

Family carer responses when a loved one receives a diagnosis of Motor Neurone Disease - *'our life has changed forever'*

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Abstract

While the experiences of family members supporting a person with a terminal illness are well documented, less is known about the needs of carers of people with neurological diseases, in particular, Motor Neurone Disease. This paper describes the qualitative data from a large Australian survey of family carers of people with Motor Neurone Disease, to ascertain their experiences of receiving the diagnosis. The aim of the study was to describe the experiences of family carers of people with Motor Neurone Disease in receiving the diagnosis in order to inform and improve ways in which the diagnosis is communicated. Anonymous postal surveys were sent to people with Motor Neurone Disease in Australia and their family carers respectively. The perceived ability/skills of neurologists was assessed using a five-point scale from excellent to poor. Attributes of communication of bad news was measured by the SPIKES protocol. Each survey question invited further written responses. Eight hundred and sixty-four questionnaires were posted to people with Motor Neurone Disease and their family carers, with assistance from MND associations. One hundred and ninety-six family carers submitted responses, of which 171 (88%) were patient-carer dyads. Analyses were conducted on 190 family carers. Five themes emerged from reading and re-reading written responses: frustrations with the diagnosis; giving information; family carer observations of the neurologist; the setting; and what would have made the diagnosis easier? The delivery of the diagnosis is a pivotal event in the MND trajectory. Satisfaction for patients and their family carers is related to the neurologists showing empathy and responding appropriately to their emotions, exhibiting knowledge and providing longer consultations. Neurologists may benefit from education and training in communication skills and further training in communication skills to respond to patients' and families' emotions and development of best practice protocols.

Keywords: Motor Neurone Disease; Family carers; Neurologists; Diagnosis

What is known about this topic:

- the delivery of the diagnosis is a pivotal event in the Motor Neurone Disease trajectory.
- very little is known of how family carers receive this bad news while supporting people with MND .
- how the diagnosis is given greatly affects carers .

What this paper adds:

- the attitude and demeanour of the neurologist is pivotal in delivering the diagnosis.
- family carers need to be present when the diagnosis is given.

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INTRODUCTION:

The experiences of family members supporting a person with a terminal illness have been well described in the literature (Borasio, Sloan & Pongratz 1998, Chio & Borasio 2004, Johnston, Earll, Mitchell et al 1996, Aoun et al 2005). Much attention has been paid to carers of people with cancer and dementia but less is known about the experiences and needs of carers of people with neurological diseases. Motor Neurone Disease (MND) is a neurological disease that begins with symptoms of weakness, falls, communication and swallowing difficulties (Mitsumoto & Rabkin,2007).

Symptoms progression is rapid and the disease is always fatal (Connolly, Galvin & Hardiman 2015, Mitchell & Borasio 2007). Because of the poor prognosis and inevitable decline that a diagnosis of MND brings, the caring tasks for family members have been described as 'unrelenting' (Aoun et al 2012, Locock & Brown 2010) .However, a review of 20 qualitative studies highlighted the increasing dependencies of living with the progression of MND, but none of the papers described the role of the family carer when receiving the diagnosis (Sakellariou et al 2013).

The delivery of the diagnosis is a pivotal event in the MND trajectory. Studies have explored the aspects of how the diagnosis was given, and have examined perspectives of the neurologists delivering the diagnosis, the patients receiving the diagnosis, and carers supporting the patients during the consultation. Guidelines have subsequently been developed to guide the experience of imparting the diagnosis of MND (NICE Guidelines 2016, European Association of Neurological Societies).

Surveys of neurologists in the US and Australia showed that approximately two-thirds

report the delivery of a diagnosis of MND to be stressful (Aoun et al 2016a, Schellenberg et al 2014). Surveys of people living with MND (PwMND) in the United States indicated that fewer than half were satisfied with how the diagnosis was communicated (McCluskey et al 2004); in Australia, another survey showed about a third were similarly dissatisfied (Aoun et al 2016b). Interviews with PWMND in the UK revealed themes that centred on aspects of the diagnosis –communication, reactions, time before diagnosis; and coping (Hugel et al 2006). Interviews with PwMND showed that the delivery varied from informative and sensitive, to being abrupt and lacking empathy (O’Brien et al 2012). In relation to family carers, researchers have described the physical and emotional exhaustion from the caring demands for a person with MND, in aspects like loss of sleep, lack of support, loss of independence and emotional isolation, suggesting the development of a tool to assess carer needs (O’Brien et al 2012). Because of the complexity of the symptoms commonly experienced by PwMND, it is argued that there is a requirement for educational interventions in aspects like managing aids and manual handling (O’Brien et al 2012). An Australian study of bereaved family caregivers of PwMND, described an absence of compassion when delivering the diagnosis (Aoun et al 2012). A more recent survey of 190 family carers in Australia found that two-thirds were satisfied with the delivery of the MND diagnosis (Aoun et al 2017). However, for the remaining one-third, the unsatisfactory experience of the diagnosis had ongoing effects.

While much research into MND uses a quantitative paradigm, measuring various aspects of the disease, including psychological functioning, qualitative research assesses the experience of the illness in relation to care; for example, receiving the diagnosis, loss and change, and building models of care (Mistry & Simpson 2013). This paper describes the qualitative data from a large Australian survey of family carers of PwMND. The larger study involved surveys of PwMND, their family carers, and neurologists, to ascertain their experiences of giving and receiving the diagnosis.

Purpose

To describe the experiences of family carers of PwMND in receiving the diagnosis in order to inform and improve ways in which the diagnosis is communicated.

METHOD

The study was approved by Curtin University Human Research Ethics Committee (HR 188/2014). Anonymous postal surveys comprising 51 to 52 questions, were sent to PwMND in Australia and their family carers respectively. Questions included: demographic information (age, gender, marital status, education, postcode); date of first symptoms and diagnosis; time spent by neurologist giving the diagnosis. Respondents were accessed through the network of all Australian MND Associations.

The perceived ability/skills of neurologists was assessed using a five-point scale from excellent to poor. Attributes of communication of bad news was measured by the SPIKES protocol (Baile et al 2000). Each survey question invited further written responses, by asking: 'do you wish to add further comments?'. This article focused on the qualitative feedback of family carers from these written responses. The quantitative results of the survey of family carers were reported elsewhere (Aoun et al 2017).

ANALYSIS

Content analysis was applied to the data, once de-identified (Hsieh & Shannon 2005). The coding schema was drawn from the focus of sections of the questionnaire and responses were systematically coded inductively. Aided by comparing the data and the literature, emergent themes were refined throughout the analysis; excerpts were then chosen to illustrate the themes.

FINDINGS

Eight hundred and sixty-four questionnaires were posted to PwMND and their family carers (if they had any and if their carers were present at the diagnosis), with assistance from MND

associations and nine were returned to sender. There were 248 responses received from PwMND, estimated as about 29% of those receiving care from all Australian MND Associations and these findings are reported elsewhere (One hundred and ninety-six family carers submitted responses, of which 171 (88%) were patient-carer dyads; two carers responded for one patient, and 24 family carers submitted without patient responses. The response rate of PwMND was 29% but we could not calculate a response rate for family carers because it was not possible to ascertain if all respondents were present at the diagnosis, a stipulated requirement of completing the questionnaire. Analyses were conducted on 190 family carers, as six had missed data in the questionnaire.

Respondents' profile

As reported in Aoun et al [13], the mean age of respondents was 62.1 years (SD=12.4, range 25-88), 67.2% were female, 93.8% were married, and 52.9% were retirees. The majority of family carers (97%) reported that the diagnosis was given to the PwMND by a neurologist; about a third of PwMND had seen another neurologist prior to their diagnosis, and 39% had seen another medical specialist. Forty-percent of PwMND had two visits to the neurologist, 13% had three visits and 18% had more than 3 visits. The median length of the consultation was 40 minutes (range 10 to 200).

Five themes emerged from reading and re-reading written responses: frustrations with the diagnosis; giving information; family carer observations of the neurologist; the setting and what would have made the diagnosis easier?

Frustrations with the diagnosis

It seems that the family carer held a key to initiating the medical investigations which led to diagnosis. They recalled their observations over time, of physical changes in their loved one, in a range of aspects like increased falls, stress, chronic fatigue, a pinched nerve, slurred speech, leg weakness or old age. CID 141 described: *'My husband had a new denture inserted in Nov*

and we thought that was why he was talking differently!

Family carer frustration with misdiagnoses or delayed diagnosis was expressed: *'In the year between onset of symptoms and diagnosis my Mum was treated as though she had a stroke because she was 80yrs old'* (CID 144). And *'My husband attended a GP for 3 years with symptoms and was never diagnosed, he told my husband to exercise more to strengthen his muscles!!'* (CID 244).

Understandably there were many emotions, both positive and negative, described by family carers as they accompanied their loved one in hearing of their diagnosis. One family carer described her husband as receiving the diagnosis with *'amazing calmness'* (CID 238); conversely there were tears for many PwMND, like one family carer observed his wife who *'broke down in tears outside the clinic'* (CID 173). Shock was described by many family carers, one said her husband *'wanted to be alone'* (CID 204).

Both PwMND and their family carers were forthright about the frustrations of lengthy waiting time to see a neurologist. There was however, more understanding expressed by the family carers, who noted for example, there being only one neurologist in their region, so there was a delay in seeing him; another described the massive workload of a neurologist who covered most of their large state. Others had the experience of being extradited to their consultant appointment by their General Practitioner (GP).

Being confronted with a diagnosis, about which the PwMND and their family carer knew little, seemed to add to the shock. *'Not knowing anything about MND this came as a terrible shock. It took time to accept this report'* (CID 200).

Giving information

Most family carers said the neurologists gave information over a series of consultations, so that the initial consultation, when the diagnosis was given, did not contain too much detailed

information. For the neurologist to impart knowledge in a timely manner, but not overwhelm the PwMND and their family carer seemed quite a challenge to family carers.

Some family carers were protective of the PwMND, like this carer who said: *'My friend didn't want detailed info at this stage – she was completely overwhelmed by the diagnosis'* (CID 199). And *'I was so upset I just wanted to make sure my husband was not panicked at this time'* (CID 133). One requested the information about the diagnosis in writing (CID 117).

There was frequent mention of the state-wide MND Associations and the information and practical support that was received. This connection was often supplied by the neurologist. One family carer said that pacing the information was important: *'The neurologist was quite honest and technical but happy to re-explain things that we didn't understand. He also made it clear that we'd forget things/ need to go through them again. He also said when it was 'too early' for us to be asking some questions'* (CID 351).

Second opinions were discussed by a number of family carers, in many cases initiated by the neurologist. Some family carers described their schedule of follow-up visits to the neurologist or GP; while others listed referrals to MND clinics, MND Associations, palliative care inpatient and home care, and ongoing involvement of hospital multi-disciplinary teams.

A range of supports were regarded as vital by family carers: *'Planning and follow-up is vital to feel care and important, considering especially the rapid progression of MND - emphasis on getting the clinician to start a program needs to be a priority so as not to feel like left on own! Can be very dis-heartening'* (CCID 283).

One family carer followed the advice of their neurologist who said: *'Neurologist told me not to look on the internet as I would experience first-hand that there was no "same" cases'* (CID 244). Other means of giving information were noted by family carers as helpful. *'Information given a later appointment, was providing us with a DVD - excellent way to do this'* (CID 156).

There were understandably many aspects of receiving the MND diagnosis that were described in a negative manner, most particularly the lack of clarity about disease progression and prognosis. Balancing the timing of giving information to a required level seemed quite a challenge, especially when the PwMND and their family carer had different expectations and different levels of need for information. One family carer was not satisfied with the given information: *'Just enough info for my partner, not enough for me!'* (CID 307). And another said: *'My husband left with little understanding of MND whilst I knew plenty - difficult to marry both perceptions - no other support offered'* (CID 326); neither the PwMND nor this family carer were satisfied with the neurologist and the information offered.

Family carer observations of the neurologist

Even though many respondents expressed dissatisfaction with the neurologist; those satisfied expressed their gratitude for any positivity that was expressed, especially in relation to prognosis and making connections to other supports.

While not underplaying the devastating news of an MND diagnosis, family carers highlighted their appreciation in recalling small positive details of the clinical exchange. For example, the consultant took their time, gave the diagnosis in a private setting, was *'warm and caring and a touch of humour'* (CID 123) and assured the PwMND and their family carer that they would have *'support every step of the way'* (CID 156).

Amidst many descriptions of shock, being stunned and disbelieving, a family carer described the sensitivity of the *'caring and considerate neurologist'* (CID 202) as he gave the diagnosis. CID 103 said: *'He watched our shocked reactions, but gave us time to digest his information. He came around the table and offered support for us both'*. One family carer said the neurologist was very sensitive, and another suggested the neurologist was *'just as upset as we were'* (CID 200). *'Despite the neurologist delivering the diagnosis quite sensitively there was no*

opportunity to express emotions, no "how do we feel" (CID 326).

Many made comments about the demeanour of the consultant as he discussed the diagnosis. One family carer said: *'The neurologist was very sympathetic to both of us; he treated us with dignity and compassion'* (CID 327). Another said: *'our neurologist always makes you feel positive, which is important'* (CID238). An invitation to involve other family members was also appreciated by a number of family carers. For example: *'Dr L. gave an explanation of MND and answered our questions. He then suggested we talk to family and arrange an appointment at end of his normal session so he could answer any questions they might have. We did this 2 weeks later. He gave unlimited time and then would not take any fee for his time'* (CID 269).

Importantly one family carer said: *'our neurologist always makes us feel that there is always hope!!'* (CID 238). For some family carers, especially if the diagnosis had been difficult to make, there was appreciation for finally knowing what was wrong with their loved one, and for the neurologist's practical manner.

These positive observations were not universally experienced, and other family carers described aspects like: *'the neurosurgeon delivered the blow bluntly and without apparent care'* (CID 349); PwMND *'was told in a clinical way'* (CID 174); the neurologist was *'very detached'* (CID 309), and had *'little empathy'* (CID 321). These aspects of a lack of communication from the neurologist evoked angry comments like: *'You cannot tell someone there is nothing we can do. Go home and die!!'* (CID 138); and *'You must treat all clients differently and carefully - NOT like a robot'* (CID 204).

CID 138 noted the lack of hope given in the encounter with the consultant: *'No empathy... No hope given, very blunt.* The 'busyness' of the neurologist who did not take their time with breaking the news of the diagnosis, also left family carers feeling angry and disappointed: *'Told goodbye. Next patient please'* (CID 214).

Personal traits of the neurologist were also remembered by family carers; aspects like: *'lack of empathy'* (CID 285), *'the doctor would not look at us and speak to us'* (CID 221) and *'the doctor was quite blunt in his deliverance...he treated me with disdain'* (CID 204). One family carer was disappointed not to have her concerns heard, about the genetic inheritance of MND (CID 742). Another family carer described being *'left alone to care for dad at home for three years without any help to understand'* (CID 348).

Setting

Most family carers were satisfied with the setting where the diagnosis was given, usually in a consultant's rooms, but for some, in hospital. There were family carer comments about how *'difficult it was to process'* the news (CID 110), which inhibited their ability to ask questions.

There were however several issues raised by family carers where the setting was not optimal. The lack of privacy in a hospital ward was described by one family carer as: *'in semi-private room; another patient in second bed; curtain in between'* (CID199). The lack of time given to the clinical encounter when the diagnosis was given as part of the ward rounds, was not appreciated: *'We were given diagnosis at bedside during doctor's rounds. So neurologist had her team of two other people with her. Time spent was just like normal doctor's rounds - in, tell you, then out'* (CID 174).

And lack of staff awareness and sensitivity was an issue for CID 111 who described this encounter: *'Neurologist's receptionist made an unfortunate remark when wife said she would not need any more appointments - receptionist said "Oh, that's good" - but my wife meant she had just received a death sentence!'*

Most family carers noted that they were the only other person at the appointment where the diagnosis was given to their loved one.

What would have made the diagnosis easier?

For many family carers there were no suggestions as to what would have made the diagnosis easier to receive, such as the devastation of the news, as *'nothing can prepare you for the road ahead as a family carer – our life has changed forever'* (CID348) and *'I guess we were living with a time bomb...'*(CID 349).

Many stated that nothing would have helped them, except hearing they didn't have the disease. It was important for family carers to have been present when the diagnosis was given. Others commented on the need for a cure, initiating early investigations and being connected to other supports. Being told the diagnosis with sensitivity and empathy was important, as well as *'being spoken to respectfully and a little more softly'* (CID 204).

As noted, others were unhappy with the efforts of their neurologist in breaking the diagnosis. Memories of such blunt conversations like: *'The doctor said: "There is no cure, go and die", that was shock to us'* (CID 118), were reported by family carers. Another said: *'We were literally "hit between the eyes" with the blunt way in which the diagnosis was given - but maybe this is the only way it can be handled'* (CID173).

Describing their isolation, one family carer said: *'I have had to do all the research myself and strongly feel that apart from the MND Assn convener we have met, the neurologists and other doctors just don't understand the needs of the patient's partner in order that he (or she) is better able to cope and provide support!!'* (CID 146).

This lack of referral to other supports, meant that some PwMND and their family carers had to seek these out themselves. Additionally, a lack of information from the neurologist meant: *'Had to Google, and find information ourselves. Find MND [association] ourselves and a new specialist ... No support, no information, no hope'* (CID 138). 'One person who was not satisfied with the

neurologist said: *'It would have been helpful to receive printed information then & information about allied health support'* (CID 326).

Involvement in research trials was noted by two family carers, with one suggesting further research beyond the diagnosis consultation: *'Delivering this diagnosis is very difficult; however, I feel that more sensitivity and a personal touch would help. It would be good if you could look into the attitudes and conduct of ongoing consultations'* (CID 227). Another family carer sought to get involved in research: *'We asked numerous times to speak to research people direct, to convey our opinion on possible causes with NO RESPONSE FROM ANYONE'* (CID 249).

DISCUSSION AND CONCLUSION

To our knowledge, this study is unique in that it has captured the qualitative feedback of a large sample of family carers (n=190), across a whole country. Because both PwMND and family carer surveys contained open-ended questions to capture such further comments, it is possible to compare and contrast their experiences from their responses.

When comparing these findings from the family carers' perspective, with those of the PwMND, there are many commonalities, in terms of the detail in how the diagnosis of MND was given (Hugel, Grundy, Rigby et al, 2006). This is not surprising, since many family carers accompanied their loved one to their appointments, so would have shared and discussed their experiences. In the covering letter sent with the surveys it was suggested: *'Patients and family carers are encouraged to complete the surveys independently. Patients requiring assistance of family carers are urged to express their own opinions'*. However, one could speculate on whether the surveys were filled out together, with discussion; or whether the family carer had even completed the survey on behalf of the PwMND, because of their physical limitations.

Family carers spoke with appreciation when the neurologist sought to provide privacy when giving a diagnosis to the PwMND; and used words which implied exposure and being

dismissed, when privacy did not occur (Connolly, Galvin & Hardiman, 2015). That family carers felt significant responsibility in this role was very evident, in the immediacy of their observations, of both the PwMND, as well as their interactions with the neurologist.

There were frustrations expressed about the length of time to diagnosis as well as the length of time it took to see a neurologist; this may be reflective of health care system issues, as well as not having one definitive test to diagnose MND, requiring time to make several tests to eliminate other possibilities. Clinical guidelines, including the SPIKES protocol will assist in guiding the clinician through aspects of making the diagnosis (Baile et al 2000).

Like other studies, these family carers appreciated the time that neurologists gave (Seeber, Pols, Hijdra et al 2016), when imparting the diagnosis, as well as the pacing techniques they used (Borasio, Sloan & Pongratz 1998, Chio & Borasio 2004). Family carers described that information given at the first appointment was then followed up in a number of helpful ways - with family members, given in writing, referral for a second opinion and referral to MND associations for support. All these were noted as helpful for family carers in coping with the news.

On the other hand, family carers said that a lack of clarity about the progress of the disease and the prognosis was not helpful. This is a particular feature of MND in comparison to other diseases, where trajectory and prognosis may be more predictable (Glare et al 2008).

There was nothing that could have assisted the family carer with bearing the devastating shock of a diagnosis of MND for their family member. Of note however is the influence of the neurologist's demeanour on how this news is received. If the neurologist worked with sensitivity, was warm, and respectful and (in one case) moved to the other side of the desk, this seemed to be remembered as a positive experience by family carers. If the neurologist was lacking in empathy or blunt in his delivery, family carers suggested this took away their sense of hope. Above all, they did not want hope to be taken away from the PwMND.

These qualitative results echo the quantitative findings, namely that better satisfaction for patients and their family carers is related to the neurologists showing more empathy and responding appropriately to their emotions, exhibiting better knowledge about detail and amount of information and available supports, providing longer consultations and referrals to MND associations (Aoun et al 2016b, Aoun et al 2017). The results support the recommendations of international guidelines regarding giving the diagnosis of MND (European Association of Neurology 2012, NICE Guidelines, 2016) and Australian clinical guidelines for giving prognosis in advanced illness (Clayton, Hancock, Butow et al 2007). Neurologists may benefit from education and training in communication skills especially that two-thirds of responding neurologists to a national survey expressed interest in further training in communication skills to respond to patients' and families' emotions and development of best practice protocols (Aoun et al 2016a).

Communicating the diagnosis of MND should always include family carers and attention by service providers needs to be given to family carers as they shoulder the burden of ongoing care which mainly takes place at home (Aoun et al 2017, European Association of Neurology 2012). MND family 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 (Aoun et al 2016c, Creemers et al 2016).

Strengths and Limitations

The researchers have undertaken a number of studies in MND, and are aware of the possibility of a biased approach to the data; that is, evidence to support (or not) the quantitative aspects of the study, would stand out. These limitations relate to neutrality or confirmability of trustworthiness as the parallel concept to objectivity (Lincoln & Guba, 1985).

The large sample of respondents (n=248, 29%) in this study is more than many qualitative studies on this issue. However, and while the profile of respondents is similar to a comparable

study (Locock & Brown, 2010), and despite participants coming from all over Australia, we cannot be certain of the representativeness of this group of the population of PwMND; in particular the uncertainty of whether more satisfied or dissatisfied people responded.

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