

**Identifying and addressing the support needs of family caregivers of people with
Motor Neurone Disease using the Carer Support Needs assessment Tool**

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Abstract

Objectives

Family caregivers of people with Motor Neurone Disease (MND) experience adverse health outcomes as a result of their caregiving experience. This may be alleviated if their support needs are identified and addressed in a systematic and timely manner. The objective of this study is to assess the feasibility and relevance of the Carer Support Needs Assessment Tool (CSNAT) in home based care during the caregiving period, from the perspective of family caregivers of people with MND and their service providers.

Methods

The study was conducted during 2014 in Western Australia. Thirty family caregivers and four care advisors participated in trialing the CSNAT intervention which consisted of two visits from care advisors (6-8 weeks apart) to identify and address support needs. Family caregivers' feedback was obtained via telephone interviews and care advisors' feedback via a self-administered questionnaire.

Results

Twenty four caregivers completed the study (80% completion rate) and identified support priorities being "knowing what to expect in the future", "knowing who to contact if concerned" and "equipment to help care". The majority found that this assessment process has adequately addressed their needs and it gave them a sense of validation, reassurance and empowerment. Care advisors advocated the CSNAT approach as an improvement to standard practice, allowing them to more clearly assess needs and offer a more structured follow-up and a focus on the caregiver and family.

Significance of Results

The CSNAT approach for identifying and addressing family caregivers support needs was found to be relevant and feasible by MND family caregivers and care advisors. The tool provided a formal structure to facilitate discussions with family caregivers to enable needs to be addressed. Such discussions can also inform an evidence base for the ongoing development of services, ensuring that new or improved services are designed to meet the explicit needs of family caregivers of people with MND.

Keywords: Motor Neurone Disease, Amyotrophic Lateral Sclerosis, carer support needs assessment tool (CSNAT), support needs, family caregivers, service providers.

Background

The significant psychological, social and physical impact on family caregivers when providing home based family caregiving for the terminally ill is well documented (Schulz & Beach, 1999; Aoun et al., 2005; Grande, Stajduhar, et al., 2009; Stajduhar et al., 2010). Family caregivers' psychological outcomes can be improved if good support is received during caregiving (Ferrario et al., 2004; Grande et al., 2004; Kissane et al., 2006; Grande, Ewing, et al., 2009). Identifying and addressing concerns early, leads to better carer health outcomes (Grande et al., 2004; Grande, Stajduhar, et al., 2009). However, adequate assessment of family caregivers' support needs by service providers is often informal due to their limited time to undertake this whilst focussing primarily on the care recipient (Ewing et al., 2013).

Family caregivers of people with Motor Neurone Disease (MND) often describe their caring experiences as unrelenting due to the progressive nature of the disease and the hopelessness of recovery compared to cancer (Locock & Brown, 2010; Aoun et al., 2012; O'Brien et al., 2012). MND or Amyotrophic Lateral sclerosis (ALS) is a progressive neurodegenerative disorder with incidence 1-2 in 100,000/year, peak age at onset is in the sixth decade of life and median survival is about 3.5 years from onset of symptoms (Van Teijlingen et al., 2001; Leigh et al., 2003; Bromberg, 2008). People with MND can progress rapidly to high levels of disability changing over months rather than years and the consequent need for support, including assistance with feeding, communication, movement, transferring, toileting and other personal daily living tasks (Oliver & Aoun, 2013).

Studies have reported that family caregivers suffer from anxiety, depression, strain, burden, fatigue, impaired quality of life and reduced social contacts (Hecht et al., 2003; Chio et al., 2005; Goldstein et al., 2006; Aoun et al., 2013). Whilst management of physical symptoms in

MND is paramount, attending to such family caregivers' psychosocial factors is crucial to prevent deterioration in health outcomes (Goldstein et al., 2006; Oyebode et al., 2013). Most individuals with MND live at home, where their psychosocial functioning is intimately connected to the extent and quality of support they receive from family members.

Interventions to reduce caregiver burden and distress related to MND have been reported with varying success (Goldstein et al., 2006; Murphy et al., 2009; Aoun, Chochinov, et al., 2014). Therefore, it is important to design and evaluate effective interventions and find ways to deliver them to families living and caring for someone with MND (Pagnini et al., 2012; Aoun et al., 2013; Oliver & Aoun, 2013).

However, there is a lack of suitable tools for assessment of family caregivers' support needs in end-of-life home care (Hudson et al., 2010; Ewing & Grande, 2013) and in particular between diagnosis and end-of-life care in MND (Goldstein et al., 2006; Oyebode et al., 2013).

The Carer Support Needs Assessment Tool (CSNAT) is a validated evidence based tool used to identify family carer support needs in a systematic way, rather than the existing ad-hoc manner. As such the tool also serves as a supportive carer intervention and is carer-led, but facilitated by the health professional (Ewing et al., 2013; Ewing & Grande, 2013). The CSNAT adopts a screening format, structured around 14 broad support domains. This format allows it to be brief but also comprehensive, enabling caregivers to identify the domains in which they require further support which can then be discussed with health professionals. Each item represents a core family carer support domain in end of life home care, and these domains fall into two distinct groupings: those that enable the family caregiver to care and those that enable more direct support for themselves. There are four response options for each of the 14 CSNAT items that allow family caregivers to indicate the

extent of their support requirements for each domain: no more, a little more, quite a bit more, or very much more (Table 1).

The CSNAT has been trialled using a stepped wedge cluster trial in Silver Chain (a large community based service provider in Western Australia) with 322 family caregivers of terminally ill people (mainly cancer) and 44 nurses. The intervention group showed significant reduction in caregiver strain relative to controls ($p=0.018$, $d=0.35$) (Aoun, Grande, et al., 2015b) and feedback of family caregivers (Aoun, Deas, et al., 2015a) and nurses (Aoun, Toye, et al., 2015c) using the CSNAT was positive. Although the CSNAT appeared to offer a practical approach to assessing and addressing family caregiver needs in the cancer field, it was deemed important to assess the extent to which the tool would be appropriate for use in other settings and with different disease groups. Therefore, this study was designed to implement and test the suitability of the CSNAT with family caregivers of people living with MND in the community, across the caring experience and not only at end of life.

[Table 1 about here]

Objective

To assess the feasibility and relevance of the CSNAT in home based care during the caregiving period, from the perspective of family caregivers of people with MND and their service providers.

Methods

The study was conducted in Perth, Western Australia (WA), April-July 2014. The study was approved by Curtin University Human Research Ethics Committee (SONM11-1014). All

participants provided written informed consent to participate in this study and the ethics committee approved this consent procedure.

Study design

This study design was descriptive and longitudinal. Family caregivers' support priorities were obtained through the set of items on the CSNAT, their feedback was obtained via semi-structured telephone interviews and care advisors' feedback via a self-administered questionnaire with open ended questions. Feedback from both groups was obtained at the completion of the intervention (as described below). Family caregivers were considered to have concluded the study if they have completed two CSNAT contacts with the care advisor (6-8 weeks apart).

Participants

The study was conducted with primary family caregivers of clients of the Motor Neurone Disease Association of WA (MNDAWA) and their care advisors. The service has in its database about 120 clients at various stages of disease progression. All adult caregivers (aged 18 years or older), who were caring at home and were able to read and write in English were eligible for the study, unless the care advisors had concerns about the caregiver's ability to cope with research because of the exceptionally high levels of distress. A primary family caregiver is defined as a person who, without payment, provides physical care (and emotional care) to a person who is expected to die during provision of the caring role. This care may be provided on a daily or intermittent basis.

Participation in the feasibility study was voluntary, with no undue influence placed on family caregivers of people with MND receiving assistance from care advisors. They were assured

their decision would not in any way affect any supportive care they were receiving now, or may receive in the future from any agency.

The four care advisors working for the association were invited to participate, with no undue influence placed on them. They were assured that their decision will not affect in any way their employment with the association. The standard practice of care advisors is to regularly visit clients at home and their role consists of complex case coordination, provision of disability aids and equipment, delivery of information and facilitated support programs, in order to enable people with MND to live as independently as possible for as long as possible.

The intervention

The intervention consisted of the following steps:

- The CSNAT tool is introduced to the family caregiver by the care advisor
- The family caregiver is given time to consider which domains they require more support with
- An assessment conversation takes place where the care advisor and family caregiver discuss the domains where more support is needed to clarify the specific needs of the family carer including which are their priorities
- A shared action plan is made where the family caregiver is involved in identifying the type of input they would find helpful (rather than delivery of 'standardised' supportive input that the service is able to deliver)
- A shared review is planned within 6-8 weeks

Data Collection

The four care advisors working for MNDAWA, who regularly visit clients at home, introduced the study to the family caregivers who met the inclusion criteria, and obtained written consent from them to trial the CSNAT and provide feedback to the researcher at the end of the trial. The care advisors collected the CSNAT data from the caregiver, during their usual visits. For the purpose of this feasibility study, a baseline visit and then a follow-up visit were undertaken within 6-8 weeks.

The researcher liaised regularly with the care advisors during the data collection period to ensure the research process was followed and collected feedback information from family caregivers after they had completed the study. Patient deaths were monitored with the care advisors throughout the data collection period to ensure that bereaved family carers were not contacted by phone for completing the follow-up interview, as it was not sensitive to do so once death occurred.

Family caregivers were interviewed by an experienced research nurse who telephoned at a pre-arranged time convenient to them, on average within 2 weeks after completion of the intervention, to seek their feedback on the appropriateness, relevance and benefit of the assessment process to them. Participants were given the opportunity to describe any other benefits or problems and ways of improving their experience of the CSNAT intervention. The questions were (as described in Aoun et al, 2015)(Aoun, Deas, et al., 2015a) :

- How easy or difficult was it for you to complete the CSNAT assessment of your support needs?
- Did you feel that completing the assessment process was helpful in getting the support you needed?
- Did this experience of identifying your needs affect what you did yourself?

- Did you feel that your needs as a carer were acknowledged/listened to in a way that was distinct from the needs of the patient?
- Do you think the CSNAT assessment process could be improved in any way?

Care advisors preferred to give feedback by completing a self-administered questionnaire with open ended question format to report on their experience in facilitating this process, the benefits of, or barriers to implementing the CSNAT with MND family caregivers, the optimal stage and time for administration and review, and suggestions for improvement to assist with future planning. Care advisors chose written feedback as this gave them time in their busy schedules to consider their answers and return the survey when completed in their own time. An anonymous self-administered survey was sent to each care advisor and collected later by the researcher from the MNDAWA office in a sealed envelope.

To get an indication of the disability of the care recipients and by consequence the burden this might pose on the family caregivers, care advisors also completed a standard tool on the functional status of the person with MND using the Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) which has 12 items assessing activities of daily living (ADL) functions and changes in fine motor, gross motor, bulbar and respiratory function (Cedarbaum et al., 1999). Higher scores are indicative of less impairment.

Analysis

Descriptive statistics, using SPSS 22, were used to describe the demographic characteristics of family caregivers and their support needs as identified by the CSNAT. Data from the interviews with caregivers were subjected to a thematic analysis (Guest et al., 2012). Initial coding was carried out independently by the first two authors and was supported by the NVivo 10 software programme. The interviews were not audio-recorded,

but thorough note-taking of interviews were verbatim. Transcribed interview notes were read and re-read to identify key words and phrases that were then grouped into categories labelled with codes. To enhance the credibility of findings, the interviewer was involved in the analysis process so that consideration of the nonverbal context was assured. Themes emerging after comparisons within and among individual interviews identified key messages. These themes were initially identified independently, with differences resolved by discussion and by returning to the data. Exemplars are provided to explain themes and how interpretations have been reached.

The care advisors' written feedback data was subjected to content analysis by the first two authors following the same rigor, with responses grouped according to each survey item, ensuring the context or explanation could be considered and establishing overarching categories through comparison of content. Exemplars demonstrate how interpretations have been reached. (Hsieh & Shannon, 2005).

Results

Thirty family caregivers were recruited by four care advisors from the MNDAWA and 24 completed the study in the four month period (completion rate of 80%). Given the progressive neurological disease of this patient group, four patients died before the family caregiver completed the intervention, one carer declined due to her husband not wanting her to be involved anymore and one carer had gone on an extended holiday and was not contactable. The sample size was based on the number of clients visited regularly by the care advisors during the four month study period, and whose family caregivers met the selection criteria and accepted to participate.

Family caregivers completed two CSNAT forms (at a median interval of 7 weeks) followed each time by a discussion about their support needs with the care advisors. Visits occurred face to face for the first CSNAT contact (79.2%), or by telephone for the follow-up contact, in keeping with the care advisors' usual practice. Feedback interviews by the researcher were undertaken on average 15.9 days from study completion, and interviews lasted on average of 12.4 minutes.

The majority of family caregivers found the CSNAT form easy to complete (83.3%), taking a median time of 10 minutes (range 3-20) to complete the form. All caregivers found the questions clear and appropriate and that they adequately addressed their support needs.

Participants' characteristics

The majority of family caregivers were female (75%), married (87.5%), spouses/partners (79.2%) and 54% of them were retired. Their mean age was 63.8 years (SD= 12.9) (Table 2). People with MND were predominately male (70.8%) with mean age of 62.8 years (SD=10.8) and a median time since diagnosis of 20.5 months (range 4-89). The ALS functional rating scale of fine motor, gross motor, bulbar and respiratory function measured a median score of 27 (range 9-46), indicating moderate functional impairment (Table 2).

Care advisors were female and had been working in the health field in nursing or physiotherapy between 20-35 years and had worked as MND Care Advisors between 0.5-5 years.

[Table 2 about here]

Family caregivers' support needs and provided solutions

The top five support needs reported by family caregivers consisted of (Fig.1): knowing what to expect in the future (83%), knowing who to contact if concerned (71%), equipment to help care (66%), dealing with your feelings and worries (58%) and having time for yourself in the day (58%). When asked if there was anything else not addressed in CSNAT items, one caregiver mentioned support “to communicate with other family members to help them cope with husband's illness & progressive decline”. Another caregiver reported support “to communicate with wife who lost her speech because of disease and [caregiver] feels isolated from wife”.

[Fig.1 about here]

The solutions put in place by the care advisors for “knowing what to expect in the future” consisted of discussions around end of life issues, advance health directives and future care and the role of palliative care. For the second priority on “knowing who to contact if concerned”, discussions centred around ambulance cover, referral to palliative care services, and a contact number at night/weekend. For the third priority on “equipment to help care for your relative”, information was provided on the association’s equipment pool and possibility of financial help for hire of equipment if required; a bedside commode was provided to aid with deteriorating mobility; and liaison with a disability service to provide the next level of bathroom modifications. The solutions put in place for “dealing with your feelings and worries” consisted of information on various avenues for counselling and encouragement to attend the association’s carer luncheon for social support. For the fifth priority on “having time for yourself in the day”, care advisors liaised with service providers to increase hours available for respite, discussed strategies for creating time for the caregiver and encouraged caregiver to allow more people to help with relative's care, giving caregivers more time for themselves.

Family caregivers’ experiences of the assessment process

Four themes emerged from feedback interviews with family caregivers: the overwhelming caregiver journey with MND; the CSNAT practicality and usefulness; validation of the caregiver role and empowerment; and reassurance of support.

Theme 1: The overwhelming caregiver journey with MND

Feedback on the assessment process triggered caregivers describing their overwhelming journey with the disease. Caregivers related their experience of personal stress: *“I do have to go to see 'a shrink' - it's very stressful at times.”* (FC18) and shared how difficult they find coping with the losses brought about by MND: *“They should bring in euthanasia - you wouldn't put a dog through what MND does - I find it very difficult. It really rips you apart.”* (FC27)

Expectation and acceptance of the personal demands of the caregiving journey was acknowledged by caregivers as articulated by this participant: *“Once you become a carer – ‘you have to throw part of yourself away’. I expected that.”* (FC14). However with the focus being primarily on the person with MND, unmet needs of the caregiver often get missed:

I don't think much of me - I have... been through breast cancer myself and don't need a lot. Yes, I did find it's all 'him, him, him'. I have come across that at times. I get a bit sick of it sometimes and think 'I'm here too!' (FC11)

I lost my partner 12 months ago & I was his carer before, and now I'm caring for my son. It's my whole life...I don't think of myself...I've got no issues really, but I mainly worry about how I'm going to cope. It's a terrible disease. (FC28)

Participants described being devastated by the hopelessness of the MND trajectory, making comparison with a cancer diagnosis, where there is often treatment and more support available and some hope of remission or recovery: *“It [CSNAT] was very good. Maybe more detail about the fact that MND is terminal unlike cancer where some recover”* (FC27).

Family caregivers commented on community, friends and health professionals’ limited knowledge of support available to assist people like them in their caregiving journey:

We’re meeting people who have family and friends with MND and they don’t seem to know much about MND. Maybe the doctors don’t tell them? When we go to the GP they say ‘You know more about MND than I do.’ (FC11)

[I’m] looking at the support I need to give to other family members to help them cope with my husband’s illness & progressive decline. (FC12)

Theme 2: The CSNAT practicality and usefulness

Ease of completion of the CSNAT was considered important by family caregivers of a person living with MND as they often have a myriad of forms to contend with. Caregivers described using the CSNAT as *“Quite a good form – one of the better ones...”* (FC26) with one considering it essential to complete it by themselves: *“I completed it on my own - you don’t want someone else to influence what you need.”* (FC29)

Family caregivers appreciated the opportunity to rate their needs as listed in the CSNAT: *“The scale was good to rate how much you needed, then the 3 [priorities] more thoroughly was good to add more detail.”* (FC23)

The assessment process of working together with the care advisor was valued by the caregivers: *“The form was really well done... It puts those little stars up there to consider. It*

works with the 2 parts - the carer's answers and the care advisor's discussion – it can only work with the 2 together – it's very beneficial.” (FC18)

The stage of the MND disease trajectory and how this can affect the wide range of needs of the family caregiver was considered important when implementing the CSNAT, highlighting how these needs can change rapidly. Some caregivers expressed this usefulness when their own needs changed as the disease progressed:

It was very easy. I was given the first form when it was early stages and I didn't think I needed much. By the time the 2nd form, as it [MND] had progressed, my needs changed and the questions were more about what I needed then. It was helpful to talk to the Care Advisor about what she could do to help, going through the form together. (FC30)

As the disease progresses you are more aware of symptoms. At first you don't need much and it would be 'No' to nearly all [questions] but later it would be 'Yes' to nearly all questions.(FC04)

The CSNAT was considered by caregivers as “a stimulus for conversation” prompting them to “*think things through and things to be put in place*”. (FC09)

It covered everything. Another box to say ' Not needed yet' would be helpful. I've been through the emotional stage and now I'm in the practical stage and thinking about what needs to be done. (FC30)

Theme 3: Validation of the caregiver role and empowerment

It was evident that this assessment process has validated the caregiving role as articulated by this participant: *“The form made me think the role of carer was important - the fact they were being asked shows it is considered important...The form shows some evidence someone is caring to ask.”* (FC18)

The CSNAT process allowed caregivers to reflect on what they needed or could do themselves:

It jogged me into thinking about what I might need. Equipment, financial issues - the form had things I never even dreamed about needing. It made me realise what I can do at night if I need to call someone - I have a plan now and I know I don't have to wait until the next morning. (FC30)

It focussed your mind on issues and a method to address it - It's not something you can sweep under the carpet- an outcome resulted from going through the form.
(FC12)

The CSNAT seemed to have helped when there were conflicting needs between family caregivers and patients such as when caregivers felt restricted in accessing support for their own needs as articulated by this participant: *“It [CSNAT] helped me to have counselling & [service] was helpful. My husband isn't wanting to be involved much. It can be a daunting process.”* (FC03)

The process of completing the CSNAT provided an opportunity for carers to consider their own needs when the focus was being mostly directed towards the patient: *“Some of the questions I hadn't thought about. Yes, I think it was beneficial for me - this time it was ‘Oh this is about me!’”* (FC11)

The following participant wanted to go a step further and have the focus of the needs assessment to be specifically on the caregiver, in a way reaffirming the two domains that the CSNAT covered:

The distinction between the needs of the carer and the person cared for can sometimes be blurred. You as a carer tend to focus on 'How can I improve my caregiving?', rather than looking at 'What I need as an individual'. Perhaps that can be accentuated - that this is looking specifically at you & your needs as a carer – distinct from the person cared for. (FC12)

Theme 4: Reassurance of support

A sense of relief was apparent when caregivers received the expertise and support provided by MNDAWA: *“Care advisors see these people [with MND] - they know about the disease whereas friends don't have an understanding of MND. So even just talking with the care advisors is a help.” (FC25)*

I found it very helpful - yes, she [care advisor] was able to answer some of the questions straight away and explained what to do to get different things done. (FC30)

Completing the CSNAT assessment process involved discussion with the care advisor which often prompted awareness by the caregiver of the need for support in patient symptom management. This was improved by family caregivers being encouraged to attend education sessions at MNDAWA:

Definitely, especially from MND AWA and the course they were doing [for caregivers]. It increased my knowledge about the help available - some things were a bit confronting as we weren't at that stage. (FC03)

Participants were offered equipment or solutions to meet a particular need as explained by this participant: “Yes, now I can help him out in many ways, but I can't lift, so that is the only thing I worry about. [Care Advisor] is organising a hoist for me and that will help.” (FC20)

I wasn't aware of all the equipment that was available -it's very good. I went along to a Carer's Lunch and was amazed at all the support available - we're so well looked after. The questions get you to think about things - you have a starting point and then can talk it through & it gives you points you may not have considered - you have a rapport with the Care Advisor. (FC18)

Due to the potentially rapid deterioration associated with MND, end of life issues (EOL) issues are perhaps being considered earlier in the disease trajectory than with other life-limiting diseases. The CSNAT can provide an opportunity to discuss this important issue when it may have been overlooked or postponed:

One of the hardest issues to discuss is EOL issues. It, the form, focussed my mind on the need to discuss this, and I ended up talking to people – I spoke to a counsellor about EOL as a direct result of going through the survey. (FC12)

Care advisors' feedback

All care advisors found the CSNAT format simple to complete, and the questions easy to understand. Care advisors reported that the CSNAT helped identify issues “*that perhaps*

would not have come up in a normal home visit or phone call, acknowledging it had 'been a springboard in several instances to allow a carer to explore their needs' (CA3), giving the caregivers an opportunity to "verbalise their fears in a non-threatening way" (CA2) and "It made me realise that it paid to ask the question, even though I thought I sometimes knew what the answer might be."(CA1)

The CSNAT was considered by care advisors to assist in *'providing an holistic approach to carers' needs'* and was seen as highlighting the support provided for caregivers, *"It does open doors for that... It does let the carer be the focus of the support"*(CA4). One care advisor explained: *"It can uncover areas which may not have been recognised or adequately dealt with"*(CA1), another suggested the CSNAT *"acknowledges the important role carers play and the pressure put on them emotionally and physically"*. (CA2)

An important aspect of the CSNAT process was considered by the care advisors to be *"...accountability and a documented record to assist the care provider"*(CA3). They all advocated the CSNAT approach as an improvement to standard practice, formalizing the process, providing a structured follow-up and a focus on the caregiver and family:

...it is more comprehensive, provides a structured follow-up process and there are aspects that are measurable. (CA3)

...it formalises the process and provides a means of documenting carer's needs.
(CA4)

Consideration of the caregiver and patient status and a sensitive approach was important when care advisors were introducing the CSNAT:

Finding the right time. There were instances when there had been an outpouring of issues... (CA1).

Sometimes when I planned to do it on a visit, it wasn't always appropriate (eg. there were other pressing needs/issues) (CA4).

Using the CSNAT for regular reviews of caregiver needs was described by the care advisors as offering “*an opportunity to allow focus to be on carer rather than client - allows them to have a safe place to recognise their needs too*” (CA4). An awareness of the changing and sometimes unpredictable needs of the family caregivers was outlined as follows:

I think it is interesting to see how carer needs change over time and that their needs don't always follow the same trajectory as the person with MND. ...sometimes what I perceive as a very stressful time for the carer they seem to sail through, whereas something minor (for me) at another time can unleash a great emotional tide for the carer. (CA1)

Another care advisor explained it was useful to complete the CSNAT regularly “*...because even if things don't change or deteriorate, it's again acknowledging their [family carers] needs.*” (CA2).

However, there is a conscious struggle to keep the focus on family caregivers with the constant pressing issues of the care recipients:

If the time is right, the discussion points can have an immediacy that works very well. At times though, even with the best intentions from all parties, it is often the person with MND whose needs are addressed first. It's good to be constantly reminding

ourselves that the bigger picture of carer and family support have an equally important role. (CA1)

Discussion

Participants' involvement in this study provided them with an opportunity to share their difficult experiences, gaining increased insight of emotional concerns and awareness of supports and acknowledgment of their role as a caregiver. In addition, participants described benefits related to their increased timely access to support and links to resources.

The CSNAT approach for identifying and addressing family caregivers' support needs was found relevant and acceptable by MND family caregivers and care advisors. For caregivers, a carer-led assessment process gave them a sense of validation, reassurance and empowerment, as reflected by their quotes. Compared to standard practice, care advisors found the approach more comprehensive and formalised, with similar results to previous studies using the CSNAT approach (Ewing & Grande, 2013; Aoun, Grande, et al., 2015b; Aoun, Toye, et al., 2015a). It provided a structured follow-up process and a means of documenting caregivers' needs and acknowledging their important role. The middle stage of the disease trajectory was suggested as when the CSNAT is best administered for regular reviews because the time of receiving the diagnosis is highly emotional and the needs are not as easily identifiable in the early stage when the symptoms are not as advanced. By contrast, more changes occur towards the middle stage and thus more care is required then. The middle stages of the MND disease trajectory is the period of time when neurological symptoms have developed significantly and the person with MND requires more assistance from their family caregiver.

By structuring and reviewing caregivers' needs two months apart, evidence was obtained of a steady reduction in their perception of needs, providing good evidence for the benefit of systematically repeating this review of needs using the CSNAT approach. The single domain that revealed a rise in need over time was caregivers' beliefs and spiritual concerns, which became important across time. This could reflect the benefit of caregiver reflection and recognition that a domain such as this can be valued.

Knowing what to expect as the illness progresses remained prominent for more than 60% at the second follow-up assessment, pointing to the continued need to educate and build the understanding that caregivers' have about the future. A gradual educational process about care needs and what to expect might happen with MND is clinically appropriate.

Communication issues are particularly important for people with MND and their family caregivers (Oliver & Aoun, 2013; Aoun, Chochinov, et al., 2014) compared to most other life-limiting diseases. This is difficult for all types of MND as deterioration occurs, but especially when symptoms include speech impairment, suggesting health professionals need to integrate support in all facets of communication for MND caregivers into their routine practice. Strain relating to loss of intimacy can be experienced by MND caregivers (Goldstein et al., 2006) as their partners' cognitive or physical ability to communicate diminishes as evident in our study and others (Oliver & Aoun, 2013; Oyebode et al., 2013), or if behavioural changes develop (Lillo et al., 2012). At another level, the needs of the broader family will likely depend upon the functioning of each group, their openness of communication, teamwork or cohesion, and their ability to tolerate differences of opinion and remain mutually supportive (Kissane et al., 2006; Schuler et al., 2014). Communication issues were raised in this study, however a larger national trial would be needed to warrant including a communication-related item to the CSNAT.

This is the first application of the CSNAT in an MND setting, a different setting to the one where the tool was developed in the UK (Ewing et al., 2013) and further trialled in Australia (Aoun, Grande, et al., 2015b) in home based palliative care settings. In addition the tool has been tested in this study earlier in the caregiving journey and not just towards end of life, a suggestion that was voiced in previous family caregiving research in the cancer field (Aoun, Deas, et al., 2015a) and MND field (Kissane et al., 2009) where interventions were deemed beneficial earlier in the caregiving trajectory. Compared to caregivers who used the CSNAT in the cancer field (Aoun, Grande, et al., 2015b), MND caregivers shared three of the top five priorities for support related mainly to direct carer support: “Knowing what to expect in the future”, “dealing with your feelings and worries” and “having time for yourself in the day”. However “knowing who to contact if you are concerned” and “needing equipment to help care” were more prominent priorities for MND in this study, reflecting the earlier timing in the caregiving journey, the rapidly progressive nature of the disease and the need to focus on the practical help for the patient.

Conclusions

Results indicate that it is feasible to deliver this supportive intervention in the MND setting. Incorporating the tool into the routine practice of MND care advisors, would require minimal change to practice and cost for the organisation. Travel costs and interview times would not increase as care advisors already visit patients and their family caregivers regularly, and follow-up assessment can be done by telephone as per usual practice. Further inquiry into implementation throughout the MND associations nationally and internationally is considered valuable.

This is a feasibility study with a small sample size and undertaken in one geographical location and therefore findings cannot be generalised. Limitations also include what has not

been revealed because of the socio-demographic profile of those assessed. The needs of caregivers who are still working, how single, separated or divorced caregivers fare, and what special needs arise for parents, siblings and children of patients with MND has not been explicated with this cohort (Del Gaudio et al., 2012). Furthermore, the care recipients were at the moderate stage of functional impairment, and there are significant challenges nearing the end of life. Therefore, such unaddressed needs that are specific to such circumstances could be explored in a larger national trial that would also ascertain the effectiveness of this assessment approach in improving caregivers' psychological outcomes in the MND setting.

While it may be considered a limitation in other contexts, eliciting written responses via a questionnaire from care advisors has worked well and has captured a breadth of opinion, in addition to being the care advisors' choice of providing feedback on their experience.

The CSNAT has provided a formal structure to facilitate discussions with family caregivers to enable needs to be addressed. Such discussions can also inform an evidence base for the ongoing development of services, ensuring that new or improved services are designed to meet the explicit needs of family caregivers of people with MND.

Competing interests

The authors declare that no competing interests exist.

Author's contributions

Conceived and designed the experiments: SMA KD

Performed the experiments: SMA KD

Analyzed the data: SMA KD

Interpreted the findings: SMA KD LJK DWK

Wrote the manuscript: SMA KD LJK DWK

All authors read and approved the final manuscript.

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Table 1. Carer Support Needs Assessment Tool (CSNAT) Domains

(Ewing et al., 2013)

Support that enables the family caregiver to care for the patient

Do you need more support with:

- Understanding your relative's illness
- Knowing what to expect in the future when caring for your relative
- Managing your relative's symptoms, including giving medicines
- Providing personal care for your relative (eg dressing, washing, toileting)
- Knowing who to contact if you are concerned about your relative
(for a range of needs including at night)
- Equipment to help care for your relative
- Talking with your relative about his or her illness

Support for the family caregiver in their caring role (more direct personal support)

Do you need more support with:

- Having time for yourself in the day
 - Your financial, legal or work issues
 - Dealing with your feelings and worries
 - Looking after your own health (physical problems)
 - Your beliefs or spiritual concerns
 - Practical help in the home
 - Getting a break from caring overnight
-

Table 2: Profile of family caregivers and people with MND, n=24.

Family caregivers		n	%
Gender	Male	6	25.0
	Female	18	75.0
Age (years)	Mean (\pm SD)	63.8	\pm 12.9
	Median (Range)	66.5	(20, 80)
Marital status	Never married	1	4.2
	Divorced/Separated	2	8.3
	Married	21	87.5
Cultural background	Australian	15	62.5
	British	7	29.2
	Other (please specify)	2	8.3
Education	Primary school (Year 7 or below)	1	4.2
	Secondary	11	45.8
	Diploma/certificate/trade qualification	7	29.2
	Tertiary	5	20.8
Employment	Paid employment	7	29.2
	Retired/volunteer	13	54.2
	Household duties	3	12.5
	Other (please specify)	1	4.2
Relationship to person with MND	Spouse or partner	19	79.2
	Parent	3	12.5
	Child	1	4.2
	Sibling	1	4.2
People with MND		n	
Gender	Male	17	70.8
	Female	7	29.2
Age (years)	Mean (\pm SD)	62.8	\pm 10.8
	Median (Range)	65.5	(38, 79)
Time since Diagnosis (months)	Median (Range)	20.5	(4, 89)
ALS functional rating scale	Median (Range)	27	(9,46)

Fig.1. Percentage of caregivers expressing need for more support with each Carer Support Needs Assessment Tool domain at baseline and follow-up (n=24).

(on separate file)

