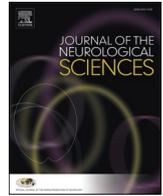


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The diagnostic experience for people with MND and their caregivers in the U.K.

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ABSTRACT

Objective: How an MND diagnosis is communicated has implications for how individuals adapt to their illness. The consultation process with the neurologist, diagnosis delivery, and adherence to UK guidelines, were explored from the perspectives of people diagnosed with MND and family caregivers.

Methods: A cross-sectional approach with people with MND and their caregivers in UK. An anonymous online survey, based on the SPIKES protocol for delivering bad news and containing questions focusing on the UK NICE MND guideline, was distributed in 2018–19.

Results: 69 people with MND and 39 caregivers responded. People with MND were more likely than caregivers to rate highly their neurologist's skills and ability and their satisfaction with delivery of the diagnosis. The amount of time spent with the neurologist at diagnosis had an impact on the level of satisfaction and rating of the neurologist's skills and abilities. The SPIKES criteria were generally not met. Many of the NICE MND guideline recommendations were not met, though adherence was greater in MND Centres.

Conclusions: While there is evidence of satisfaction with the delivery of the diagnosis amongst people with MND and caregivers, there is room for improvement. There is a need for greater awareness of the requirements of people with MND and caregivers. There is also a need to raise awareness of the NICE MND guideline and ensure adequate training, time and funding to ensure communication at this difficult time is acceptable and effective. Where possible it would be preferable for referrals to be made to MND centres.

1. Introduction

Motor neurone disease (MND) is a progressive neurological disease, characterised predominantly by motor neurone damage leading to progressive muscle weakness. The average prognosis is two to three years although 25% of people diagnosed with MND live 5 years and 10% survive 10 years [1]. However, there are often delays in diagnosis, with an average delay of just over 14 months [2]. Many people with MND (pwMND) have a short prognosis and may have appreciable disability at the time of diagnosis. Cognitive change is common, with frontal lobe dementia in about 15% and other cognitive change in up to 35% of cases [3].

Delays in arriving at a diagnosis contribute to feelings of uncertainty and anxiety amongst patients and their families [4–5]. The time of the diagnosis of MND is challenging for both the person receiving the

diagnosis and the clinician delivering it [6–7]. Studies vary on the level of satisfaction with delivery of the diagnosis with figures ranging between 36% and 50% of pwMND being dissatisfied [6,8–9]. Whilst recognising and appreciating the difficulties experienced by neurologists, pwMND and their families have expressed concern at communication of the diagnosis being abrupt, insensitive and lacking empathy [6,8]. A Japanese study reported increased anxiety amongst patients and their families at the time of the diagnosis with many feeling that insufficient time was allocated for communication and inappropriate information about ventilatory support was provided [10]. How the diagnosis is communicated has implications not only for future patient-professional relationships, but also for the way individuals adapt to their illness [11].

Studies have shown that neurologists do find the telling of the diagnosis stressful. An Australian study, which influenced the current study, sought to ascertain the nature and extent of challenging

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experiences at the time of the diagnosis from the perspective of pwMND, their families and also their neurologists [5–8]. Neurologists reported experiencing stress and lacking confidence in communicating the diagnosis. They expressed an interest in further education regarding diagnosis delivery [7]. Similarly, in the UK, a study of 49 neurologists showed that nearly half reported moderate levels of stress when giving bad news, even though they attempted to meet the standards of good practice [12]. Over 75% of the neurologists did not follow any specific guidelines or protocols [12].

The use of protocols to help in the telling of the diagnosis has been widely recommended. The European Association for Palliative Care and European Academy of Neurology Consensus document on palliative care for progressive neurological disease recommended that communication with patients and families should be structured following validated models [13]. An example of a validated protocol is SPIKES [14] which follows a six step process (see Table 1).

The UK National Institute of Health and Care Excellence (NICE) has developed guidance for the assessment and care of people with MND [15] which complements the international guidance on delivery of the diagnosis [16–18]. The NICE guideline (NG42) [15] includes a number of recommendations regarding support at diagnosis (see Table 2). There are a number of specialist MND care centres and networks across England, Wales and Northern Ireland, funded by the MND Association, staffed by professionals with specific and extensive expertise in MND. However, not everyone diagnosed with MND will be referred to one of these specialist centres but will receive follow up from general neurology services.

1.1. Aims

The aims were to:

- explore the experience of receiving a diagnosis of MND from the perspectives of pwMND and their caregivers.
- investigate how current UK practice was adhering to the recommendations set out in the NICE MND guideline as this had not previously been investigated [15].

2. Materials & methods

The same approach and data collection tools adopted in the earlier Australian study [5–8] were utilised, involving a cross-sectional approach with an anonymous national survey of pwMND and their caregivers. The questionnaires were developed from the international literature, including published MND guidelines, and extensive consultation with appropriate stakeholders including MND associations and clinicians. The SPIKES protocol [14] was used to measure features of effective communication of bad news. To build on the original study we added questions directly relating to the NICE guideline NG42 (NICE 2016) [15] which were published after the Australian study was conducted.

Links to the participant information sheets and surveys were made available through various social media platforms, websites and newsletters, including those of the MND Association (England, Wales and N. Ireland) and MND Scotland as well as other MND-related charities and appropriate organisations. Staff from these organisations also shared

Table 1

Six domains of the SPIKES protocol (Baile et al., 2000).

Step 1: SETTING UP – establishing the appropriate setting
Step 2: PERCEPTION – finding out what the patient knows and understands about their condition
Step 3: INVITATION – finding out how much the patient wants to know; being invited to give bad news
Step 4: KNOWLEDGE – providing knowledge and information to the patient
Step 5: EMOTIONS – exploring the patient's feelings
Step 6: STRATEGY – creating a strategy with the patient to take forward

Table 2

Recommendations for support at MND diagnosis (NICE guideline NG42 2016).

- The diagnosis should be given by a neurologist with up-to-date knowledge of the disease and experience of treating people with MND
- Patients should be asked about how much information and support they wish to receive about MND, and about their preferences for involving their family. They should be provided with information at diagnosis or when they ask for it.
- People diagnosed with MND should be provided with a single point of contact and information about how to address concerns between appointments and in an emergency.
- People with MND should be offered a face-to-face, follow-up appointment with a healthcare professional from the multidisciplinary team within 4 weeks of diagnosis
- When MND is suspected or confirmed, the person's GP (family physician) must be informed without delay
- Sufficient time should be set aside to discuss the person's concerns and questions
- Referral for social care assessment should be made if the person has any social care needs
- Carers should be advised that they have a legal right to have a Carer's Assessment of their own needs

study information with potential participants. Paper copies of the participant information sheet and survey were also available should they be preferred by participants, with pre-paid envelopes provided for their return to the research team.

The survey for pwMND consisted of questions concerning demographic information, symptom onset, date of diagnosis and time spent by the neurologist when delivering the diagnosis. The ability/skills of neurologists in delivering the diagnosis, as perceived by pwMND, were assessed using a 5-point Likert scale ranging from poor to excellent. Directed questions requiring either 'yes', 'no' or 'do not recall' responses, or directed statements with responses on a five-point Likert scale from strongly agree to strongly disagree were used to assess each of the six SPIKES [14] protocol domains (Table 1). Open ended questions were included for each domain to capture more in-depth information from respondents.

The family caregiver survey replicated the pwMND survey with the addition of a question on their relationship to person with MND.

2.1. Analysis

Descriptive statistics are reported for categorical variables with mean, standard deviation and range being calculated and reported for continuous and discrete variables. As in the original study, further statistical analysis was performed with the use of non-parametric tests to explore the relationship between variables. Responses were split into two groups based upon responses to rating questions; those rated 'poor, below average or average' were assigned to one group (average or below = low rating), while those rated 'good or excellent' were assigned to a second group (above average = high rating). Indicative responses to the open ended questions were selected to illustrate the above and below average experiences within each domain.

Thematic Analysis [19] was used to identify patterns of meaning in the open text responses across the dataset, following a rigorous process of data familiarisation, coding, and theme development and revision. Measures to assure the rigour of the data were incorporated, with members of the research team independently undertaking aspects of analysis before coming together to compare and agree coding [20].

2.2. Ethics

Potential participants were provided with a link to an online Participant Information Sheet explaining the purpose of the study and containing contact details for the research team should they have any outstanding questions. The surveys were submitted anonymously but if any identifying features were included, these were removed prior to analysis. Details of organisations to contact should participants be in need of support as a result of taking part in the study were provided. Ethical approval (Ref: SC38) was obtained from the University Faculty

of Health & Social Care Research Ethics Committee.

3. Results

3.1. Participants

109 pwMND accessed the survey and 69 submitted completed responses (59 completed by the person themselves, 5 with help of a family caregiver and 5 help not known). Thirty-nine family caregivers completed to the survey. See Table 3 for demographic details.

3.2. MND centres

Twenty (29%) pwMND who responded to the survey received their diagnosis at an MND Centre while 42% ($n = 16$) of caregivers who responded to the survey reported that their family member was diagnosed at an MND Centre.

3.3. Ratings of neurologists' abilities/skills and satisfaction with delivery of diagnosis

The skills and ability of the neurologist was assigned a high rating (above average) or a low rating (average or below). People with MND were more likely than caregivers to provide a high rating for their neurologist's abilities and skills at delivering the diagnosis. Those pwMND seen at an MND Centre were substantially more likely to provide a high rating than those not seen in MND Centres (See Table 4).

Satisfaction with the delivery of the diagnosis was given a high rating (above average) or low rating (average or below). People with MND were more likely than caregivers to highly rate their satisfaction with the delivery of the diagnosis. As previously, pwMND seen at an MND Centre were more likely to provide a high rating for satisfaction than those pwMND not seen at an MND Centre (see Table 4).

There was a correlation between caregivers' rating of skills and ability of the neurologist and caregiver satisfaction with the telling of the diagnosis $r_s(33) = 0.830, p \leq 0.005$. There was also a correlation between pwMND's rating of the skills and ability of the neurologist and their satisfaction with how the diagnosis was delivered $r_s(63) = 0.797, p \leq 0.005$.

Open text responses indicate aspects of the delivery of the diagnosis impacting on level of satisfaction (see Table 5); quotes are labelled with identification codes indicating FC for family caregiver and pwMND for person with MND.

Table 3
Participant characteristics.

	People with MND	Caregivers
Number	69	39
Mean Age	61 (32–89) SD 10.22	55 (29–80) SD 12.83
Male	59% (41)	22% (8)
Female	39% (27)	78% (28)
Married / partner	75% (51)	79% (30)
Education University	38% (26)	53% (20)
No formal education	3% (2)	0% (0)
In work	23% (15)	42% (16)
Retired	59% (41)	38% (14)
Time since diagnosis to survey completion (in days)	Mean 1378 days (3.78 yrs) SD1697 (4.65 yrs) Range 8–7097 days (8 days to 19.44 yrs) Median 849 days (2.3 yrs)	Mean 714 days (1.95 yrs) SD 796 days (2.18 yrs) Range 36–3187 days (36 days to 8.73 yrs) Median 468 days (1.9 yrs)

Table 4
Satisfaction with skills of neurologist and delivery of the diagnosis.

	pwMND (All)	pwMND MND Centres	pwMND Not MND Centre	Caregivers (All)
n	69	20*	49*	39
Rating of Skills & Abilities of Neurologist				
Non Response	5.80% (4)	5% (1)	6.12% (3)	10.26% (4)
Above average	62.32% (43)	85% (17)	53.06% (26)	43.59% (17)
Average or below	31.88% (22)	10% (2)	40.81% (20)	46.16% (18)
Satisfaction with Delivery of Diagnosis				
Non Response	4.34% (3)		6.12% (3)	10.26% (4)
High rating	52.17% (36)	70% (14)	44.9% (22)	41.02% (16)
Low rating	43.4% (30)	30% (6)	48.98% (24)	48.72% (19)
Satisfaction with information Provided at Diagnosis				
No Response				5.13% (2)
Low Rating	53.62% (37)	40% (8)	59.19% (29)	48.72% (19)
High Rating	46.38% (32)	60% (12)	40.82% (20)	46.15% (18)

* 6 respondents were unable to recall if they were seen at an MND centre. They have been assigned to non MND centre group.

Table 5
Open text responses on aspects of the diagnosis impacting on satisfaction.

Negative comments	Positive comments
"Anything would have been better, than just a diagnosis, and a see you later we will be in touch" (FC32)	"The MND consultant was gentle and kind when delivering the diagnosis. I felt very supported by him". (pwMND36)
"Neurologist just came over as completely uncaring" (FC37).	"[Diagnosis] Delivered in a very professional way but in a very caring and understanding manner" (pwMND60)
"[MND]Diagnosis is never going to be easy, but this experience set us back psychologically and has made it all much harder to deal with. We felt, and still feel one year on, quite traumatised and angry about how we feel we were treated (FC17).	"He was compassionate and answered our questions to the best of his ability" (FC15)

3.4. Timing of appointments

People with MND stated ($n = 57$) that the time between the initial onset of symptoms and the first appointment with the General Practitioner varied greatly, with a median of 126 days, (range 12 to 1461 days). The median time from first symptom to being told the diagnosis stated by pwMND ($n = 63$) was 398 days, (range 35 to 3348).

Most pwMND (93% $n = 64$) reported that the diagnosis was given by a neurologist. Thirty-seven (54%) pwMND reported being offered an appointment for further discussion with a team member; this was almost always undertaken by neurologists at MND centres (80%, $n = 16$) but was only offered to 41% ($n = 20$) of pwMND where the neurologist was not at an MND centre. The average time before a further appointment with a neurologist was reported by pwMND to be 65.4 days, with a range of 4 to 182 days (median 56). Caregivers provided further insight into the diagnostic process. Many pwMND had been to several appointments before the diagnosis was given; 34% ($n = 13$) reported one previous appointment, 24% ($n = 9$) had two appointments, 16% ($n = 6$) had three appointments and 24% ($n = 9$) more than three appointments.

PwMND who rated the skills of the neurologist highly had longer diagnosis appointments (Mean 36.83, SD16.115, $n = 41$) compared with those pwMND who gave a low rating (21.58, SD10.145, $n = 19$) (p

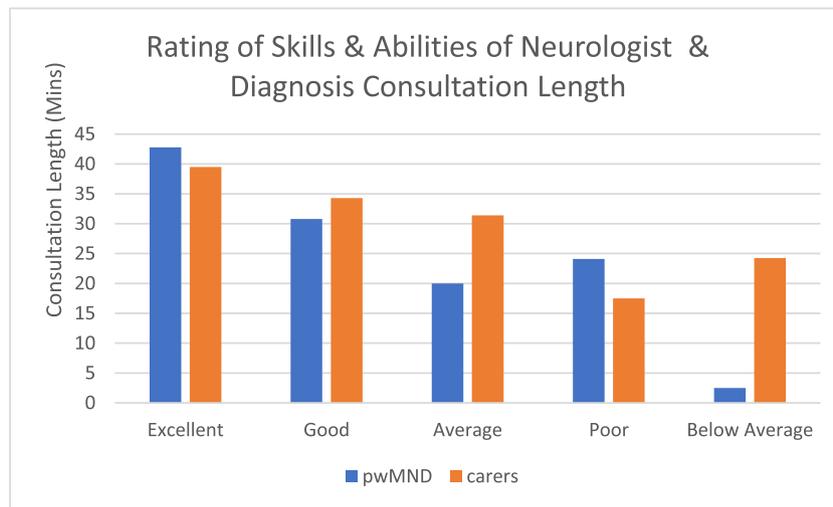


Fig. 1. PwMND and carer ratings of the neurologists' abilities/skills against the duration of consultation.

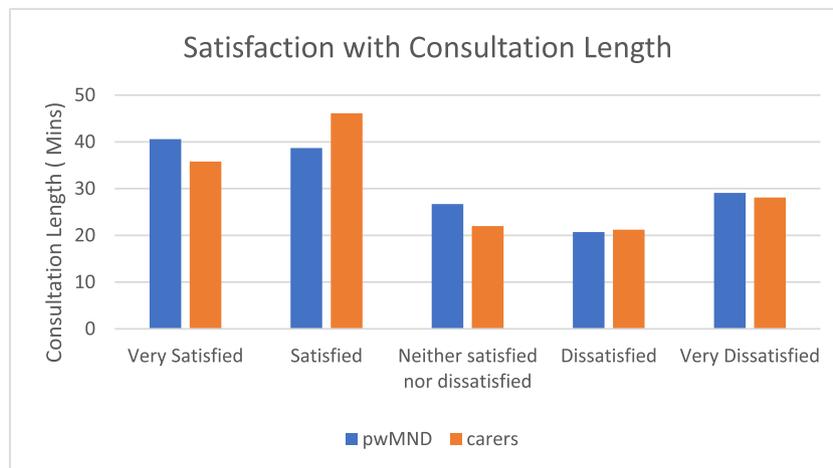


Fig. 2. PwMND and carer satisfaction with the delivery of diagnosis against the duration of consultation.

≤0.005). PwMND and caregiver ratings of the neurologists' abilities/skills increased as the duration of the diagnostic consultation increased (see Fig. 1) as did their satisfaction with the delivery of the diagnosis (see Fig. 2).

3.5. SPIKES protocol

The responses of the pwMND and caregivers when asked about the six aspects of the SPIKES protocol are shown in Table 6. The elements of the protocol reported to be most highly adhered to were in the 'Settings' domain. With 95% (n = 65) of pwMND and 87% (n = 33) of caregivers reporting having privacy during diagnosis consultation. However, the domains focused on what they knew (Perception) and what they wanted to know (Invitation) were equally poor for both groups. Only 29% (n = 20) of pwMND and 24% (n = 9) of caregivers were asked how much they knew about MND. With 32% (n = 22) of pwMND and 24% (n = 9) of caregivers being asked how much they wanted to know. Under half of pwMND (46%, n = 32) and caregivers (47%, n = 18) were satisfied with the information they were given at diagnosis (Knowledge).

Open text responses provide greater depth to understand respondents' experiences of communication in relation to the SPIKES protocol during the delivery of the diagnosis (see Table 7).

Table 6

Comparison of SPIKES between pwMND and caregiver. Most questions had a yes/no format and unless otherwise stated in the table the figures refer to a response of 'yes.'

	pwMND	Caregivers
Setting		
Privacy	94% (65)	87% (33)
No interruptions	88% (61)	87% (33)
Perception		
Person asked how much they knew about MND	29% (20)	24% (9)
Person wanted details about their condition	'A lot' 38% (26) 'just enough' 46% (32) 'a little' 16% (11)	'A lot' 24% (9) 'just enough' 45% (17) 'a little' 24% (9)
Invitation		
Asked what they wanted to know about the condition	32% (22)	24% (9)
Knowledge		
Satisfied with details provided	46% (32)	47% (18)
Emotion		
Diagnosis given with warmth and empathy	62% (43)	58% (22)
Strategy		
Referral to MND team	54% (37)	45% (17)
Details of MND Association	36% (25)	32% (12)

Table 7
Open text responses relating to the SPIKES protocol domains.

Domain	Open text response
Setting	<p>"I could not believe such devastating news could be given over the phone" (FC29)</p> <p>"The diagnosis was given, from behind a desk. We were then told to join a queue for a blood test. I had to ask a nurse for a private space as were distraught" (FC17)</p> <p>"We needed more time to get used to the news. A smaller room, cup of tea and a nurse would have been good. Was no time to take in the news. MND pack and phone number would have been good. I felt the way they handled it was really bad." (pwMND32)</p>
Perception	<p>"He didn't ask if we understood anything he was explaining and felt uncomfortable when we asked questions." (FC3)</p> <p>"Although I knew a lot about MND it was still a shock to get the diagnosis. I was told far too much (i.e. about feeding and breathing tubes, house adaptations) when I was first diagnosed" (pwMND6)</p> <p>"Caring, wanting me looked after by a specialist and understanding that I didn't want to know everything about MND straight away" (pwMND22)</p>
Invitation	<p>"No build up to the devastating news" (FC16)</p> <p>"The neurologist allowed us to drive the questions and how much we wanted to know. He kept checking whether we were happy to hear stuff." (FC25)</p> <p>"The neurologist checked with me throughout to assess how much I was able to take in (I was writing notes as well)" (pwMND39)</p>
Knowledge	<p>"He wasn't an expert and told us this many times" (FC15)</p> <p>"The lack of knowledge by both neurologists about MND was apparent. Neither referred me to an MND specialist." (pwMND88)</p> <p>"Knowledgeable consultant" (pwMND1)</p>
Empathy	<p>"He was unemotional in telling us the diagnosis, and he did not show any empathy when I was upset" (FC3)</p> <p>"The abruptness! Lack of empathy! Knowing that I was alone the neurologist SHOULD have called his CNS to support me - even for a cup of tea!" (pwMND45)</p> <p>"The neurologist was very warm and delivered the bad news as kindly as possible. He was honest about the prognosis but made us feel we would be given support" (FC39)</p> <p>"Very compassionate and not hurried" (FC24)</p>
Strategy	<p>"The worst time of our lives were made worse by not being able to sit down and talk to someone and understand what was happening and what would come next" (FC29)</p> <p>"I felt I was left to fend for myself." (pwMND31)</p> <p>"Firm and clear, with reasons. Ongoing care model agreed" (pwMND23)</p>

3.6. NICE recommendations

Most pwMND (94%; n = 65) and caregivers (92% n = 35) felt that the neurologist giving the diagnosis was knowledgeable about MND. Few respondents had been asked how much information they wanted to

Table 8
Compliance with NICE guideline NG42 comparison with MND centres and non-MND centres.

	People with MND Dx NOT at MND centre	People with MND Dx at MND Centres	Caregivers Dx NOT at MND centre	Caregivers Dx at MND centre
	Not sure/ do not recall = 4 N = 43	N = 20	Not sure/ do not recall = 2 N = 20	N = 16
What is MND				
How diagnosis was reached	70% (26)	80% (16)	60% (12)	81% (13)
Certainty of diagnosis	65% (28)	70% (14)	55% (11)	56% (9)
Types / causes of MND				
Prognosis	42% (18)	60% (12)	40% (8)	56% (9)
Symptoms	31% (11)	40% (8)	25% (5)	31% (5)
Disease Progression	43% (15)	60% (12)	40% (8)	38% (6)
Treatment	46% (16)	60% (12)	30% (6)	38% (6)
Place of appointment	56% (21)	75% (15)	55% (11)	38% (6)
HCPs involved in care	51% (17)	75% (15)	40% (8)	19% (3)
Local services	36% (9)	65% (13)	25% (5)	31% (5)
Local support	21% (5)	40% (8)	20% (4)	25% (4)
Legal rights	4% (1)	10% (2)	3% (1)	0% (0)
DVLA	33% (9)	60% (12)	20% (4)	13% (2)
ACP	7%	20% (4)	11% (2)	6% (1)

receive about their condition (pwMND 32%, n = 22; caregivers 24% n = 9) but just over half (pwMND 57% n = 39; caregivers 53% n = 17) felt they were given enough detailed information about MND at diagnosis and 46% (n = 32) pwMND and 47% (n = 18) of caregivers were satisfied or very satisfied with the information provided at that time. The average length of the consultation when the diagnosis was given was 32 min (range 10 to 60 min). Almost two thirds of respondents (pwMND 58% n = 39; caregivers 57% n = 17) felt they were allowed enough time to express their emotions and 54% (n = 36) pwMND and 57% (n = 17) caregivers felt they were allowed enough time to have their emotions responded to. More than half of the respondents (pwMND 58% n = 37; caregivers 54% n = 15) reported being offered a follow up appointment with a member of the MDT.

Although there was usually discussion about the diagnosis itself in neurology clinics the provision of basic information occurred for less than half of the respondents – including discussion of symptoms, treatment and local services and local support. For those seen in the MND Centres there was higher, but not universal, compliance with most of the recommendations (see Table 8). Discussion about legal rights was rarely held and discussion of the need to contact the Driving and Vehicle Licensing Authority (DVLA) was uncommon, except in MND Care Centres, even though MND is a notifiable condition. Advance care planning was also very rare (see Table 8).

4. Discussion

The telling of the diagnosis to someone with MND is known to be difficult not only for the pwMND and their family but also for the neurologist [5–7,21]. There is evidence of improvement in delivery of the diagnosis over the last 30 years, but many patients had not understood what they had been told or knew what to expect in the future and more than half were alone when they received their diagnosis [22]. One study found that in some instances patients and families had bad experiences at the time of diagnosis, such as being told in a large group of professionals, during a ward round, a lack of time afterwards and poor communication skills [23]. There have been several publications and guidelines suggesting ways of improving communication during diagnosis delivery [16–17].

This study did show that there are still many issues that need to be addressed. There are certainly contrasts to the results in Australia [6,8], with substantially fewer caregivers satisfied with the delivery of the diagnosis in our study. Although it is possible that our findings contain some pwMND/carer dyads, as a result of the anonymous nature of the

survey we cannot be certain if the caregivers are linked to the pwMND who responded or if they were less satisfied because they are representing a different cohort of pwMND who had a worse experience. The gender difference in the study between the pwMND and caregivers was large (see Table 3). There were more female caregivers in this study (78%) and more male pwMND (59%). This may have influenced the differences observed in the satisfaction rates between pwMND and their caregivers as studies have shown the important difference gender makes in perceptions of the quality of care [32–33].

However, there were similarities with just over two-thirds of pwMND in both studies rating neurologists' abilities and skills at delivering the diagnosis as above average [6]. Our satisfaction results are also lower than in Germany [24] and Italy [25]. However, in our study there was an increased level of satisfaction when pwMND were seen at an MND Centre.

The SPIKES criteria were generally not met. However, there was a positive response rate for the provision of privacy and ensuring there were no interruptions, which does show improvement on earlier studies [21]. The Perception aspect was not well addressed, while the Emotion aspects were more positively reported. The Strategy aspect, in particular information about the MND Association, was lower than the situation in Italy [25], and in Australia [6] where more pwMND were referred to an MND Association at diagnosis.

Many of the recommendations from the NICE guideline NG42 were generally not met but compliance was higher in the MND Care Centres. The survey was undertaken three years after the NICE guideline [15] had been issued and it is disappointing that compliance with the recommendations was limited. The respondents may have been receiving the diagnosis when the NICE guideline [15] was still newly issued and the recommendations may now be more widely known and adhered to though a recent UK study highlighted that 75% of neurologists were not following any specific guidelines or protocols at diagnosis [12]. Without appropriate strategies to alter behaviour, changes are likely to be slow and there has been no additional funding allowing extra time for clinic appointments or extra staff to facilitate these new requirements.

It has been suggested that there is the need to develop a programme to facilitate implementation to ensure that guidelines are understood and then used [26]. Guidelines are based, where possible, on randomised clinical trials and concerns have been expressed that these trials, and thus the guidelines, may be seen as less relevant in day to day practice [27]. Thus, it would seem that there is a need to prioritise the implementation of the recommendations of the NICE guideline NG42, alongside increased information and funding. Furthermore, this needs to be accompanied by training in a person-centred approach to delivering bad news. This holistic approach ensures that delivery of the diagnosis acknowledges the individual's psychosocial, spiritual and emotional needs in addition to their medical and practical concerns [28]. Empathy training is crucial for any success in implementing best practice guidelines, more so than funding or additional personnel [28]. Regular audit would also allow deficiencies to be identified.

The study shows that the care provided at specialist MND Care Centres was of a higher standard than in routine neurology clinics. There is increasing evidence that the multi-disciplinary team (MDT) approach improves the care of pwMND, can be beneficial in supporting them to help cope with the effects of the illness, and may even increase survival [29–31]. The exact nature of this effect is unclear but would seem to be due to the close collaboration and communication within the MDT and was a major recommendation within the NICE guideline [15]. Although not all pwMND are able to attend an MND Centre throughout their disease progression, the initial assessment, diagnosis and telling of the diagnosis is a very important time for a specialist team to be involved.

5. Strengths and limitations

There are limitations to this study. The number of respondents was small and may reflect a biased group of people, who were willing to

respond to the survey, as they may have experienced poor care and this had stimulated their response.

Whilst we do not claim the findings to be generalisable, the study was open to pwMND and their caregivers throughout the UK and participant characteristics broadly reflect the wider MND population and responses include the views of people from a wide range of geographical locations. The qualitative study of the free text responses also give strength to, and support, the quantitative results.

6. Conclusion

The study has shown that there is still a need for neurologists and neurology services to be more aware of the needs of pwMND and their caregivers when they are told the diagnosis. The fears of the disease and the possibility of a distressing death can be reduced by clear and honest communication, which will also build up trust, allowing open communication throughout the disease progression. The NICE guideline [15] clearly recommends how the discussion should be managed and is based both on the evidence and the personal experiences of a wide range of professionals, pwMND and their caregivers. There is a need to increase awareness of the NICE guideline [15], and ensure that there is adequate training, time, personnel and funding to allow the conversations to be most effective and acceptable for pwMND and their caregivers. Regular audit of the recommendations may be a stimulus for change. The study has shown that the experiences of pwMND and their caregivers is better at MND centres and where possible people that have suspected MND should be referred to an MND centre to ensure correct diagnosis, communication and follow up.

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