as is the difference between professional groups.

Disorder or Autism) as poor [21].

The apparent focus of epilepsy specialists on the seizure disorder perhaps reflects historical factors [25], and has resulted in a recent call for epilepsy specialists to consider standardized assessments of patients with ID and to factor in their comorbidities [26].

Our study findings have themes relevant to; clinical practice, training, policy development, and future research.

4.1. Implications for clinical practice

This work confirms clinicians can consider the same scenario differently depending on multiple factors including their professional training, which will impact on care processes in this vulnerable patient group. Clinicians should be mindful that "expectations" they will act in a certain way does not make it necessarily the best option i.e.

epileptologists alter ASMs.

A standardised checklist (Table 2) which contains all factors a clinician should reasonably consider when facing challenging behaviour could reduce variation in practice. Clinicians should review their practice against peers by looking for their clinical “Achilles heel", for any cognitive bias [27] in their training or their current clinical skills. “Anchoring bias”; and “premature closure” of diagnostic reasoning are pertinent in the evaluation of challenging behaviour to prevent diagnostic overshadowing.

4.2. Clinical Training Implications

Undergraduate and postgraduate curricula should consider the needs and deficiencies in training to date of various professional groups as identified in this study. The new ILAE epileptology curriculum rates skills in recognition and management of the needs of patients with epilepsy and ID as an advanced proficiency [28]. Similarly, the role of ID psychiatrists in the management of epilepsy has recently been clarified using a gold/silver/bronze tiered competency framework (gold representing expert) [18]. The real world implementation is less clear, with a majority of ID psychiatrists being interested in working in epilepsy, but identifying the barriers of training, resources and time [19].

Curriculum changes often target trainees, but measures to address the needs of working professionals are required. Professional development alongside multidisciplinary learning and working is key. Innovate methods of joint working and training between ID psychiatry and neurology urgently need to be considered and evaluated.

4.3. Policy Implications

A ILAE White Paper called for better care standards and pathways, multidisciplinary approaches, and improved links of relevant stakeholders to improve epilepsy care within ID settings [28]. Kerr et al [29] outlined an assessment framework by which patients with ID and epilepsy are considered from an epilepsy, medication, psychological and social perspective. The present work has built on this by assessing individual expert clinician’s training and confidence in these areas. The current study supports the need for multi-disciplinary networks of clinicians and nurses from different speciality backgrounds. Appropriate local commissioning should be engaged for this purpose.

4.4. Strengths and Limitations

This is the first in-depth exploration of clinician’s training, confidence, and practice regarding the assessment and management of behavioural challenges in patients with epilepsy and ID. We obtained a sample of experienced UK professionals from a multi-disciplinary background with long service in their respective disciplines, which facilitated a focused examination of practice in this region.

Regarding limitations, it is difficult to generalise the findings to other healthcare systems with different care pathways. Varied factors can impact on confidence which were not evaluated, such as burn-out, workplace dynamics, expectations culturally about clinical skill are possessed by certain groups, and culture. These results are hypothesis generating. There was incomplete information on non-responders, and a small sample size (perhaps as low as 4%), for which the reason is unclear. Variable effort in completing the vignette free text answers is always possible.

It is perhaps the case that psychiatrists and neurologists don’t have such different approaches, but rather working in respective silos develop different approaches based on tradition and expectation. Neurologists given appropriate MDT access and time to resolve issues may have the same approach as psychiatry professionals. Access to MDT input, and the full clinical context, including the spectrum of severity of cases of ID seen was not assessed in this survey. Confidence is partly a culturally developed notion and may have other exogenous influences such as personality, burnout, wellbeing, political or workplace specific factors not assessed.

Some psychiatrists reported expertise in epilepsy but not behavior and 8 reported expertise in neither. These responses were considered atypical, and it is unclear what the exact professional situations of these respondents were to provide further clarification.

4.5. Research Implications

Future research should assess the care pathways operational within the UK for this clinical population, as issues are likely to be particularly evident in geographical regions where care of those with ID and epilepsy is led solely by one professional discipline, with limited joint working. A future survey should examine the epilepsy/ID care provision region by region. This will provide an indication of the areas which could benefit from prioritisation of a strategy to develop multidisciplinary working between psychiatry/ID and neurology/epileptology professionals. The proposed checklist should be validated in future research. Little mention was made of ASD and ADHD and views of professionals could be the work of a future survey to see to what extent neurology specialists consider the diagnosis as influencing their decision making in epilepsy.

5. Conclusion

Differences in the training of psychiatry and neurology professionals and their clinical confidence may influence how challenging behaviours in ID and co-occurring epilepsy is approached.

Funding

This study is supported by an Eisai pharma Investigator instigated study (IIS) grant, post independent blinded peer review of the project. Eisai had no role in any study related activity including the study design, recruitment, analysis and report writing.

Declaration of Competing Interest

MK has received salary support from UCB to allow a period of elective work. He was paid via his direct employer the Belfast Health and Social Care Trust.

VC has received payment from the University of Exeter for work on this project.

ST has received salary support from Leicestershire Partnership NHS Trust, to allow for undertaking a PhD as part of an Honorary Academic Clinical Lecturer position. He has also received support from the National Institute for Health Research for his PhD study.

RTA - No conflicts of interests to declare

HAL receives salary from the National Institute for Health. HAL reports non-pharmacological research support from Eisai, Epilepsy Action and Royal Free Charity, and Honoraria from Eisai, Combigene and UCB outside this work. She has been on Advisory boards for MHRA, Association of British Neurologists, Royal College of Physicians and Sanofi women and epilepsy education boards.

MB - has received honoraria from UCB Pharma, LivaNova and Eisai

HC reports grants from U.S NIH Institute of Neurological Disorders and Stroke, non-financial support from International League Against Epilepsy, E-learning Task Force, non-financial support from European Academy of Neurology, personal fees from Bial and Eisai, other from Novartis, other from GW Pharma, outside the submitted work.

JD - No conflicts of interests to declare

AH - No conflicts of interests to declare

MM - has received consultancy fees from UCB and Eisai.

MR has received an educational grant from UCB-Pharma and speaker’s fees from UCB Pharma, Eisai and Livanova.

HR - No conflicts of interests to declare

AR - No conflicts of interests to declare

MS has received fees from UCB for talks, this is paid to the Trust rather than to him personally.

RS has received institutional, research support and speaker fees from LivaNova, UCB, Eisai, Special Products, Bial and Desitin, outside this work. He is a contributor and author in the development of the non-commercial SUDEP and seizure safety checklist, working with SUDEP Action and the e-app EpSMon.

Acknowledgements

We wish to thank colleagues across the UK who gave their time to fill in the questionnaire.

We wish to thank Eisai UK for their IIS grant for the project

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.seizure.2020.07.018.

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