

Title: Staying just one step ahead: providing care for patients with motor neurone disease.

Authors:

McConigley R, School of Nursing and Midwifery, Curtin Health Innovation Research Institute, Curtin University, Perth, Australia

Kristjanson LJ, Swinburne University of Technology, Hawthorn, Australia; School of Nursing and Midwifery, Curtin Health Innovation Research Institute, Curtin University, Perth, Australia; Western Australian Centre for Cancer and Palliative Care, Edith Cowan University, Joondalup, Australia

Aoun SM, School of Nursing and Midwifery, Curtin Health Innovation Research Institute, Curtin University, Perth, Australia

Oldham L, Curtin Health Innovation Research Institute, Curtin Health Innovation Research Institute, Curtin University, Perth, Australia

Currow D, Discipline of Palliative and Supportive Services, Flinders University, Adelaide, Australia

O'Connor M, Palliative Care Research Team, School of Nursing and Midwifery, Monash University, Melbourne, Australia

Holloway K, School of Nursing and Midwifery, Curtin Health Innovation Research Institute, Curtin University, Perth, Australia

Correspondence:

Dr Ruth McConigley

R.McConigley@curtin.edu.au

School of Nursing and Midwifery, Curtin University

GPO Box U1987, PERTH, Western Australia, 6845

Key Words

Motor Neurone Disease

Education needs

Supportive Care

Health professionals

Qualitative study

Word Count: 2981

ABSTRACT

Introduction: There is limited information about the experiences and educational needs of health professionals who may be required to provide care for people with Motor Neurone Disease (MND) especially in the later stages of the disease. The aim of this study was to determine the experiences of, and need for, education of these health professionals.

Method: Interviews and focus groups were conducted with 31 health professionals with some experience in providing palliative care for people with MND. Thematic content analysis was used to identify common themes.

Results: A key theme, *Just One Step Ahead*, emerged, that describes the central capability health professionals identified as necessary to help individuals plan and prepare for disease and lifestyle changes just before they arise. Two subthemes also emerged: *Expertise in MND* and *Bespoke Communication*. *Expertise in MND* described the required understanding of the disease and the particular individual's version of the disease to allow the health professional to plan, advise, support and anticipate the needs of the person living with MND. *Bespoke Communication* was the facility to tailor care messages sensitively and effectively to the range of people involved in care (patients, family, health care team members).

Conclusions: Care of people with MND requires up-to-date expertise about the disease and skilled communication abilities to manage complexity and change. Timely and focused education and specialist MND support for care providers are essential to tailored and responsive care and a widely available education program has been developed to address these needs.

INTRODUCTION

Motor neurone disease (MND) is a neurodegenerative disorder characterised by progressive and often rapid physical deterioration related to the degeneration of motor neurones that control limbs, respiratory muscles and bulbar musculature. MND may affect mobility, speech and breathing in varying combinations [1] and, in late stages, can also cause cognitive impairment related to frontotemporal dementia. MND has a prevalence of 6-7:100000 people.[2] Generalist health professionals will care for one or two people with MND throughout their career.[3] It can therefore be difficult for health professionals to obtain and maintain the specific skills and knowledge required to provide care to patients and families with MND.

In Australia, much of the day-to-day care for people with MND is provided by general practitioners and community nurses, with specialist input at diagnosis and for management of complex symptoms. To date, there has been limited information about the experiences and specific needs of Australian generalist health professionals providing care to patients and families living with MND.

The aim of this project was to explore the educational needs of health professionals, especially for care in the later more complex stages of MND.

METHODS

Ethics: Approval for this study was granted by the Curtin University Human Research Ethics Committee [RD-20-07].

Design: A descriptive, exploratory qualitative design was used to understand the

experiences of providing MND care in the community. This research was part of a larger study reported elsewhere.[4]

Sample: Approximately 250 health professionals who registered for the Australian National MND conference in Melbourne, Australia, in June 2008 were sent a letter of invitation and an information sheet by the conference organisers prior to the event. This group represented an accessible national cohort of health professionals from a range of disciplines with experience or interest in MND. Meeting times during the conference were arranged. Eleven participants attended a focus group. An additional purposive sample of 20 health professionals providing care for people with MND in Australia was identified using a snowball sampling technique to augment the data collected in the focus group. These participants were interviewed face-to-face or by telephone, depending upon participant's choice, location, and accessibility. Sampling continued until data saturation was reached.

Data collection: Interviews and focus groups were conducted by health professionals with experience in this methodology. Guiding questions were used to elicit responses about experiences of providing care to people with MND and the need for education including how to promote specific aspects of care. Interviews and focus groups were audio-taped and transcribed verbatim. Data collection and analysis were undertaken concurrently to assist purposive sampling.

Data Analysis: Data were managed using NVivo 8 software. Key themes that described aspects of patient care and health professional education needs were identified using inductive thematic analysis.[5] Each transcript was read and

analysed independently by two researchers and inter-coder agreement was reached. [6] Rigour of the analysis was ensured by applying the criteria of credibility, auditability, neutrality and fittingness.[7] Credibility was maintained by the researchers completing independent coding. Auditability was demonstrated by keeping memos to document all theoretical decision making. Neutrality was addressed by having two researchers independently analyse the data. Inclusion of participants from various professions, locations and clinical expertise helped to establish the fittingness of findings.

RESULTS

Demographics

Thirty-one health care professionals were involved in 20 interviews and one focus group. Table 1 summarises the backgrounds of participants. The average length of time since participants had graduated was 24.3 years (SD=13.1; median=25 years, min=0, max=42). Twelve participants had attended previous training about MND, however, only four said they had received formal MND-specific education. Twelve participants also reported having a special interest in MND, such as sitting on a board or interest group. Twenty-two of the participants reported having palliative care experience. Of these, 15 had undertaken some palliative care education; nine had undertaken formal postgraduate education in palliative care.

Insert Table 1 about here

Emerging Themes

A key theme, *Just One Step Ahead*, describes the central capability identified as necessary to help individuals plan and prepare for disease changes and implementing relevant contingencies before they arise. Two subthemes also emerged: *Expertise in MND* and *Bespoke Communication*.

Just One Step Ahead

To provide good care for people with MND, health professionals described having to stay one step ahead of the patient by being aware of what was likely to happen next, anticipating needs and problems arising and implementing immediate solutions expectantly but not too soon. Care providers had to be able to predict changes in care needs, rather than waiting until a crisis occurred before making changes. If changes were not predicated or a patient's condition changed rapidly, then a rapid response to a change in condition was required. One participant explained:

You have to work quickly. It's also being a step ahead of their problems. So planning for the next stage, so knowing what is ahead because it will be on you before you know it with some people. [Occupational Therapist]

Another discussed how they felt they needed to plan care for patients:

I think by being a step ahead. Knowing what may be needed so it's there for when it's required. So looking at other care that might be needed, whether it's respite, whether it's more hours

*of care, whether it's equipment ... or somebody else how might
be needed to be brought in. [Occupational Therapist]*

MND has many possible manifestations and, as such, disease trajectories may vary. Health professionals needed to be aware of potential changes because this was the key to staying just one step ahead in the domains of mobility, breathing and swallowing. However, this required careful negotiations with patients and families because it was important to be *only* one step ahead and not too far ahead. Staging of information and timing of support were important to allow patients and families to cope with new information and the changes being made in clinical care before giving them more information. For many patients and families, too much information too soon was likely to be detrimental and care providers were careful to ensure they did not overburden or frighten people. Information had to be carefully tailored and presented at appropriate times. One participant said:

*Once the diagnosis has been established and the person has
had enough opportunity to understand the diagnosis and its
implications... care needs are anticipated rather than reacted
to. [Medical Practitioner]*

Connecting the person to a palliative care service was considered one way that MND care providers could stay one step ahead, by providing a framework for planning proactive care, tailored to an individual's care needs. The early introduction of palliative care was considered essential to facilitate good end-of-life care for people with MND. There was agreement that palliative care should be introduced following

diagnosis and a shared care model between general practitioners, community nurses, MND services and palliative care services considered for all patients. A participant said:

I think it would be really good if the patients could be managed in a palliative care service from time of diagnosis... MND is very variable isn't it, and length of life varies hugely. [Registered Nurse]

Expertise in MND

The first sub-theme that emerged described the required knowledge of the disease and an understanding of each patient's version of the disease to allow the health professional to plan, advise, support and anticipate the patients' and carers' needs. Having knowledgeable and credible health professionals was considered essential if people's needs are going to be met. However, generalist providers of care to people with MND are not MND specialists. Participants in this study reported instances where members of the care team were poorly prepared to provide care to people with MND. One participant spoke about how poorly prepared staff could undermine the efforts of the care team:

[Patients and families] need access to services quickly and they need people who are used to dealing with MND. To have to educate people at the same time as looking for help from them I

think it erodes credibility and confidence in the services that are being provided. [Speech Pathologist]

Participants perceived their own limitations in having the necessary knowledge, skills and experience to provide MND care. Generally participants suggested a need to provide education about the diseases aetiology, progression and management. One participant said:

I think the most important thing is people need to have an understanding of the disease process. You know, what is motor neurone disease, how it may progress, particularly an understanding about how it's hard to predict sometimes what course it will take...The other important area is for people to understand how to manage particular symptoms that arise...with motor neurone disease. [Medical Specialist]

The importance of differentiating what people with MND required, as distinct from people with other life-limiting conditions, and to recognise their unique care needs was also paramount.

Keeping up to date with current knowledge and services related to MND was difficult for participants who provided care infrequently:

It's really been keeping abreast of what developments are happening in the area. New research that's going on, what the findings are. Because the clients with MND usually know about them before us... You know, they're on the internet. [Medical Specialist]

Although participants highlighted the need for education for health professionals, they also discussed the need for non-professional staff (such as nursing assistants) to receive education about the disease and its progression:

Because health care workers don't have a medical background, they might not understand certain things, they need to have some education about what the condition is because they might see one neurological condition being the same.... [Occupational Therapist]

Bespoke Communication

Bespoke Communication was the second sub-theme identified and referred to the health professional's ability to tailor and personalise care messages effectively with the range of people involved in care. Specialised communication skills were required for interaction with patients, carers, and the care team. Sensitivity and experience were also required in communicating about end of life matters.

Communication with patients

Participants said that care providers needed to communicate carefully, to ensure that they met the needs of patients and families and adequately prepared them for the next stage of their illness. The negotiation of care required skilled communication. Communication was vital if people were to make informed choices:

They need to have good communication. They need to be able to talk to patients about what is happening and how it's affecting them. [Medical Specialist]

In addition to active listening skills, allowing enough time for communication and relationship building was described as essential.

Communication with people with MND presented particular challenges because of the potential for communication deficits relating to the disease process, in particular dysarthria and anarthria, and on the use of a variety of devices to assist communication. Knowledge of these devices and using them effectively to communicate was an important skill when working with people with MND. One participant explained:

For many people they're going to have to use communication aids so that they may need to be familiar with those.
[Occupational Therapist]

Participants said that staying one step ahead required the introduction of communications aids early in the disease trajectory, which was beneficial in ensuring patients were well practiced in their use, as they began to need them.

Communication with carers

Health professionals also needed to ensure that they developed a good relationship with families. In many cases a family carer acted as a conduit between the patient with communication difficulties and the care team and provided information about care needs. Developing a good rapport with family carers also ensured that their care needs were discussed and planned for:

The carer is important to us because the journey they're going on is very complicated and never ending... it's the exhausting care that the family members have to give and the emotional exhaustion that goes along with the deterioration. [Counsellor]

Communication within the care team

The complex care needs of a person with MND and their family necessitate a large team being involved to manage particular symptoms experienced by the individual. In Australia, it is not uncommon for people with MND to receive care from a number of different organisations, making team communication more difficult. Participants stressed that communication between team members was also crucial so that care was coordinated and seamless. Difficulties with communication between the various disciplines involved in providing MND care were described:

It's very difficult ... to navigate the number of people that are involved. And one hand doesn't know what the other hand's doing. [Physiotherapist]

Ensuring that all members of the care team were kept informed and involved with care was seen as important, but sometimes difficult, with teams often being located some distance apart and having few face-to-face meetings. One participant described the need for improving team communication:

I think the challenge with shared care is good communication. And making sure that everyone is aware of what's happening and what the issues are...For example, if the person has come to a clinic here that we then disseminate that information to all the relevant people that are involved... [Registered Nurse]

Communication about end of life issues

When the team wanted to introduce palliative care, they sometimes met resistance from patients and families who were unprepared to take the step of admitting to the terminal nature of the disease and thus the need for palliative care. Being with the person as they moved towards acceptance of the progression and prognosis of MND represented a hurdle for health professionals, who considered a palliative approach would best meet care needs. Careful, empathic communication was required to assist families to accept

the changes in condition that led to the requirement for a palliative approach to care.

One participant described the communication skills required:

You really need to learn to have some empathy and also be quite comfortable talking about end of life issues and just how we go about educating some of those things I think is a real challenge because I think some of that has to come through life experience. [Registered Nurse]

DISCUSSION

To date, there is little specific information about the needs of Australian health professionals who provide care to people with MND on an occasional basis only. This study has begun to address that deficit and offers some direction for the types of knowledge, skill development and support needed to assist generalist health professionals to provide the level of specialised care required by people with MND. However, the findings of the study are limited by the small number of participants. The focus group was run during a national conference with many competing sessions and offerings, likely limiting the uptake of participation. It is recommended that if such an approach were to be used in future, alternate dates and times for focus group meetings would be arranged to increase probability of participation. However, further interviews were conducted to provide a more diverse sample.

In Australia, care for people with MND is often fragmented and provided by a number of health professionals, few of whom have specialist knowledge about MND. The variable

speed of changes and the individualised nature of deterioration in this condition make it particularly challenging for health professionals to be adequately prepared to provide responsive care. Remaining one step ahead of the disease throughout a person's illness requires a skilled and knowledgeable practitioner with experience of caring for a relatively large number of people with MND in order to guide other health professionals. Oliver [8] described the need for care of people with MND to be flexible and responsive, so forward planning is essential to prevent crises stemming from inadequate planning. However, it is difficult to prepare in advance without a sound experience of the many disease trajectories that can occur. This depth of clinical knowledge is not possible to accumulate without extensive ongoing experience of providing care for people with MND. Therefore, accessible, systematic links between MND specialists and other health professionals is necessary. A small group of clinicians who have frequent, in-depth contact with people with MND could act as a resource to others, providing support and guidance as needed. This would allow health professionals to access MND expertise on the occasions that this specialised knowledge was required.

Findings from this study underscore the need for health professionals who are providing care for people with advancing MND to have access to education and expertise on MND. However, it is important to emphasise that education is likely best offered on an 'as needed' basis. There is likely to be little benefit from providing education to large groups of health professionals who do not regularly provide care for someone with MND. Instead, ensuring that health professionals have access to education about MND when they are actually caring for someone with the disease, will provide knowledge that is timely and relevant. It is also necessary to tailor the education program to meet the

varied needs of different groups involved in care of people with MND. The format of an educational program on MND needs to be adaptable to suit those who need occasional access when they have a patient requiring assistance.

Results from this study have been used to develop and test an education program appropriate for people working in palliative care and other health professionals who need to be better prepared to provide care to people living with MND [4]. This education program is available Australia-wide to health professionals and addresses some of the knowledge deficits of health professionals regarding MND, with an emphasis on a palliative approach to care.

CONCLUSION

This paper has described a project aimed at eliciting the experiences and educational requirements of health professionals who occasionally care for people with MND.

Information gained from both focus groups and individual interviews indicated that health professionals needed to feel they were *Just One Step Ahead* in meeting the needs of people whose needs change rapidly as the disease progresses. A widely available education program has been developed to address these needs.

Acknowledgements

This project was supported by the National Health and Medical Research Council [Grant number 425565]. The authors gratefully acknowledge the contribution of the health professionals and Motor Neurone Disease agencies that provided invaluable assistance to facilitate the research.

Licence for Publication

The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence (or non exclusive for government employees) on a worldwide basis to the BMJ Publishing Group Ltd to permit this article (if accepted) to be published in BMJ Supportive and Palliative Care and any other BMJ PGL products and sublicences such use and exploit all subsidiary rights, as set out in our licence (<http://group.bmj.com/products/journals/instructions-for-authors/licence-forms>).

Competing Interest

Competing Interest: None declared.

REFERENCES

1. Wood-Allum C, Shaw PJ. Motor Neuron Disease: a practical update on diagnosis and management. *Clin Med* 2010;**10**:252-258.
2. Mitchell JD, Borasio GD.). Amyotrophic lateral sclerosis. *Lancet* 2007;**36**:2031-2040.
3. McDermott CJ, Shaw PJ. Diagnosis and management of motor neurone disease. *BMJ* 2008;**336**:658-662.
4. McConigley R, Aoun SM, Kristjanson LJ, et al. Implementation and evaluation of an education program to guide palliative care for people with Motor Neurone Disease. *Palliat Med* 2011;**26**(8):994-1000.
5. Braun V, Clarke, V. 2006, Using thematic analysis in psychology. *Qual Res in Psych* 2006,**3**:77-101.
6. Burla L, Knierim B, Barth J, et al. From text to codings: intercoder reliability assessment in qualitative content analysis. *Nurs Res* 2008;**57**:113-7.
7. Emden C, Sandelowski M. The good, the bad and the relative, part one: conceptions of goodness in qualitative research. *Int J Nurs Pract* 2002;**4**(4):206-12.
8. Oliver D. Palliative care for motor neurone disease. *Pract Neurol* 2002;**2**:68-79.

Table 1: Health professionals represented in sample

Profession	Number of Participants
Registered nurse	8
Occupational therapist	6
Case coordinator/care advisor	5
Medical specialist	3
Physiotherapist	3
Speech pathologist	3
Complementary therapist	1
Counsellor	1
Dietician	1
Prosthetist	1
Chaplain	1
Total	33

NB. Some participants listed more than one professional role