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Management and attitudes toward patients with epilepsy in general practice: How far have we come in three decades?

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ABSTRACT

Background: Previous surveys of Australian primary care physicians' attitudes regarding epilepsy and persons with epilepsy (PWE), conducted 20–30 years ago, identified the need for further education in epilepsy care for frontline clinicians. This follow-up study of general practitioners (GPs) in Sydney was conducted to determine the degree of changes in knowledge, attitudes, and management of PWE, with the purpose of evaluating if there had been significant improvement during this period.

Methods: A questionnaire, evaluating various aspects of epilepsy care, including investigations, preferred healthcare provider (HCP), and attitudes toward epilepsy was developed, largely based on the previous work, piloted, and completed by a representative sample of Sydney GPs.

Results: A total of 52 completed responses were received. Thirty-six out of 47 GPs (77%) chose neurologists as the most important HCP followed by the GP (9/47; 18.7%). Almost half of the GPs (25/51; 49%) mentioned that they never initiated antiepileptic medication (AEM) therapy by themselves yet half of these GPs would alter the neurologist's regimen, without necessitating referral back to that neurologist. Another 27% (14/51 GPs) rarely commenced AEM therapy. Six out of 50 GPs did not mention an electroencephalogram (EEG) as a routine investigation, and 21/50 did not mention magnetic resonance imaging (MRI) as routine for PWE. The five most commonly used AEMs, identified by at least 10% of respondents, were sodium valproate (42), carbamazepine (37), levetiracetam (31), lamotrigine (16), and phenytoin (15). Emotional, behavioral, and psychosocial issues were perceived to be more common among PWE; however, they could contribute equally well to society as people without epilepsy.

Conclusion: The results of the study indicate a perceptual shift regarding GP's attitudes to epilepsy; however, there remain deficiencies in knowledge, particularly with regard to investigations and management. The study highlights the need for more formal training of GPs in caring for PWE.

1. Introduction

Epilepsy is a common, chronic illness associated with several comorbid conditions [1]. There is stigma and potential bias that has been pervasive to the point that even medical practitioners have been identified as contributing to the bias [2]. In addition to persons with epilepsy (PWE) experiencing stigma and bias, treating medical practitioners also face difficulties in managing issues related to it. Medical practitioner's knowledge and attitudes can impact on healthcare delivery [2] and hence impact on the quality of life of PWE.

There have been two surveys which examined the perspectives of Sydney general practitioners' (GPs) management and attitudes regarding PWE. The first of these studies by Beran and Read was published in 1983 [3] and repeated 11 years later by Frith et al. [4]. The original survey showed stereotypic attitudes and management of PWE among GPs. It suggested a need to reconsider undergraduate training and indicated a need to reappraise the total healthcare package offered to PWE.

The follow-up survey, conducted by Frith et al., evaluated changes in knowledge and management of epilepsy and attitudes of GPs toward PWE. It found that the stereotyped perceptions of GPs had improved after a decade of medical education. It confirmed that there was insufficient improvement to allow either complacency or sufficient satisfaction that the intervention had been adequate. The present study offers

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an audit of the outcome following three decades of educational promotion regarding epilepsy.

1.1. Aim

The current survey revisited the issues raised in the previous two studies and evaluated if there had been significant changes/advances in knowledge, attitudes, and management of PWE among Sydney GPs over a period of more than three decades. The study recognized that the field of epileptology had made great progress with newer antiepileptic medications (AEMs), better imaging, and more advanced patient evaluation [5–7]. The purpose of the investigation was to evaluate if there had been commensurate change among GPs during this period.

2. Methods

A piloted survey was conducted within a sample of GPs in the McArthur area, located in southwestern Sydney, Australia, in 2015. The study was approved by Sydney South West Area Health Service Human Research Ethics Committee (HREC Ref. No. LNR/15/LPOOL/419/Local Project Number HE15/232). To allow comparison, the questionnaire (see Appendix) was largely based on that previously used by Beran and Read. Medicare Local, an Australian primary healthcare organization, was contacted to obtain the number of GPs in active practice in this catchment area. Seventy-four GPs were identified that were in active practice. These GPs were contacted to seek consent to participate in the survey, either by phone call with a predetermined telephone script or by face-to-face appointment at their practice. Informed consent was obtained for voluntary participation by each doctor. Completed questionnaires were returned to researchers via fax or e-mails. There was no financial incentive provided to the participants.

2.1. Statistics

Descriptive statistics such as mean and standard deviation were obtained for all continuous data points in the survey, while percentages were used for questions with discrete variables. All data were analyzed using SPSS statistical software (Version 23 for Windows, SPSS, Armonk, NY, IBM Corp, USA).

3. Results

3.1. Demographics

Of 74 GPs, 62 (84%) agreed to participate. Of these, 52 (84%) completed the survey. One GP who had no experience with PWE was excluded providing a response rate of 69%.

Thirty-five GPs were between 31 and 50 years (68.6%). A total of 42 age ranged between 31 and 60 years (82.4%). Twenty-nine GPs graduated from Australian and New Zealand universities (56.9%). Among the 22 overseas GPs, 20 came from Asian countries (90.9%). Thirty-nine GPs answered questions regarding their postgraduate status. The majority (87.2%) had a postgraduate degree equivalent to specialist training in family/primary care medicine (Fellowship of the Australian College of General Practice). Demographics regarding age and country of basic qualification was compared with government data and confirmed this to be representative of Sydney practitioners and hence considered reflective of the wider Sydney GP population [8].

3.2. Previous experience

Most respondents witnessed their first seizure as a medical student or prior to medical study (37/48; 77.1%). Most GPs first managed a seizure during their internship (32/46; 69.6%), another 21.8% (10/46) during postgraduate training or in their private practice.

3.3. Diagnosis and management

Forty-five out of 51 GPs (91%) answered questions regarding seizure classification. Answers consistent with the International League against Epilepsy (ILAE) 1989 classification [9] or the revised 2010 classification [10] were accepted. Twenty-seven out of 45 (60%) distinguished focal and generalized seizures in their responses. Thirteen out of 45 (29%) were able to correctly identify three or more seizure types. Thirteen out of 45 (29%) did not identify any seizure types correctly.

Almost half of the GPs (25/51; 49%) mentioned that they never initiated AEM therapy. Another 27% (14/51 GPs) rarely commenced AEM therapy.

Among the GPs who never initiated AEM therapy, half of them (12/24; 50%) would change the management, initiated by the consultant, without referring back to that initiating neurologist. This is in keeping with the previous studies.

Among the 26 out of the 51 GPs (51%) who would initiate therapy by themselves, the majority (23/26; 88.5%) would refer the patient for further advice. This group of GPs would also check the AEM levels before altering a regimen. Two out of these 23 GPs (~9%) mentioned that they would never alter the regimen without referral back to the consultant.

"Investigations which should be routinely undertaken for epilepsy" are summarized in Table 1 and compared with Beran and Read. Six out of 50 GPs (12%) did not recommend an electroencephalogram (EEG) as a routine investigation, whereas, in the Beran and Read study, EEG was recommended by all GPs. Almost all GPs in the present study would routinely perform full blood count (49/50; 98%) and biochemical profile (50/50; 100%). Only four out of 50 GPs in this study would recommend chest X-ray and one out of 50 a skull X-ray, as routine investigations. Twenty-nine out of 50 GPs (58%) recommended routine magnetic resonance imaging (MRI) brain for PWE.

Healthcare providers (HCPs) used in management of PWE and satisfaction with them were determined on a scale ranging from one to seven. Scores of one to two indicated a low degree of satisfaction whereas scores of six or seven indicated a high degree of satisfaction. Scores from four to six were categorized as having a moderate degree of satisfaction. Healthcare providers identified by at least 10% of the respondents were analyzed (Table 2). Neurologists were chosen by all the GPs (51/51; 100%) and achieved high levels of satisfaction (45/51; 88.2%) and perceived to have good expertise, experience, professionalism, accessibility, and long-term care management. Casualty doctors (20/51; 39.2%) were chosen as the next most important, after neurologists; however, they achieved lower rates of high satisfaction (3/20; 15%) and were perceived to have lower levels of expertise. General physicians were chosen by 18 out of 51 GPs (35.3%) with the majority receiving a high satisfaction rating (12/18; 66.6%). Eleven GPs (11/51, 21.6%) chose radiologists as important HCPs whereas they were not chosen in the previous two studies [3,4].

Table 1
Investigations performed by GPs for PWE.
Investigation choices among GP respondents caring for PWE. One GP out of 51 did not answer this question in the study.

Choice of investigation	Current study cohort n (%)	Beran and Read [3] cohort n (%)
Electroencephalogram	44 (88%)	50 (100%)
Full blood count	49 (98%)	40(80%)
Biochemical profile	50 (100%)	42 (84%)
CT brain	33 (66%)	24 (48%)
Chest X-ray	4 (8%)	23 (46%)
Skull X-ray	1 (2%)	41 (82%)
Electrocardiogram	24 (48%)	8 (16%)
Psychometric testing	1 (2%)	5 (10%)
Nucleotide brain scan	0 (0%)	13 (26%)
MRI brain	29 (58%)	Not asked
PET scan	2 (4%)	Not asked

Table 2
Healthcare provider used by GP and degree of satisfaction.
A score of 1 or 2 indicates a low degree of satisfaction with care provided by the healthcare professional, a score of 3, 4, or 5 a moderate degree of satisfaction, and a score of 6 or 7 a high degree of satisfaction.

Healthcare provider	Number referred n (%)	Degree of satisfaction with care		
		Low n (%)	Moderate n (%)	High n (%)
Neurologist	51 (100%)	2 (4%)	4 (8%)	45 (88%)
Casualty doctor	20 (39%)	3 (6%)	11 (22%)	6 (12%)
Consultant physician	18 (35%)	0 (0%)	6 (12%)	12 (24%)
Radiologist	11 (22%)	0 (0%)	3 (6%)	8 (16%)
General practitioner (not self)	9 (18%)	2 (4%)	3 (6%)	4 (8%)
Neurosurgeon	9 (18%)	1 (2%)	5 (10%)	3 (6%)
Occupational therapist	7 (14%)	0 (0%)	5 (10%)	2 (4%)
Psychologist	6 (12%)	1 (2%)	4 (8%)	1 (2%)
Rehabilitation expert	6 (12%)	0 (0%)	4 (8%)	2 (4%)

Regarding the perception of the most important HCP in the management of PWE, 36 out of 47 GPs (77%) chose neurologists. The second most important HCP was the GP (9/47; 18.7%). These findings are similar to Frith et al.

The five most commonly used AEMs, identified by at least 10% of the respondents (50 GPs answered this question), according to frequency were sodium valproate [42], carbamazepine [37], levetiracetam [31], lamotrigine [16], and phenytoin [15]. Sodium valproate achieved greater preference whereas phenytoin attracted less preference in comparison to the initial study (Table 3). Newer AEMs such as levetiracetam and lamotrigine (previously not available) were added to the list of preferred AEMs. Older AEMs, such as primidone and phenobarbitone, no longer attracted similar preference. Recent additions to the list of AEMs, such as topiramate, oxcarbazepine, lacosamide, zonisamide, or parempanel, all of which are available on the Pharmaceutical Benefits Scheme (the publically subsidized formulary in Australia), were not listed.

3.4. Knowledge

In terms of where they gained most of their knowledge, 15 out of the 44 respondents (34.1%) selected “undergraduate medical training”; 12 (27.3%) mentioned “post graduate training”; nine (20.5%) chose “informal medical experience”; and seven (15.9%) mentioned “private reading”.

3.5. Perceptions of PWE

The perception of psychological, emotional, and behavioral issues in PWE was determined using a scale from one to seven. A higher score indicated that the issue was perceived to be more prevalent, among PWE. Overall, psychological and behavioral issues both achieved a mean score of four while emotional issues achieved a mean score of five. Greater than 20% of GPs believed that PWE were more likely than others to have emotional problems, behavioral problems, mood swings, and difficulty relating to other persons. Thirteen out of 44 GPs (30%) also believed that PWE were more likely to be absent from work or school. These results are consistent with the results of both Beran and Read and Frith et al. Compared to Beran and Read, there has been an improvement where mood swings, behavioral, and emotional problems were perceived to be more likely in PWE by over 30% of respondents [3]. The number of respondents reporting aggression as more frequent was dropping from 28% to 15%.

However, most GPs 41/50 (82%) indicated that PWE could contribute to society equally as well as those without epilepsy, which has improved from the Frith et al. study, with 68% providing the same response.

Table 3
AEM usage.
Five most commonly prescribed AEMs by GPs in current study and in Beran and Read [3].

AEM	Frequency of AEMs prescribed in current study n (%)	Frequency of AEMs prescribed in Beran and Read n (%)
Sodium valproate	42 (84%)	23 (46%)
Carbamazepine	37 (74%)	34 (68%)
Levetiracetam	31 (62%)	0 (0%)
Lamotrigine	16 (32%)	0 (0%)
Phenytoin	15 (30%)	50 (100%)
Primidone	0 (0%)	25 (50%)

4. Discussion

This study sought to identify whether there had been changes in knowledge and attitudes concerning epilepsy among Sydney GPs, since those studies performed more than 30 years ago. Previous studies indicated that there were significant gaps in knowledge among GPs with respect to their diagnosis and management of PWE. The findings from the current study revealed that there continues to be deficiencies in epilepsy knowledge and management among GPs.

The recent reclassification of seizures and epilepsy by the ILAE [11] presents a challenge. Most respondents could not correctly identify more than two seizure types in the current study, according to the 1989 or revised 2010 classification. General practitioners who may not be aware of or use the new classification may not be able to accurately and effectively communicate with other epilepsy care providers, such as neurologists, regarding their patients' diagnosis and management. In addition, medications approved only for specific seizure types mean that errors in classifying seizure type may lead to ineffective treatment [12].

Choice of investigations also requires further attention. Only 58% of GPs would obtain an MRI for PWE, and 12% did not mention EEG as a diagnostic investigation tool. Magnetic resonance imaging has long been considered one of the gold standard imaging tests in epilepsy [6].

Similarly, EEG remains a primary and valuable diagnostic tool for the assessment of PWE, yet >10% of respondents failed to recognize its role, thereby demonstrating a shift in its appreciation and a potential need to reinforce appropriate investigation of PWE. Certain forms of genetic generalized epilepsy have characteristic EEG patterns which are essential to diagnosis [13]. Electroencephalogram itself can be a tool to guide further management [13,14]. The reason for the decline, since Beran and Read, may be due to more advanced imaging modalities such as MRI, possibly seen as supplanting the need for an EEG, but it fails to recognize the ongoing diagnostic and differentiating roles provided by EEG, especially if positive for epilepsy [14]. The number not advocating EEG should also be seen within the context that ~40% of respondents who did not include MRI in the routine assessment of PWE. This suggests a definite gap in the understanding and evaluation of PWE and a need to reappraise GP teaching of the assessment of PWE. Almost all GPs would perform a full blood count and electrolyte profile which provides further confounding picture when considered in light of higher yield tests for the diagnosis of epilepsy such as MRI [15].

These results indicate a need for better education for GPs regarding epilepsy diagnosis, investigations, and management.

There remains a perception among many GPs that PWE are more likely to have behavioral, psychological, and emotional issues than persons without epilepsy. The reasons for these perceptions have not been well studied; however, those with chronic diseases are more likely to have concurrent mental health disorders [16–18] as well as poor coping strategies [19]. Some forms of epilepsy can be associated with cognitive impairment [18]. Previous studies [3,4] suggested that a degree of stereotyping of PWE may be contributing to attitudes, given the uniformity of responses across behavioral and social domains. Stigma has

been a real problem for PWE [3,4], and these results suggest that doctors may be contributing to this problem with stereotypic attitudes which may impede empathic management.

Despite these perceptions, most GPs indicated that PWE could contribute to society equally as well as those without epilepsy. This would indicate that these issues are not seen as a barrier to functioning in society but rather are associated with the diagnosis. There appears to be a paradox between the responses to these contradictory questions which may indicate that respondents provided answers expected by the researchers while there may persist significant covert stigma which could still include GPs. This would suggest that future educative programs directed at GPs (and possibly to the wider medical community) should include a segment on psychosocial and attitudinal aspects to improve levels of covert prejudice. A further issue which may warrant exploration is the management of mental health issues in PWE, given the higher incidence [20,21]. General practitioners still see themselves as an important primary care provider in PWE. Hence, it is of high importance that GP attitudes toward PWE are reflective of current evidence and not based on stereotyped attitudes, given the impact attitudes can have on patients' self-esteem and by extension, the doctor–patient relationship.

It is important to acknowledge that the newer AEMs were not included in the list of agents available to PWE. This, together with the shift in perceived value of EEG and changing attitudes toward imaging, also suggests a need for further education on treatment and management. General practitioners are the backbone of the Australian medical system and yet a significant number of them will alter a neurologist's regimen and may do so without AEM levels yet show gaps in knowledge regarding available AEMs. These concerns should be addressed and incorporated into future educational programs. The role of epilepsy surgery did not attract attention, and newer evaluative tools likewise did not rate consideration.

Our study has limitations. The small sample size and restricted geographic locale may limit its generalizability. The authors tried to minimize potential bias, by electing to use a sample representative of Sydney GPs based on government data, the same method used in the original Beran and Read paper. We acknowledge, however, that despite this, the results will be limited by the small sample size and a response bias, common to all surveys.

Despite this, there has been consistency of survey responses across three studies, over 30 years apart, supporting the validity of the present studies' results.

5. Conclusion

There is a need for further education of GPs across all aspects of epilepsy care. Despite 24 years elapsing since Frith et al., stereotypic attitudes toward PWE remain, and there remain significant knowledge gaps with regard to epilepsy and its management. The ongoing evolution and complexity of epilepsy management demands more formal training of primary care providers as well as resources to support them. Future studies should be aimed at elucidating the reasons for the continuation of stereotypic attitudes among many GPs toward PWE.

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Declaration of competing interest

None of the authors have any conflict of interest to disclose. We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2019.05.020.

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