Describing the role and function of Care Advisors in the Motor Neurone Disease Association of West Australia.

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Abstract

Background: The Motor Neurone Disease (MND) Association of Western Australia provides information, education and advocacy for people living with MND. The role and function of the personnel who provide this service has not been described in the literature and is therefore poorly understood by both healthcare professionals and the public.

Purpose: To describe the role and function of the West Australian Motor Neurone Disease Association (MND Association WA) Care Advisors (CAs).

Method: Ethnographic observation of seven MND Association WA CAs in their normal daily setting. Interviews with end users of CA service (people living with MND and their carers). Analysis of the observations and interview transcripts was undertaken to identify themes.

Findings: The CAs were observed to undertake their supportive role with passion. Clarity around the role and function was ambiguous, even amongst the people in the roles. It is suggested this is due to limited formalised processes and procedures in an organisation that has moved from originally being run by volunteers through to a professional not-for-profit organisation. This in turn led to issues in recruitment and retention, clinical knowledge versus clinical care and demonstrating capabilities against Key Performance Indicators (KPI's) for reporting to funding bodies.

Conclusion: Multiple opportunities were highlighted during this study for these service providers to develop robust procedures to record the nature of their work, develop resilience in their work place, and ensure ongoing professional development processes are engaged.

Keywords: motor neurone disease, Care Advisor, case management.

Introduction

Motor Neurone Disease (MND) is an aggressive, degenerative neurological disease with no known cause or cure. It is indiscriminate in the age cohort in which individuals are affected; and no particular race is more or less prone to the impact or incidence of this disease (Craft, Tiziani, & Gordon, 2011). MND is a “fatal neuromuscular condition that afflicts as many as 1 of 350 males and 420 females over the age of 18” (Kiernan, 2007, p 2). The disease is most commonly diagnosed after the age of 40 years and is usually slowly progressive over 3-4 years. The incidence of MND globally is 1.5 – 2 patients diagnosed per 100,000 per year (Doyle, Hanks, Cherny, & Calman, 2005) with an approximate lifetime risk of developing the disease of 1 in 800 (Phukan & Hardiman, 2009). The MND Association of Western Australia (MND Association WA), has approximately 140 MND patients and their families registered to receive support at any given time. The volume of clients fluctuates as new clients register with the Association and others succumb to the disease. The support the Care Advisors supply may include approximately six months’ grief support (Department of Health, 2008).

The clinical presentation in MND is one of muscle weakness which may involve all muscles, or a paresis (partial paralysis) which corresponds to a single muscle group, with possible hyperreflexia (over responsive reflexes) and neurone degeneration affecting both the upper and lower neurological pathways. Muscular wasting and weakness of the limbs become evident, with eventual progressive involvement of motor neurones controlling speech, swallowing and respiration (Gent, 2012). Due to the devastating implications of the disease, and with no single diagnostic test presently available, there may be a long period of symptoms, often up to a year, with exhaustive testing to eliminate alternative diseases prior to a definitive diagnosis (Oliver et al., 2006). It is at the point of diagnosis a per-
son living with MND, their family and significant others, may access the support of the MND Association.

The MND Association provides the primary source of advocacy, social, physical and emotional support to people living with MND and their families and carers across Australia (Kiernan, 2007). The key contacts who provide this service are the Care Advisors (CA). The role of the CA developed from its inception in Western Australia some twenty years ago as a group of volunteers, to the present situation where the Association, as well as case coordination the Care Advisors has moved from that of a supportive friend to a professional service.

To date, the work of the Care Advisors has been poorly described in the Australian context and not at all in West Australia. A needs analysis of patients and carers living with MND conducted by Colyer (2009) indicated the MNDA (WA) Care Advisors are highly regarded however what CAs actually do, what supports they require as individual healthcare professionals, and what risks the organisation faces if their corporate knowledge is lost through attrition, has not previously been analysed. This paper reflects the key learnings from an internal research study to observe, question and document the work, role, function and processes of incumbent and past Care Advisors from MNDA (WA).

Methodology
The theoretical framework for this study is set in social research, with grounding in the qualitative research method and logic of thematic analysis. Ethnography challenges quantitative research by observing interactions, behaviours, and written reflections, asking questions of the inhabitants (informal interviews), then taking this data and eliciting themes to develop a rich depiction of the culture. Ethnographic research stresses discovery and takes the position human behaviour and the ways in which people form and make meaning of their worlds and their lives are variable and locally specific (LeCompte & Schensul, 1999).

In this case, the ethnographic study included a combination of non-participant observation, review of organisational processes, record-keeping and staff interaction, as well as semi-structured interviews with incumbent and former Care Advisors, clients of the service, current and former carers of people living with MND, and some members of the public who were identified as bereaved from the loss of a partner to MND.

Ethical Considerations
This research was supported by the Motor Neurone Disease Association of Western Australia Board of Directors and was conducted under ethics approval of the Edith Cowan University Human Ethics Research Committee. Participants were informed about the nature of the project, their right to withdraw at any time and that ultimately the findings would be presented to both the MND Association of Western Australia Board of Directors, and be submitted for publication. In order to provide a level of anonymity to the participants, comments are attributed to either a patient (P 1), family member (F 2), bereaved (B 3) or Care Advisor (CA 4).

Sample
The sample for the observation was purposive as there was a finite number of Care Advisors working for the organisation at the time of the research. A total of four CAs were observed in their daily workplace, including during telephone, face-to-face and home interviews with people living with MND. Consent was gained from all CAs to observe their work. Consent was obtained from all clients, families and carers where their interaction with the Care Advisors was observed by the non-participant researcher.

The sample for the interviews included two separate groups:
- Current and former Care Advisors (N=7); and
- People living with MND who were supported by Care Advisors (N=6), and current carers (N=17). This second group included bereaved family members (B=5) or carers who were willing to talk of their experiences with Care Advisors.

The review of organisational processes and record-keeping was undertaken over a period of one week and consisted of documented administrative processes related to the work undertaken by Care Advisors, organisational job descriptions, and the organisational Operational Plan, with associated policies and procedures.

Data Collection
Research was undertaken over a three month period. This included a period of observation and interviews. The Motor Neurone Disease Association of Western Australia
(MNDA WA) was keen to support this research and thus agreed to use their website as the primary recruitment location for people living with MND and/or their carers to volunteer to be interviewed.

An additional group of interviews came unexpectedly through word of mouth, with several carers and people living with MND contacting the researcher through their individual Care Advisors requesting to be involved in the research. Care Advisors were either interviewed, or interviewed and observed in the carriage of their daily duties. Interviews were conducted with 17 carers (both current and bereaved) and six current clients.

Data Analysis
The interviews and observation notes were transcribed verbatim and this data was entered into a computer program which picks up similar words or phrases to identify nodes that are consistent across all (or most) of the data (Nvivo). These nodes were then linked together in similar groupings or themes. The themes identified through this process included understanding the service, recruitment and retention, development of data collection capability to support describing the service, clinical knowledge versus clinical care, and the nature of supportive resources.

Findings

Role Ambiguity
When asked, all the CAs described their role as “providing education, advocacy and information”... to people living with MND and “their families or carers”, and “healthcare professionals who worked with these clients” (CA 1, 2, 3, 4). Consistency, however, was absent when the CAs were asked specifically how they provided this service. Some CAs described their role as to support the clients by providing knowledge and information, others suggested they journeyed through the disease progression with the clients, and a third group of CAs spoke of advocating for services, equipment and clinical care for their clients.

Understanding the Service
MNDA WA has approximately 140 clients registered with the organisation. As people living with MND are in various stages of their disease progression, some require more interaction than others, and others require no support. The complexity of understanding when to engage with a client, their family or carer comes to the CAs only through time and experience in the role. It is suggested key to understanding the role and function of the Care Advisors, is gaining an understanding of the interaction which may be required

<table>
<thead>
<tr>
<th>Client Registered Only</th>
<th>Initial Interaction Phase</th>
<th>Secondary Interaction Phase</th>
<th>Tertiary Interaction Phase</th>
<th>Terminal Interaction Phase</th>
</tr>
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<tbody>
<tr>
<td>Client has requested no interaction at this time. Access to MNDA(WA) website for information now available.</td>
<td>Minimum of six monthly telephone contact. May have had initial physical, environmental &amp; psychosocial assessments conducted. May still be working (independently managing activities of daily living)</td>
<td>Minimum of monthly telephone contact. Initial assessments have been conducted. Referral to service providers may have commenced. May still be working (increasing support to manage activities of daily living)</td>
<td>Minimum of weekly home visits leading up to daily or second daily. Home visits and supports now aimed primarily at end-of-life care, supports for carers and family. Hospice care may be considered.</td>
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Figure 1 (Above): Phases of MND client interaction (Developed for this study).
at various different stages through the disease. A short descriptor of five different phases of client interaction is offered in Figure 1.

**Recruitment and Retention**

By 2013 the Association had moved from a volunteer basis to a service provided by personnel with professional healthcare backgrounds, and it recognised that in order to recruit and retain the right people to be Care Advisors, they needed to be able to describe the processes associated with the role. Having come from a volunteer service where the records were handwritten, there was an inconsistent approach to assessment. There was no standardised assessment, filing system or computer filing processes, thus the processes to capture the actual work associated with the support and advocacy roles of the Care Advisors was less than clear or simple. This was found to result from a lack of policies and procedures, inconsistent staff induction, inconsistent mentoring and a lack of professional development structures.

Some staff reported they had received excellent induction experiences from supportive mentors, while others reported their experiences indicated the level of induction and mentoring was personality-based. Those staff who had not received positive experiences in their induction or mentoring articulated this was one of the primary reasons they ultimately left the Association.

Electronic and manual folders of information and process mapping were provided to each CA and these were updated annually (or on an “as needed” basis) by the senior CA. The Association moved from individual staff networks of healthcare service providers to a generic listing available to, and updated by all, staff working in the Association. Protocols for interaction with service providers outside the Association were mapped and a consistent approach adopted by all CAs. The Association recognised the impact of not having these processes clearly mapped and quarantined time for each of the CAs to map one process. They then added time to the weekly staff meetings to review these maps in order to deliver a consistent approach to any given process. The process engaged the staff rather than imposing a top down set of rules. The following quotes exemplify this experience,

> “In the past I’ve either done it the way I was shown when I first started here, or developed my own way of doing things. Looking at the different ways we all did the same thing was a real eye opener” (CA 1).

> “Initially I thought this whole mapping thing was a complete waste of time I didn’t have. Because we’ve developed set plans for how to do things and we are all doing it the same, we save so much time and it’s forced us to work together rather than independently” (CA 5).

Induction also included a review of the interprofessional set of guidelines for the office setting, including communication, access to client information (electronic and manual filing systems), and administrative processes such as notification of death.

Induction and mentoring also included a period of “shadowing” where the new CA did not take on a full case load initially; instead they worked alongside and experienced CA for a period of two weeks, gradually taking on their own client load. On the occasion of a first home visit or new client intake, the experienced CA was observed to take the lead in interactions. On the following two or three occasions, the experienced CA supported the new CA, allowing them to take the lead, then provide feedback to the new staff member on ways to improve on their interaction and/or assessment.

Meeting the professional development needs (PD) of the Care Advisors commenced at the time of their employment with the induction and mentoring processes, but were felt by all interviewees to be limited. They wanted opportunities to develop their skills and knowledge around the care of people living with MND, and implementing evidence of best practice in the support of people who care for people living with MND.

> “Part of the problem is the lack of research published about caring for people living with MND. There’s lots of publications about the science of the disease, but very little evidence of best practice for care” (CA 4).

In the absence of any formalised PD, staff determined to develop other capabilities to ensure the smooth functioning of their workplace. Inclusive in these capabilities was data collection.

**Development of Data Collection Capability**

Opportunities to improve the manner in which statistics for reporting day-to-day business were identified as a result of the CA task process mapping, as a potential way to gain time
for CAs to spend less time on documentation tasks. The development of electronic assessment tool(s) and an electronic client database which links to each client’s electronic file, has had an immediate impact on the calculation of statistics required for monthly reporting to the Department of Health. These included data sets for how many hours per client per day per CA for home visits, telephone contact, interviews with clients, carers and families; clinic attendance, interaction with member of the interdisciplinary team, coordinating support services and respite.

This study identified further opportunities for the Association to develop robust processes upon which data collection capabilities may be enhanced to articulate how much time intake, registration, allocation of services, provision of education, developing educational programs and administration of equipment allocation takes.

**Clinical Knowledge vs Clinical Care**

It was made clear to the researcher on several occasions that the role of a Care Advisor is not clinically based and they do not provide any clinical intervention. This is sourced within the Perth metropolitan area primarily through the neurological nurse employed by the Multiple Sclerosis (MS) Society. At this point there is only one neurological nurse and this presents an immense risk to the Association in terms of succession planning, sick leave, annual leave and age of the incumbent. The current incumbent is an extremely experienced nurse, however they are working toward the end of their nursing career and the members of the Association who rely upon her clinical skills and knowledge would be poorly supported in the event she leaves or is unable to continue in her role.

A similar situation was noted to exist with the clinic nurse at the State rehabilitation clinic. This person has an enormous amount of corporate clinical knowledge about the care required for people living with MND, yet no processes have been put in place to ensure their knowledge is captured prior to retirement. Succession planning and development of clinical practice guidelines are required.

A third group of clinician nurses the Care Advisors interact with are the rural and remote community nurses. Observation and interviews with several Neuroscience Council-funded rural community nurses indicate an overlap of services provided by the MS Society nurse, the MNDA WA Care Advisors and the community nurses who have developed a therapeutic relationship with clients in their community. Several carers interviewed indicated their frustration with “too many fingers in the pie” (F2) and “too many people giving different information” (F7). This may be one of many reasons articulated in the needs analysis survey as to why individual clients registered with the Association and then chose not to use the services, or of more concern, elect not to join the Association initially. Word-of-mouth in small rural communities will always provide “evidence” where an Association has not shown itself to be a functional organisation working together with all the components of the health care team.

The need to have a background in clinical healthcare was noted to be a major theme, when considering the capacity of the CAs to perform their primary function of assessment. Whether the first interaction with a person living with MND was by telephone, in the Association office building, or in the client’s family home, all CAs performed assessments which could be clearly observed to fall into three discrete categories: psychosocial, physical and environmental.

Psychosocial assessments documented less consistently than physical and environmental assessments. The CAs interviewed suggested this was a result of the subjective nature of psychosocial assessments and the fact these were most often based on conversations not formalised assessments using psychometrically tested tools. These assessments looked at how well or poorly the person living with MND, as well as their family and primary carer, were coping with the change in their health and wellbeing.

“It’s hard enough trusting someone else to look after him the way I do, but asking him to go to some place that isn’t familiar with what MND is…that’d be too much for both of us to cope with” (CA 4).

CAs were seen to suggest respite when either the person living with MND or their carer needed time out or time away from each other. The CAs noted a move away from respite being provided by facilities, instead moving toward a preference for service providers to come into their home to provide respite.

“It’s hard enough trusting someone else to look after him the way I do, but asking him to go to some place that isn’t familiar with what MND is…that’d be too much for both of us to cope with” (F4).

The CAs also suggested interactions with other people who had the disease and other carers, not only for the social interaction with people who understood the situation the cli-
ents and carers were experiencing, but also
to learn how others coped. Learning strate-
gies from others who were "living" the same
life was seen to be of greater value to the
carers interviewed than "reading it from a
book".

"I think we were really fortunate to have
CA3 as our Care Advisor. We met many
other people with MND over the three
years of [husband's name] illness. We
needed someone to be really profession-
al and that's what we got. I wouldn't have
liked someone who was just there for a
social chat. I have family for that" (B2).

"When CA 1 came the first time she
brought a book along written by someone
who had MND. I thought it was a nice
book but there was too much information
all in words. I only read the beginning bit
and then bits when things changed, but
then she left and CA5 came instead. She
gave me a smaller pamphlet of infor-
mation and a website to look at. That
was easier for me as it was in smaller
snippets of information "(B5).

Physical assessments followed a more pre-
scribed, subjective process looking at mobili-
ty, speech, swallow, communication, cogni-
tion and physical capabilities related to
strength and gait. Interventions and referrals
resulted from changes to physical assess-
ment, for example a Speech Pathologist,
Respiratory Physician or for mobility or com-
unication aids.

Finally, the CAs were circumspect in their
assessments of the client's environment.
Carers and clients both insisted remaining in
their home where they felt "safe" was para-
mount to living with the disease for as long as
possible. In order for them to be able to
achieve this, the CAs introduced the concept
of minor alterations to the home in such a
way as the client and carers did not feel the
change was imposed. Such interventions or
alterations included the change of stairs to
include ramps, risers over entries, handles in
showers, removal of mats and other trip/fall
hazards.

"CA3 brought the shower chair one day.
I didn't even know what one was. It
made it so much easier in the mornings
that he could sit down. Neither of us had
realised he was that weak, but she
must've just seen the changes from her
last visit" (C4.)

"CA3 was amazing for dad. She'd arrive
with bits of equipment that made mum's
life much easier. First it was a sort of ex-
tension clip to lift things off the ground.
That was great because his balance went
really early and he had lots of falls trying to
pick things he had dropped up off the floor.
Later a chair arrived with a delivery van,
thunder was the lifter. I don't remember
mum ever saying she did an assessment
or snooped through the house, but she
must've done to know what he needed. Or
more correctly what mum needed to care
for dad" (F7).

Supportive Resource

Interviews with current and former clients of
the CA service provision were unanimous in
their description of the Care Advisors being
"angels" who helped them to navigate
through the minefield of available health care
services and provided information and edu-
cation about the disease both in a timely
manner relative to their physical, psychoso-
cial or financial needs. They were also seen as
"partners in the journey" from diagnosis
through the disease trajectory and into the
first months of bereavement.

Patients, carers, family members and be-
reaved listed similar support services provid-
ed by CAs. These included information about
the disease and prognosis regarding physical
deterioration; information about services for
people living with MND, how to access finan-
cial support for people living with MND, how
to access equipment, completion of forms
relating to accessing equipment or services,
and provision of equipment; knowing when
the patient needed physical aids or the ser-
vice of home care or nursing support; know-
ing when the carer or family needed support;
and most often cited, someone who would
listen to them and share a cup of tea.

"Even though [husband's name] has been
gone for five years, I still miss my cups of
tea with CA1. She rang every week and
then started visiting more often. She
would always stay for a coffee while I had
a cup of tea. We wouldn't necessarily talk
about MND, but she was a good listen-
er" (C1).

"It's only a couple of months since
[patient's name] died. CA2 drops in once a
week to check on me "(C7).

Discussion

This study has provided a description of the
previously unpublished role and function of
the Care Advisor Service provided to people living with Motor Neurone Disease in Western Australia. Similar titles for MND staff exist across Australia with nomenclature differences (Regional Advisors in New South Wales, Victoria and Tasmania). However to date, no studies have been undertaken to determine if the role and function is the same for each of these positions. The MND Associations for each state have briefly described these positions on their organisational websites. However these are insufficient for people external to the organisation to understand fully the complexity of the role.

Part of the lack of understanding about the role may be attributed to the role title. The title “Care Advisor” may imply a level of clinical care not commensurate with the actual role function. For this reason, discussion about the appropriateness of the role title may be due, not only in Western Australia, but more widely across the country. The role is more aligned with the broad title of “case coordinator” which is defined throughout literature as “providing a continuum of healthcare services for a defined group of clients” (White & Hall, 2006, p E99). The emphasis for case coordinators is on the word “services” rather than on “care”.

Based on the findings of this study, the Association would provide a more consistent approach to their service delivery, developing a process for induction - A “buddy” mentoring system, whereby an experienced CA is appointed as the mentor for new CAs which would be beneficial. Development of clear relationship parameters are also important, particularly where CAs interact with community nursing staff. Development of clear processes will avoid duplication of effort and reduce confusion for clients. Leading on from these professional development processes, is the need to clearly articulate reporting processes and robust data collection processes with infrastructure to support the CAs to collect and collate this information.

**Conclusion**

The role of the MND Care Advisor developed from its inception in Western Australia to the present situation where the Association and the service the Care Advisors provide has moved from a supportive friend to a professional service. The growth in service delivery for Care Advisors has not been supported by growth in documentation of this service, electronic records, consistency in service delivery, consistency in information being provided clients, and moderation of service delivery amongst the various Care Advisors.

Development of mentoring programs and processes for new staff, along with the development of key practice guidelines based on evidence of best practice as is the industry standard for all health care service delivery are fundamental to the ongoing professional development and professional image of the Care Advisor. The current incumbent Care Advisors and supportive Executive are moving to address these issues, bringing the ad-ministration of the service into line with the professional clinical application of knowledge to the role of MND Care Advisor.

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