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Public awareness of motor neuron disease

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Abstract

A concerning lack of awareness of the symptoms and natural history of motor neuron disease was found in a street-based survey of 118 members of the general public.

Dear Sir

Motor neuron disease (MND, or amyotrophic lateral sclerosis) is a rare condition. The prevalence of MND in the south-east region of the UK was reported as approximately 5/100,000 (1). Those with MND require a large amount of community support that in some settings may need to be prioritized over more slowly progressive neurological disorders by individuals with variable levels of specialized knowledge. Anecdotally we have noted that many patients, and those who attend clinic with them at diagnosis, have very little understanding of MND, and community care managers may also lack understanding of the urgency for provision of support. Frequently there are misconceptions relating to other neurological disorders, such as multiple sclerosis (MS) or Parkinson's disease (PD). We therefore sought to assess the general awareness of MND among the public outside the clinical setting.

Adults found along the main pedestrianized thoroughfare of central Oxford during the standard working hours of a weekday, were approached to answer a short series of questions concerning MND. They were asked to provide their age (categorized), and gender was also recorded. Verbal consent for publication of anonymized group results was taken prior to responses. For six of the MND related questions, respondents were asked to choose from a range of possible answers, with two further open questions concerning symptoms and famous people. Responses were collated and analysed using 'freeware' (www.surveymonkey.com).

There were 118 respondents with approximately equal gender representation and spread across a wide range of ages. The results are summarized in Table I. There were no significant variations in response with regard to gender or age group.

We confirmed a lack of public awareness of MND issues. Nearly half those asked reported a younger patient group being most commonly affected. More than two-thirds of respondents thought that there were effective treatments to halt MND progression, and nearly 80% that those diagnosed with MND generally had at least a 10-year or normal lifespan. One quarter

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of those asked could not name a single symptom of MND, with nearly 10% suggesting Parkinsonian features instead. Two-thirds of respondents had misconceptions about aetiology, with over 40% of the view that MND was essentially a familial, genetic disease.

Nearly all (90%) of those asked in our survey knew that MS was not a synonym for MND, although we did not seek to compare the specific understanding of other disorders (which might have revealed a generally poor awareness of neurological disease). A survey of 196 adult neurology patients and carers reported that epilepsy and dementia were “the most well known” neurological disorders presented, and MS “the least well known”, although MND was not included in this study (2). Surveys like ours undertaken in other countries might reveal cultural differences, e.g. greater awareness through Lou Gehrig as a famous person with MND in the USA.

We conclude that the devastating impact of MND is not well recognized by a representative sample of the general population of the UK, which may have a wider impact on healthcare planning and delivery for patients, as well as on governmental and charitable fund raising to support research. The MND Association UK recently launched a web-based campaign, with a simultaneous radio broad-cast by a high-profile patient, calling for a ‘National Strategy for MND’ to raise awareness of the unique care needs of the MND patient (see <http://mnd2010.org/manifesto>). This might serve as a practical model for other countries to adopt, in conjunction with the increased use of mass media to highlight individual patient experiences. Our study also suggested that MND might not be perceived as a disease of the elderly (compounded by probable under-ascertainment in this group by clinicians). With a globally ageing population, more active education of the public (and clinicians) about MND and other neurodegenerative disorders seems warranted.

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Table I

Questions and response frequencies. Correct answers are highlighted.

Question	Frequency
Gender	
Male	54%
Female	46%
Age category (years)	
18–24	28%
25–39	20%
40–59	26%
60–69	18%
70+	8%
What is the approximate number of MND patients in the UK at any one time?	
500	3%
5000	31%
50,000	38%
500,000	9%
What is the commonest age group for people who develop MND?	
30–50	48%
50–70	49%
70+	3%
What is the cause of MND?	
Genetic, i.e. it runs in families	42%
Lifestyle factors, e.g. obesity, smoking, drugs	11%
Infectious	9%
It is not known	38%
Treatments for MND	
There is no effective treatment	27%
There are effective treatments to halt progression	68%
There is a cure	5%
What is the expected lifespan of a person with MND?	
Three years	21%
10 years	63%
Normal life expectancy	16%
MND and MS are different names for the same condition	
False	90%
True	10%
Name a typical symptom of MND *	
Unable	24%
Muscle symptoms, mobility problems	40%

Question	Frequency
Speech difficulty	11%
Shaking	9%
Balance problems or incoordination	8%
Memory impairment	4%
Headache	3%
Incontinence	1%
Name a famous person with MND *	
Unable	51%
Stephen Hawking	33%
David Niven	10%
Michael J. Fox	3%
Lou Gehrig	1%
Willie Maddren	1%
Christopher Reeve	1%

* Open questions.