Incidence of motor neurone disease in Hawke’s Bay and Gisborne/East Coast

Philip C H Baker

The observational study reported by Dayel et al\textsuperscript{1} suggests that motor neurone disease (MND) may be more common in the greater Wellington region than expected, although the authors acknowledge that their annual prevalence of 8.5 per 100,000 cannot be directly compared to reported point prevalence studies, which give an average prevalence of about 4 per 100,000.

A previous study from Canterbury described an increasing incidence of MND from 1.6 to 3.3 over the 22 years ending 2006.\textsuperscript{2} For many years I have also had the impression that I have looked after more patients with MND than expected for my population base of almost 200,000 and so since mid-2009 I have prospectively collected data on all patients with this condition who reside in Hawke’s Bay or Gisborne/East Coast region.

Between 1/1/10 and 31/12/14 there were 25 new cases of definite MND. As the sole Neurologist in this area until August 2013 I personally saw all these patients apart from one seen in 2014 by my new colleague. The average annual incidence was 2.5 per 100,000. This is higher than reported from overseas (1.89 in a 2001 review\textsuperscript{3} and 2.08 reported in 2013 from a meta-analysis of 37 recent studies.\textsuperscript{4})

None of my patients had a known family history of MND but no genetic studies were done. Thirteen of my patients (52\%) had a predominantly bulbar onset, which is significantly higher than in other studies from New Zealand or overseas. Seven had mixed lower and upper motor neurone signs at diagnosis (definite amyotrophic lateral sclerosis) and five had only lower motor neurone signs. All patients progressed to definite ALS.

To determine point prevalence of MND I counted all known patients at the beginning of the study and then recalculated the figure each time a new patient was diagnosed or died. Between mid-2009 and mid-2012 prevalence varied between 5 and 10, and rapid changes could be explained in part by the high mortality rate, especially in patients with bulbar onset, where median time from diagnosis to death was only 12 months.

Overall the average point prevalence was just under 4 per 100,000 which is the same as reported in overseas studies. The annual prevalence calculation used in the Wellington study is likely to overestimate how common motor neurone disease is in that region. To demonstrate this I have looked at my figures for the year 2011.

In January 2011 there were 10 patients with MND living in my region and another 6 patients were diagnosed that year which would give an annual prevalence of 16 or 8 per 100,000 which is quite different than the average point prevalence for the whole study. However my data provide more evidence that there may be a small increased incidence of MND in New Zealand than expected.

The second part of the paper by Viyal et al discusses aspects of management of patients. There are good American\textsuperscript{5} and European guidelines which emphasise proactive management of nutritional needs, including PEG tube feeding, respiratory failure and palliative care. In my experience it is possible to follow these guidelines in a general Neurology clinic in a regional centre and management can be audited.\textsuperscript{6}
Close liaison is required between the Neurologist and a large team of others including the Neurology nurse, therapists and other medical specialities.

I agree with the editorial\textsuperscript{7} by E. Scotter stating that both regional and nationwide studies of motor neurone disease in New Zealand are needed.

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**References**


