



Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey



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ABSTRACT

Family carers have a central role in the care and support of people with MND and face the challenges of the disease from diagnosis to progression and the multiple losses of MND, but their support needs are often neglected. This study aimed to investigate the experiences of family carers at the time of diagnosis and their satisfaction with receiving the news. An anonymous postal survey was facilitated by all MND Associations in Australia (2014) and 190 family carers completed the questionnaire. The questions centred on the SPIKES protocol for communicating bad news.

Two-thirds of family carers rated the skills of their neurologists as above average and were satisfied with the delivery of the diagnosis, in terms of having a significantly longer consultation time, the neurologist being warm and caring, satisfaction with the amount and content of information they received and relevant supports, and a plan for following up support. Conversely those who rated the neurologist's skills as below average commented on the difficulties they encountered and the long term emotional stress engendered by poor communication.

The study emphasises previous research that suggested that neurologists may require education and training in communicating the diagnosis and this should include family carers as a vital member in MND care.

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1. Introduction

Motor Neurone Disease (MND), also referred to as Amyotrophic Lateral Sclerosis (ALS), is a progressive neurodegenerative disease that is always fatal [1]. There is a range of presenting symptoms, with the most common being weakness in the extremities, falls, difficulty in swallowing and speaking [2] and impairments in cognitive function and frontotemporal dementia are increasingly recognised [2,3]. Currently, there is no effective treatment for the disease and the average

time between diagnosis and death is two to three years with a small tail of long survivors [1,4].

The disease tends to progress rapidly and family carers provide considerable support across several domains of feeding, communication, movement, and hygiene [5]. Much of the care of people with MND is provided by family carers in the home and these carers may experience a range of physical and psychological concerns such as anxiety, depression, strain, burden, fatigue, and impairments in quality of life and social contacts [6–9]. Receiving a diagnosis of MND is recognised as a central challenge for MND patients and their families [6]. In particular, issues concerning misdiagnosis [10] and dissatisfaction with the communication of the diagnosis [11–15] have been highlighted. Surveys of neurologists demonstrate that the delivery of a diagnosis of MND is stressful and an area in which they would like more training [16,17]. Given these issues, improving the communication of the MND diagnosis has been of increasing concern in recent years. Neurology practice guidelines underscore the challenges neurologists face in communicating

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MND diagnoses and provide several strategies to optimise the communication consultation, such as communicating the diagnosis in a stepwise fashion, being face-to-face in a private room without distractions; taking at least 45 to 60 min to convey and discuss the diagnosis; providing printed materials about MND and relevant support services to supplement the discussion; and ensuring that a follow-up appointment occurs within two to four weeks of diagnosis [18,19].

To date there are no studies with large samples that focused separately on MND family carers' experiences of receiving the diagnosis. Typically, studies have focused on the patients' experiences of diagnosis [10,14,20,21], and some combined the experiences of patients and family carers [13,15], without due attention to the unique experiences of MND family carers. One study of caregiving experiences of current and former MND carers documented a range of support needs including respite, counselling, and access to funded and trained carers to assist them to provide care; however, they were not asked about their experiences of receiving the diagnosis [22]. Another study focused on the broader experience of support needs of a small sample ($n = 16$) of bereaved family carers of people with MND in Australia [12]. Themes reflected the work of family carers; role changes; unremitting losses; coping mechanisms; supportive and palliative care experiences of family carers; and the experiences of receiving the diagnosis from their neurologists were poignantly mentioned: "the lack of empathy left them feeling shocked, bewildered, angry and devastated" [12, p.847]. Documenting these issues is important for two reasons. First, given that family MND carers' experiences of adverse health outcomes due to caregiving may be alleviated when their support needs are identified and addressed in a systematic and timely manner and as early as the time of diagnosis [23]. Second, the manner in which the diagnosis is communicated to families has implications for the way they adapt to the actions required for symptom management and support throughout the illness trajectory [21,24] and through to their bereavement outcomes [12]. As such, the diagnosis of MND requires great sensitivity in the manner in which it is communicated to family carers of people with MND.

2. Objectives

We aimed to identify the experiences of family carers of people with MND in receiving the diagnosis, determine their overall satisfaction with the way they were given the news, and assess which aspects of the process of receiving the news were associated with greater satisfaction.

3. Methods

The methods described below are similar to those reported in the article on the patient survey [11], as the two surveys included the same questions and hence the statistical analysis was the same.

The study was approved by Curtin University Human Research Ethics Committee (HR 188/2014). The methods consisted of a cross sectional design using an anonymous postal survey. The development of the questionnaire was undertaken after a comprehensive review of the international literature in this field and with extensive consultation with clinicians and the executive officers of the MND Associations in Australia.

3.1. Data collection

Australian MND associations provided the number of patients on their lists who were diagnosed in the last three years and were still alive. Envelopes were mailed to each association, with each envelope containing an invitation letter bearing the letterhead of the association, one patient survey and one family carer survey with an information sheet, and a reply paid envelope. Patients and family carers were encouraged to complete the surveys independently. Carers were invited

to complete the questionnaire only if they were present when the diagnosis was given to their relative/friend. MND associations attached names and address labels and posted the envelopes in their state. No further contact was made to encourage response. Data collection spanned a period from April 2014 to January 2015.

3.2. Survey instrument

The survey comprised 52 items: demographic information (age, gender, marital status, relationship to person with MND, education and postcode), date symptoms first started, date the diagnosis was first made, time spent by the neurologists giving the diagnosis. The perceived ability/skills of neurologists in delivering the diagnosis was assessed using a five-point scale from excellent to poor. Attributes of effective communication of bad news was measured by the SPIKES protocol, a well-accepted system for communicating bad news developed by Baile et al. [25] and used by McCluskey et al. [14]. The six domains are presented in Box 1. Each domain of the SPIKES protocol (setting, perception, invitation, knowledge, emotion and strategy) was assessed using directed questions requiring a "yes", "no" or "do not recall" response, and directed statements requiring a response along a five point scale from "strongly agree" to "strongly disagree". Open ended questions were included to capture more details from respondents.

3.3. Analysis

The carer responses were sent back in the same reply paid envelope as the patient responses but they were coded separately. Frequencies and proportions were calculated and reported for categorical variables, and mean, standard deviation, median and range were calculated and reported for continuous and discrete variables. Normal distributions were tested using parametric means tests, and non-Normal distributions were tested using nonparametric means tests.

The SPIKES domains were analysed by calculating a summary score for each domain. There were 3 questions each in the setting and emotion domains, and 2 questions in each of the perception, emotion, knowledge, invitation, and strategy and support domains. Responses of "Yes" and "No" were coded 1 and 0, respectively. The sum of the questions in each domain was divided by the number of questions in that domain to give an average score. These scores were reported as per a continuous/discrete variable with mean, median, standard deviation and range. Responses of "do not recall" were not included in the analysis but these were few cases. The internal consistency (Cronbach's alpha) was good to acceptable for four SPIKES domains: emotion ($\alpha = 0.866$), knowledge ($\alpha = 0.723$), invitation ($\alpha = 0.549$), and strategy ($\alpha = 0.564$).

Further analysis was also undertaken with family carers of people with MND split into two groups based upon responses to question about how they rated the ability and skills of the neurologist giving them their diagnosis: those that were rated "poor, below average or average" were assigned to one group (average or below = low rating),

Box 1

The six steps, domains and associated tasks of SPIKES.

Steps	Domains	Tasks
1	Setting	Creating the right setting
2	Perception	Determining what the patient/family knows
3	Invitation	Exploring what patient/family are expecting or hoping for
4	Knowledge	Sharing the information and suggesting realistic goals
5	Emotion	Responding empathically to the feelings of patient/family
6	Strategy	Making a plan and follow through

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