Inequities in provision of seizure care across the Wellington Region

Purwa Joshi, Eloise Watson, Ian Rosemergy, Sisira Jayathissa

ABSTRACT

AIM: We wanted to determine whether adult patients presenting with a seizure to the emergency department (ED) of Wellington Hospital and Hutt Hospital, in the Wellington region, were equally likely to be referred for neurology input.

METHODS: A retrospective review was conducted of 250 consecutive patients presenting with a seizure to the ED of each hospital. Patient electronic records were examined to determine the proportion of patients discussed with the inpatient neurology team and referred to neurology outpatient clinic.

RESULTS: Fifty-two per cent of the patients presenting to Wellington Hospital ED with a seizure were referred to neurology, compared to 13.4% of those presenting to Hutt Hospital ED. The proportion of ‘first seizure’ patients referred to neurology was 63.1% for Wellington Hospital and 9.8% for Hutt Hospital. The difference in referral rates was primarily attributable to the difference in inpatient referrals. Māori were over-represented in the patients presenting to ED with a seizure, compared to their population composition.

CONCLUSIONS: This study demonstrated unequal referral practices and therefore provision of neurology care for adult seizure patients across the Wellington region, for patients with established epilepsy and those with a first seizure. There were a disproportionately high number of Māori accessing acute seizure care.

Introduction

The healthcare services in the Wellington region of New Zealand are provided by three district health boards (DHBs), Capital & Coast DHB (CCDHB), Hutt Valley DHB (HVDHB), and Wairarapa DHB. Each DHB has one acute hospital with emergency medical services. However, only CCDHB has a tertiary-level neurology department. This department is responsible for provision of neurology care to the entire region, with a total population of around 490,000.1 The department operates from Wellington Hospital (CCDHB), with two outreach outpatient clinics provided at Hutt Hospital (HVDHB). There are no outpatient clinics provided at Wairarapa DHB.

In the preceding year, there were five sudden unexpected deaths in epilepsy (SUDEP) cases amongst young adult epilepsy patients in the HVDHB area. A review of these deaths prompted us to evaluate the provision of epilepsy care in the Wellington region. In particular, we wanted to determine whether adult patients presenting to CCDHB and HVDHB emergency departments with epilepsy were managed in a similar way.

The National Institute of Clinical Excellence (NICE) guidelines recommends that all patients presenting with a first seizure, and those presenting with repeated seizures, should be reviewed by an epilepsy specialist.2 This is to ensure that patients receive an early and accurate diagnosis as well as initiation of treatment as appropriate.

Methods

We conducted a retrospective review of 250 consecutive adult patients presenting to emergency departments (ED) of Wellington Hospital and Hutt Hospital with a seizure before 31 December 2013.

Discharge coding was used to search for patients aged 16 years or higher, presenting to the Wellington Hospital ED and Hutt Hospital ED with the primary diagnosis of a seizure (ICD-10 codes G40.x, R56.1, R56.9).
starting from 31 December 2013 and going back until 250 consecutive patients were included. Repeat presenters were only included once.

A review of the emergency department electronic notes and the discharge summary for each patient was undertaken. From these sources, we collected demographic information as well as whether this event was the patient’s first seizure, whether the patient’s management was discussed with a Neurologist and whether the patient was referred to the neurology outpatient clinic. Data was entered into a secure epilepsy database, EpiNet. The t-test was used to compare the difference between proportions.

Demographic data was compared to the Ministry of Health census data for each DHB separately.

This study was done as a quality improvement activity, and according to National Health and Disability Ethics Committee guidelines, did not require ethics approval.

Results

Two hundred and fifty unique patients presented to Wellington Hospital between 11 February 2013 and 30 December 2013. For the Hutt hospital, the same number presented between 20 October 2012 and 31 December 2013. The baseline characteristics of these patients are given in Table 1.

There were more European patients presenting to Wellington ED, representing the ethnic mix of two DHBs. Māori were over-represented in the patients presenting with a seizure to both hospitals, as shown in Table 2. Sixteen percent of the seizure patients presenting to Wellington Hospital were Māori, compared to the population composition of 11.1%. Twenty-two percent of the seizure patients presenting to Hutt Hospital were Māori, compared to the population composition of 17.8%.

Rate of neurology referral for all patients

A significantly higher proportion of patients presenting with a seizure to Wellington ED (52%) were referred to

Table 1: Baseline characteristics of seizure patients

<table>
<thead>
<tr>
<th></th>
<th>Wellington ED N = 250</th>
<th>Hutt ED N = 250</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years</td>
<td>45.7</td>
<td>45.1</td>
<td></td>
</tr>
<tr>
<td>Male gender</td>
<td>137 (54.8%)</td>
<td>132 (52.8%)</td>
<td>0.65</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European &amp; other</td>
<td>196 (78.5%)</td>
<td>174 (69.3%)</td>
<td>0.03</td>
</tr>
<tr>
<td>Māori</td>
<td>41 (16.3%)</td>
<td>55 (21.9%)</td>
<td>0.11</td>
</tr>
<tr>
<td>Pacific</td>
<td>13 (5.3%)</td>
<td>21 (8.5%)</td>
<td>0.16</td>
</tr>
</tbody>
</table>

Table 2: Ethnic distribution of seizure patients compared to the regional population

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Wellington ED Seizure patients (%) (N = 250)</th>
<th>% Capital &amp; Coast DHB population (N = 302,645)</th>
<th>p-value</th>
<th>Wellington ED seizure patients (%) (N = 250)</th>
<th>% Hutt Valley DHB population (N = 145,835)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Māori</td>
<td>41 (16.3%)</td>
<td>11.1%</td>
<td>0.008</td>
<td>55 (21.9%)</td>
<td>17.8%</td>
<td>0.08</td>
</tr>
<tr>
<td>Pacific</td>
<td>13 (5.2%)</td>
<td>7.3%</td>
<td>0.20</td>
<td>21 (8.5%)</td>
<td>8.5%</td>
<td>0.95</td>
</tr>
<tr>
<td>European &amp; other</td>
<td>196 (78.5%)</td>
<td>81.6%</td>
<td>0.19</td>
<td>174 (69.6%)</td>
<td>73.7%</td>
<td>0.14</td>
</tr>
</tbody>
</table>
neurology services compared to those presenting to Hutt ED (13.6%). This difference was statistically significant. The proportion of seizure patients that were discussed with the inpatient neurology team while the patient was in ED, and the proportion that were referred to the neurology outpatient clinic are shown in Table 3. Patients presenting to Wellington ED were more likely to be discussed with neurology whilst in the emergency department, compared to those presenting to Hutt ED. First seizure patients presenting to Hutt ED were more likely to be referred to another medical specialist or discharged without a specialist referral. See Table 4.

### Discussion

The National Institute of Clinical Excellence (NICE) recommends that all epileptic patients presenting with recurrent seizures should be referred to an epilepsy specialist. Furthermore, NICE recommends that all patients presenting with a first seizure should be referred to an epilepsy specialist—and seen, ideally, within 2 weeks. These recommendations were developed after an audit of SUDEP cases in the UK in 1999 found that 35% of the patients received inadequate access to specialist care. Our study shows that the provision of epilepsy specialist care in the Wellington region falls well short of these recommendations, and that the level of provision of seizure care varies between adjacent DHBs.

The reported incidence of SUDEP is 0.35 deaths per 1,000 person-years in a population-based cohort. The population prevalence of epilepsy in developed countries is reported to be approximately 0.5–0.7%. If we apply this rate to the HVDHB population, there would be approx-

### Table 3: Rate of specialist referral or advice for all seizure patients

<table>
<thead>
<tr>
<th>Type of referral</th>
<th>Wellington ED N = 250</th>
<th>Hutt ED N = 250</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurology In ED*</td>
<td>130 (52%)</td>
<td>34 (13.6%)</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Outpatient</td>
<td>96 (38.4%)</td>
<td>9 (3.6%)</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Other specialist</td>
<td>34 (13.6%)</td>
<td>25 (10%)</td>
<td>0.21</td>
</tr>
<tr>
<td>No specialist</td>
<td>42 (16.8%)</td>
<td>90 (36%)</td>
<td>&lt; 0.0001</td>
</tr>
</tbody>
</table>

* In ED = case discussed with neurology team while the patient was in ED.

### Table 4: Rate of specialist referral or advice for first seizure patients

<table>
<thead>
<tr>
<th>Type of Referral</th>
<th>Wellington ED N = 76</th>
<th>Hutt ED N = 61</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurology In ED</td>
<td>48 (63.2%)</td>
<td>6 (9.8%)</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Outpatient</td>
<td>37 (48.7%)</td>
<td>1 (1.6%)</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Other specialist</td>
<td>11 (14.5%)</td>
<td>5 (8.2%)</td>
<td>0.25</td>
</tr>
<tr>
<td>No specialist</td>
<td>20 (26.3%)</td>
<td>31 (50.8%)</td>
<td>0.003</td>
</tr>
<tr>
<td></td>
<td>8 (10.5%)</td>
<td>24 (39.3%)</td>
<td>&lt; 0.0001</td>
</tr>
</tbody>
</table>

First seizure patients

Seventy-six of the 250 (30.4%) seizure patients presenting to Wellington ED and 61 of the 250 (24.4%) seizure patients presenting to Hutt ED were presenting with their first seizure. Patients presenting with first seizure to Wellington ED were more likely to be discussed with neurology whilst in the emergency department, compared to those presenting to Hutt ED. First seizure patients presenting to Hutt ED were more likely to be referred to another medical specialist or discharged without a specialist referral. See Table 4.
intimately 1,000 persons with epilepsy in the area. This means that the incidence of SUDEP cases in the HVDHB catchment in the last year was significantly higher than expected. This could be due to clustering of cases and we have no historical data to calculate rates or examine a trend.

Our study showed that patients presenting with any seizure to Hutt ED were less likely to be referred for neurology review than those presenting to Wellington ED. Patients presenting with first seizure to Hutt ED were also less likely to be referred for further evaluation. This could result in diagnostic or management omissions. It is not possible to say whether this contributed to the SUDEP episodes in the HVDHB catchment area but a contribution could not be completely ruled out.

A higher proportion of patients with first seizure were discharged directly from the Hutt ED with no specialist referral when compared to Wellington ED. A correct diagnosis of epilepsy requires the clinician to distinguish between seizures and other causes of transient neurological disturbance, which can be difficult. Misdiagnosis occurs in approximately 25% of the cases, especially when the diagnosis is made by a non-specialist. The misdiagnosis of epilepsy can result in serious health consequences for the patient as well as significant costs to the healthcare system.

Furthermore, the practice of discharging patients with a first seizure with no formal follow up plan possibly reflects an assumption amongst doctors that patients, having had a first seizure, will not require treatment. This is an assumption that is often incorrect and there are a number of instances where antiepileptic drug treatment may be considered after a first seizure. A history of focal onset to a seizure, the presence of any focal abnormality on neurological examination or the presence of epileptiform abnormalities on EEG all independently predict an increased risk of seizure recurrence. It is possible that some of the patients discharged with no formal follow-up may, in fact, have subtle findings that would only have been identified in subsequent neurological assessments. While patients may be subsequently referred for specialist assessment, this relies on the patient being seen again by their general practitioner and that referral being made. This has a financial cost to the patient, creates a time delay and is an inefficient use of health care resources.

As for many patients with complicated chronic disease, epilepsy patients require a cohesive interaction between primary care and hospital services. Some general practitioners acknowledge a lack of confidence regarding their own knowledge about epilepsy, as well as a lack of familiarity with new antiepileptic drugs. These issues have been identified as possible barriers to providing epilepsy care. The New Zealand chapter of the International League Against Epilepsy (NZLAE) has acknowledged these issues and is working to promote education about epilepsy amongst health care professionals.

It is probable that if the neurology service is physically located at the same hospital, this may facilitate direct communication between clinicians and thereby increase the likelihood of cases being discussed. This is consistent with the finding that the most significant difference between the two hospitals was the inpatient referral rate. It is likely that referring patients to a remote department is perceived as being more difficult. It is not possible to replicate multiple subspecialist services across a region; however it is apparent that in order for patients to receive a consistent standard of care, close liaison needs to exist between the various acute care services.

The proportion of Māori patients presenting to the emergency department with a seizure was significantly higher across the region. This difference in attendance numbers was made up by patients presenting with established epilepsy, rather than with a first seizure. We feel that the discrepancy is due to suboptimal seizure control and inadequate access to routine epilepsy care, rather than a higher incidence of epilepsy in Māori. This study did not examine the details of this discrepancy; however this difference is unlikely to represent access to hospital care alone. It is probable that this trend reflects a wider issue regarding seizure care in the community, in primary care as well as in hospital outpatient clinics. Similar findings have been reported in Indigenous Australians and in the US, where those in low
socioeconomic groups present more frequently to ED for seizure care and hospitalization, and there are lower rates of specialist care.\textsuperscript{14} Our numbers were too small to allow comparison between Māori and non-Māori for rates of neurology referral. However, we expect these rates to be similar.

The main limitation of our study is that it was a retrospective review and relied on complete and accurate documentation by the ED clinicians as to whether a specialist referral was made. As a result it is possible that the calculated figures underestimate the true referral rate. However, we expect that this should not affect the comparison between the two DHBs. Additionally, our study did not specifically look at the referral pattern for patients with repeated seizures, who represent the highest risk group and have the greatest need for specialist input. This is an important quality measure and warrants inclusion in future studies.

These results highlight the lack of equity of access for epilepsy and seizure patients across the Wellington sub-region. These results have important implications for the provision of epilepsy care by the regional neurology service and the various DHBs that make up the region. Future planning and delivery of services needs to be based on equity of access for sub-regional populations, so health resources could be distributed equitably.

**Conclusion**

This study has demonstrated that the provision of epilepsy care across the Wellington region was unequal and in many cases did not comply with the NICE guidelines. Patients with acute seizure presentations in the HVDHB area were much less likely to receive neurology input than those in the CCDHB area, primarily because of different referral patterns across the two DHBs. Māori patients were also more likely to access acute medical services for seizure care. This information is directly applicable to the Wellington region, but is also applicable to other regions and other services which share this model of subspecialist provision of care, and should therefore inform health care planners on the resourcing and provision of regional services.

**Competing interests:**

Dr. Rosemergy reports they are the national secretary of the New Zealand chapter of ILAE (International League Against Epilepsy).

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**REFERENCES:**

6. Wallace H, Shorvon S, Tallis R. Age-specific incidence and prevalence rates


