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Breaking the news of a diagnosis of Motor Neurone Disease:

A national survey of neurologists' perspectives

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Abstract

Background: Communication of the diagnosis of MND is daunting for patients and neurologists.

Objectives: To establish a knowledge base of current Australian practice of breaking the news of an MND diagnosis, to assess the neurologists' educational and training needs, to compare the feedback obtained from neurologists and patients to international practice guidelines.

Methods: An anonymous survey of neurologists was undertaken in Australia (2014).

Results: Completed surveys were received from 73 neurologists (50.4% response rate). Nearly 70% of neurologists reported finding it "somewhat to very difficult" communicating the MND diagnosis, and 65% reported feeling moderate to high stress and anxiety at the delivery of diagnosis. Compared to international guidelines, areas for improvement include length of consultation, period of follow up and referral to MND associations. Two thirds of neurologists were interested in further training to respond to patient's emotions and development of best practice guidelines.

Conclusions: This is the first national study to provide a comprehensive insight into the process of delivering the MND diagnosis from the neurologists' perspective and to make comparisons with those of patients and the international guidelines. This study forms the basis for developing protocols to improve communication skills and alleviate the emotional burden associated with breaking bad news.

Keywords: MND/ALS, breaking bad news, empathy, MND diagnosis, education, training, best practice protocols, MND multidisciplinary clinics

Introduction

Receiving a diagnosis of MND is a challenge and a source of dissatisfaction for patients and their families [1-4]. The manner in which the diagnosis is given has implications for the way patients and families move from the news of their diagnosis to the actions required for support throughout the illness trajectory [5, 6] and bereavement response [7].

Despite these findings, few studies have focussed on neurologists breaking the MND diagnosis to patients. A recent investigation of 25 neurology residents in the US showed that 68% thought that breaking the diagnosis was stressful, 45% were not confident they were communicating the diagnosis effectively, and only 9% agreed they had received adequate training [8]. Additionally, analyses of video recordings of the same residents breaking the diagnosis to a patient indicated room for improvement, especially in demonstrating empathy and communication skills. The neurology residents made several suggestions for further training (e.g., practice guidelines), practice opportunities, and skills development relevant to communicating a diagnosis of MND. These findings correspond with studies showing that physicians report the delivery of bad news is a stressful experience [9,10] yet overlooked in their training [11]. These findings point to the importance of appropriate training and supervision opportunities, as well as the development and use of guidelines and protocols for the delivery of bad news.

The SPIKES protocol is a well-accepted system for communicating bad news [12]. The protocol recommends the health professional establish an appropriate Setting, determines the needs and Perceptions of the patient, requests an Invitation to give the news, provides Knowledge and information to the patient, explores the patient's feelings and responds Empathetically, and forms a Strategy with the patient to go forward. A similar set of guidelines for communicating with adult patients with advanced life-limiting illnesses and their caregivers was developed in Australia [13].

Given the absence of controlled trials of communicating the MND diagnosis, the American Academy of Neurology [14] concluded there was insufficient evidence supporting any particular method and noted that useful strategies have been developed for communicating a diagnosis of cancer. Best practice guidelines for MND in the United Kingdom [15] stress the need for support for patients and family carers from diagnosis so that the individual's spiritual and emotional needs may be addressed alongside medical and practical needs. Further, their standards of care emphasise that people living with MND require sensitive communication of the diagnosis combined with appropriate information about MND and support services, ensuring the provision of emotional/psychological support, a follow-up appointment within two weeks of diagnosis, and direct referral to the relevant MND association. Similarly, clinical practice guidelines developed in Europe [16, 17] promote the communication of the diagnosis by a consultant neurologist with a good knowledge of the patient. The neurologist should begin by asking what the patient already knows or suspects. The diagnosis would be given in person with time available for discussion (at least 45–60 min) and complemented with printed material about the disease, relevant support and

advocacy groups, and a summary of the discussion. Patients should be reassured that they will have regular follow-up visits to a neurologist within 2-4 weeks of diagnosis and supported by a specialist MND care team, where available. The neurologist should avoid withholding the diagnosis, providing insufficient or unwanted information, and communicating in a manner that is callous or removes hope.

Multidisciplinary MND clinics are considered to provide best practice coordinated care from the time of diagnosis, where specialist MND care teams deliver integrated services dealing with neurology, rehabilitation and palliative care. They have well established links to MND associations [14,18] and care is supported by regular decisions about symptom management and quality of life as the patient's condition deteriorates [19].

Reducing the physician's emotional burden associated with breaking bad news and the development of skills in communicating bad news are increasingly recognized as priorities in medical education [8]. To date, there are no Australian guidelines for communicating a diagnosis of MND and there is limited information about how neurologists actually communicate the diagnosis in Australia and elsewhere and the nature and extent of the challenges they face.

Objectives

This study aims to inform best practice in breaking bad news in the MND field. The specific objectives of this article were to:

- 1) Determine the current practice of neurologists in breaking the news of an MND diagnosis in Australia
- 2) Assess the neurologists' educational and training needs related to breaking bad news and responding to patients' emotions
- 3) Compare the neurologists' experience to that of patients undertaken in a separate survey in the same year (2014)
- 4) Assess the current practice of neurologists in breaking news in comparison to international best practice standards and highlight differences and similarities

Methods

The study was approved by Curtin University Human Research Ethics Committee (HR 188/2014).

Neurologists' 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 MND associations in Australia. Moreover, the questions included in the sections on consultations and follow up were constructed to align with the international guidelines, where possible, to allow for comparisons. The neurologists' survey was advertised in The

Australian and New Zealand Association of Neurologists (ANZAN) e-bulletin and website (by liaising with ANZAN secretariat). It was also advertised in the ANZAN scientific meeting in May 2014. The survey was made available to be completed on-line by clicking a link in the e-bulletin that goes to ANZAN members. The three neurologists on the research team trialled this version and gave comments before it was made generally available. However, in order to improve the response rate, it was also necessary to do mail-outs based on lists provided by the MND associations in every Australian state. The neurologists' survey comprised 45 questions grouped in five sections: Demographics; how patients' consultations were conducted; the communication plan and support for patients; the personal experiences in giving the diagnosis; and the neurologists' education and training needs and interest in developing best practice guidelines.

Patients' survey

The methods for the patients' parallel survey were reported in Aoun et al (2015) [4]. The reported practice of Australian neurologists was compared to those reported by patients and addressed in the results section of this article. For every guideline, reports from both groups were compared where similar information was available between the two surveys and the international guidelines.

Analysis

Frequencies and proportions were calculated for categorical variables, and mean, standard deviation, median and range were computed for continuous and discrete variables. Neurologists' practices were analysed as a comparison according to whether they practice in an MND multidisciplinary clinic (MDC) or not. This comparison could only be undertaken in a few areas due to the sample size of those in MDCs (n=11). The analysis was largely descriptive and the inferential comparisons included were those that can be compared with the international guidelines. Non-parametric tests were used for the comparisons due to the small sample sizes. Fisher's Exact Test was used for categorical variables and Mann-Whitney U for continuous variables. The statistical correction for multiple tests is Bonferroni's multiple test correction (α/n) for the comparisons between the different groups of neurologists.

Results

Seventy-three neurologists responded to the survey corresponding to a 50.4% overall response rate, and corresponding to 80% of neurologists who work in dedicated MDCs. The response rate was based on the lists provided by the MND associations in Australia, as the link in the e-bulletin was not favoured. Four respondents were not included in the analysis as they did not diagnose or currently care for MND patients, therefore 69 surveys were subsequently analysed.

Profile

The mean age of respondents was 52.7 years (SD=10.3), 78% were male, median length of practice was 20 years (range 1-44), 90% trained in Australia, 16% (n=11) worked in a MDC and saw a median number of 10 new patients per year (range 5 to 80). Non-MDC neurologists saw a median of 5 patients per year (range 1 to 15). The median number of current patients was 45 for MDC neurologists (range 4 to 100) and 3 for non-MDC neurologists (range 1 to 30).

Patients' consultations

The median period between first clinical consultation and diagnosis was four weeks (range 1-26), and 68% of neurologists reported requiring two consultations to convey the diagnosis. The difference in consultation times was significant between the two groups ($p < 0.001$): a mean of 23 minutes for non-MDC and twice longer for those in MDC (45 minutes) (Table 1). 78% of neurologists were always able to give the diagnosis in a private space and 41% always able to avoid interruptions. 75% tended to refer for a second opinion. While 98% of neurologists reported having a relative present during the diagnosis, 23% of them reported that on some occasions they have seen patients alone, with a difference between the two settings, although not significant (MDC=9%, non-MDC=26%) (Table 1). 80% of neurologists did not have any particular day of the week and timing they would refrain from giving the diagnosis (such as Friday afternoon).

At the time of giving the diagnosis, the most discussed clinical aspects pertain to: the degree of certainty of the diagnosis (94%), the course/prognosis of the disease (93%) and how the diagnosis was reached (91%).

Follow up support

Follow up support was always initiated by 68% of respondents within 4 weeks from diagnosis (range 1-12) with subsequent follow ups of 12-weeks interval (range 4-26); 73% reported referring to an MND association for information and ongoing support. However, referral to an MND association was significantly higher for those in MDC (100%) compared to non-MDC (67%) ($p = 0.028$) (Table 1).

The follow up support was mainly provided by the neurologist (MDC=91% and non-MDC=72%); followed in non-MDC settings by the GP (40%), the MND association (31%) and then a specialist nurse (17%). However, in MDC settings, the GP took a lesser role (18%) and more of the support was provided by the MND association (55%) and the specialist nurse (36%) (Table 1).

Table 1: Summary of comparisons in practice of neurologists (MDC and non-MDC).

	Neurologists		
	MDC	non-MDC	p-value ^a
	n=11	n=58	

Delivery of diagnosis (2 or more consults)	55%	83%	0.052
Length of consultation (minutes)	45	23	0.001
Private space (yes - always/frequently)	100%	96.6%	1.000
Avoid interruptions (yes - always/frequently)	91%	91%	0.579
Patient seen alone	9%	26%	0.436
Referral to MND Association for information and ongoing support	100%	67%	0.028
MND Association publications given	64%	40%	0.190
Diagnosis in writing	27%	21%	0.694
Follow-up support: Neurologist	91%	72%	0.270
Follow-up support: MND Association	55%	31%	0.172

^aComparison between MDC and non-MDC neurologists completed with Fisher's Exact Test for categorical data and Mann-Whitney U Test for continuous data.

Personal experiences in giving the diagnosis

About 70% of neurologists found communicating the diagnosis “very to somewhat difficult”, 43% found it “very to somewhat difficult” responding to patients’ and/or their family members’ reactions and 65% experienced “high to moderate” stress and anxiety at the diagnosis delivery (Figs 1 - 3).

Fig 1: Level of difficulty in communicating an MND diagnosis

Fig 2: Level of difficulty in responding to patient's and/or their family member's reactions (e.g., crying, anger, disbelief)

Fig 3: Level of stress and anxiety experienced during the delivery of the diagnosis.

The most difficult parts of discussing the news of an MND diagnosis related to: Being honest but not taking away hope (80%); dealing with the patient’s emotion (38%) and spending the right amount of time (28%). The reasons for experiencing these difficulties included the lack of an effective treatment (77%), fear of causing distress (36%) and fear of not having all the answers (20%). One neurologist expressed such feelings: *“Having had a migraine after each MND clinic, feeling stressed and anxious about having so little to offer, I have gradually accepted the limitations of my skills, and some confidence that assisting the patients honestly and empathetically, and not ‘abandoning’ them is of value to most patients.” (P47)*

Education and Training Needs

When asked whether neurologists had training in “techniques of responding to patient’s emotions”, 44% had no training, and 28% had learnt from sitting in with clinicians. However, 25% were very interested and 49% somewhat interested to undertake further training in such

techniques. There were some differences between those interested/somewhat interested (n=50) and those not interested (n=18) in further training in techniques of responding to patient's emotions:

- interested neurologists in further training had been practicing for a shorter period of time (median 17 years) compared to those not interested (median 26 years), although the difference was not significant;

- more of the interested neurologists had found it difficult/somewhat difficult communicating the MND diagnosis compared to those not interested (76% vs 47%, p=0.049) and more of the interested neurologists had found it difficult/somewhat difficult responding to patients' reactions compared to those not interested (55% vs 11%, p<0.001);

However, one neurologist was dubious about the value of education: *"Diagnosing MND is always unpleasant for both patient and physician... I think many physicians don't deliver the news well but I don't believe it is something that can be taught.... Perhaps we should be selecting junior doctors to enter physician training on the basis of their communication skills? The science is easily learned. Trying to teach empathy, sincerity, and understanding is impossible. Selecting for those qualities is easy."* (P52)

Development of Best Practice Guidelines

When asked whether neurologists had "specific training in giving an MND diagnosis", 54% had received no specific training and 23% had sat in with clinicians. Respondents were very interested (38%) to somewhat interested (44%) in having best practice guidelines developed. There were some differences between those interested/somewhat interested (n=56) and those not interested (n=12) in the development of best practice guidelines:

- interested neurologists in development of best practice guidelines had been practicing for a shorter period of time (median 19 years) compared to those not interested (median 27 years), although the difference was not significant.

- interested neurologists tended to have a longer consultation time to deliver the diagnosis compared to those not interested (30 vs 18 minutes, p=0.053).

- More of the interested neurologists had found it difficult/somewhat difficult responding to patients' reactions compared to those not interested (46% vs 33%, p=0.019).

Comparison with patient feedback

The key comparisons between the two parallel surveys of patients and neurologists are summarised in Table 2.

Table 2: Neurologists' reported practice in delivering the diagnosis compared to the experience of people with MND from the parallel survey and the EFNS Guidelines.

	People with MND [4]	Neurologists	EFNS Guidelines [16]
	N=245	n=69	
Diagnosis by neurologist	95%	-	Always
Delivery of diagnosis (2 or more consults)	70%	78%	step-wise
Length of consultation (minutes)	30	20	45-60 mins
Private space (yes - always/frequently)	96%	97.1%	Always
Avoid interruptions (yes - always/frequently)	91%	91%	Always
Patient seen alone	21%	23%	Never
Referral to MND Association for information and ongoing support	40%	73%	Always
MND Association publications given	24%	44%	Always
Diagnosis in writing	16%	22%	recommended
Enough information given	43%	-	Always
Asked of any previous MND knowledge	43%	-	Always
Follow-up support: Neurologist	41%	75%	Always
Follow-up support: MND Association	56%	35%	Always
Diagnosis to follow-up (median, weeks)	7	4	2-4 weeks
Diagnosis given with warmth, care & empathy	67%	-	Always
Sufficient time to express emotions	63%	-	Always
Sufficient time to have emotions responded to	62%	-	Always

Seventy-eight percent of neurologists reported that they deliver the diagnosis in a stepwise fashion in two or more consultations, and 22% in one consultation. This is nearly comparable to 70% of patients reporting that they had at least two visits to receive the diagnosis [4]. The stepwise process of delivering the news is described as follows by one neurologist: *“My practice was to let the patient know that their condition was of concern as soon as MND appeared likely (e.g., at 1st consultation) and continue to prepare patient in subsequent 1-2 consults before giving the news without taking away hope.” (P16)*

Neurologists reported that in most cases a relative was present when they communicated the diagnosis, but on some occasions, 23% of neurologists saw the patient alone. This is comparable to 70% of patients reporting having a relative present with them with 21% reporting that they were alone during the delivery of the diagnosis [4].

Neurologists reported that the time spent with the patient to deliver the diagnosis was 20 minutes, however the length of consultation was twice as long in multidisciplinary MND clinics (Table 1). Seventy percent of neurologists reported having some level of difficulty finding enough time to discuss the diagnosis. Patients reported a median consultation time of 30 minutes and 70% of them felt they had sufficient time to receive the diagnosis. Patients who rated highly the ability of their neurologists had significantly longer consultation times (40 vs 30 minutes, $p < 0.001$), and felt they had enough time to receive the diagnosis (84% vs 48%, $p < 0.001$) [4].

Regarding information, support and advocacy, 73% of neurologists reported providing information about and referred to MND associations, 44% gave MND associations' publications and 22% the diagnosis in writing. However only 42% of patients reported receiving information on MND associations, 24% MND association publications, 40% referral to an MND association and 16% the diagnosis in writing [4].

Concerning plans for follow-up, half of the neurologists 'always' encouraged patients to contact them if they have additional concerns. After receiving the diagnosis, 56% of patients reported that they were supported by an MND association, 42% by their GP, 41% by the neurologist, 28% by the MND clinic and 27% by the MND nurse [4]. Only 2.4% reported not being supported. Follow up support was always initiated by 68% of neurologists within a median 4 weeks from diagnosis (range 1-12 weeks). However, patients reported a median of 7 weeks for the first follow up visit after the diagnosis (range 1-52 weeks). Both neurologists and patients reported that the median interval between follow-ups was 12 weeks. In addition, 80% of neurologists did not report that they have a best day or time to deliver the diagnosis.

When it came to the setting, 78% of neurologists always gave the diagnosis in a private space, 41% always avoided interruptions. The majority of patients (96%) reported that the diagnosis was given in a completely private space/environment; and the majority (91%) had no interruptions while given the diagnosis.

Discussion

This is the first national Australian study to provide a comprehensive insight into the process of breaking the MND diagnosis from the neurologists' perspective, considering responses came from half of the neurologists in the country. This sample size is comparable to that of a European study conducted in 2001, where 73 neurologists from MDCs responded (66% response rate) to a wider survey on ALS clinical management and terminal care (20). However, our study had 80% response rate from neurologists in MDCs.

Several aspects of good practice are met in Australia from the evidence reported by the two groups (neurologists and patients) in comparison to international guidelines. Table 2 summarises the key comparisons that align to the international guidelines. As recommended, the majority (95%) of people with MND reported receiving the diagnosis from

a neurologist in Australia, and the majority of neurologists reported delivering the diagnosis in a stepwise fashion. However, there is room for improvement in first ascertaining what the patient and family understand as only 43% of people with MND reported being asked how much they knew about their condition and 43% were given just enough information [4]. This would clarify the patients' understanding of their current situation and the context in which decisions about goals of care are to be made.

There is also scope for improvement in responding empathically to the feelings of patient/family when 30-40% of patients highlighted a gap in this skill, and a considerable proportion of neurologists reported difficulties in this domain. In particular, the largest significant difference between the two groups of neurologists (high and low ratings of skills) was in empathy as it was seen as an important attribute of highly skilled neurologists [4].

As recommended, the diagnosis is nearly always given in person. The Australian practice of communicating the diagnosis in 20 to 30 minutes falls short of the recommended guideline of 45 to 60 minutes. There needs to be a commitment to take more time to deliver the diagnosis and have 45-60 minutes available. It is evident that the longer the patients spent with their neurologists during breaking the diagnosis, the more they were satisfied with the delivery process and the higher they rated the neurologists' ability/skills [4]. There is room for improvement in making sure patients are not seen alone and are advised to have a support person with them when receiving the diagnosis.

There needs to be a routine practice for all neurologists to refer to MND associations (as per the European guidelines), as 27% of neurologists did not refer and 60% of patients reported not being referred. In addition, it would be useful if all neurologists gave the diagnosis in writing as this would help the patient and family communicate the diagnosis to support organisations (such as the MND associations) and health professionals involved in their care.

As recommended, patients were supported by a range of health professionals. The Australian practice of a close follow up visit of 4-7 weeks from diagnosis falls short of the recommended guideline within 2-4 weeks or sooner. In addition, it was interesting to find out that the vast majority of neurologists did not mention that, for example, Friday afternoons were not appropriate to deliver the diagnosis where there was little opportunity for patient support at the weekend.

Although there were a few respondents from MDCs to make meaningful comparisons, findings point to the practice of neurologists involved in MDCs being more aligned with the international guidelines in terms of length of consultation and other indicators listed in Table 1. Borasio et al [20] highlighted that standards are usually higher in areas with specialized ALS centres in Europe. In a recent Australian study [21, 22], specialized multidisciplinary MND care was found to facilitate patient engagement with clinicians in decision-making by providing an optimal environment for information provision, support, and planning, stability and care continuity. One neurologist in this study commented that: *"The major issue is lack of access to multidisciplinary MND clinics for further management esp. in rural areas. It is*

very difficult as a neurologist in private practice to coordinate and access the multidisciplinary care required esp. for patients who live at a distance". (P45)

The feelings of stress and anxiety associated with delivering the diagnosis are comparable to those reported in the literature [8,11]. However, it is worth noting that the impact of delivering a diagnosis may be milder or more severe depending on the types of MND and the prognostic differences between them. While the neurologists' survey did not collect such information, the findings from the patients' survey indicate that 69% reported having cervical/lumbar symptoms at onset, 19% had bulbar symptoms and the rest a combination of symptoms [4]. Although the two anonymous surveys were undertaken in the same year, we cannot ascertain how many of the responding neurologists were involved with the patients in the parallel survey.

The needs for education and training in communicating the diagnosis are comparable to those reported in the literature [8,11]. Essentially, two thirds of responding neurologists (46/68) were interested in both further training responding to patients' emotions and development of best practice standards. It is worth noting, and perhaps expected, that those interested had reported more difficulty in communicating the diagnosis. Therefore, it is recommended that the peak bodies (MND Australia and ANZAN) consider education and training programs aimed at improving the skills of neurologists and neurology trainees in responding to patients' emotions, based on the evidence from this study. It is also recommended that these two peak bodies develop MND specific best practice standards in communicating the MND diagnosis, based on the evidence from this study and existing international protocols.

Limitations

Limitations include that the questionnaire was not validated other than by consensus from experts that included three neurologists, a palliative care physician, two nurses, a psychologist and representatives from MND associations. However, the questions included in the sections on consultations and follow up were constructed to align with the international guidelines where possible. Due to the anonymous nature of both patient and neurologist surveys, we could not ascertain how many of the responding neurologists were involved with patients in the parallel survey. Therefore, the comparative analysis between the two groups was descriptive, and those indicators aligned with the international guidelines were mainly included.

There may have been a selection bias and those neurologists who see only a few MND patients may have had a less stressful experience and therefore may have opted not to participate. However, it was intentional to include neurologists with a frequent experience with the disease, as the introductory part of the questionnaire had a statement that said: "If the number of patients in questions 7 (number you diagnose per year) and 8 (number you currently care for) is zero, then there is no need to proceed with the rest of the questionnaire and we thank you for your time". In addition, the cohort of neurologists who responded

consisted of older and experienced neurologists (median length of practice of 20 years), with possibly the findings not reflecting the experience faced by "young" neurologists.

As this article reported on many aspects of delivering the diagnosis, it was deemed impractical to incorporate a theoretical framework for every aspect. Future qualitative articles from this study will focus on single aspects with corresponding theoretical frameworks, where appropriate.

Conclusion

To our knowledge, this is the first study to take into account the perspectives of both neurologists and patients and to address an important knowledge gap in the clinical care of individuals with MND. This study added to our understanding of the process of delivering a diagnosis of MND and the pressures it placed on neurologists in terms of stress and anxiety. The comparison between neurologists' experiences and those of patients provided a novel view of the topic. Interpreting the findings in relation to accepted international guidelines for care provided a sound benchmark against which to judge the extent to which neurologists in Australia are achieving recognised standards and pointed to areas in need of improvement. We believe that this study has filled a gap in the literature as one respondent expressed the following remark which was representative of many: *"I am glad that you are doing this questionnaire. I think that more research needs to be done in this area - so well done! Happy to support in any way I can"* (P17). This study could form the basis for improving practice to alleviate the emotional burden associated with breaking bad news as poor communication increases the risk of burnout and fatigue [5]. This is achievable by the two peak bodies in MND and Neurology, MNDA and ANZAN, instigating educational programs and developing standards and protocols with applicability at the international level.

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