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Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study

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Abstract

Objectives

Motor Neurone Disease (MND) is a progressive, life-limiting illness. Caregiving impacts greatly on family carers with few supportive interventions for carers. We report Stages 1 and 2 of a study to:

(1) explore experiences of MND caregiving and use carer-identified support needs to determine suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT);

(2) adapt the CSNAT as necessary for comprehensive assessment and support of MND carers, prior to (Stage 3) feasibility testing.

Design

Qualitative: focus groups, interviews and carer workshops.

Setting

Three UK MND specialist centres serving a wide range of areas.

Participants

Stage 1: 33 carers, 11 from each site: 19 current carers, 14 bereaved. Stage 2: 19 carer advisors: 10 bereaved, nine current carers. Majority were spouses/partners ranging in age from under 45 to over 75 years. Duration of caring: four months-12.5 years.

Results

Carers described challenges of a disease that was terminal from outset, of 'chasing' progressive deterioration, trying to balance normality and patient independence against growing dependence, and intensive involvement in caregiving. Carers had extensive support needs which could be mapped to existing CSNAT domains: both 'enabling' domains which identify carers' needs as co-workers as well as carers' 'direct' needs as clients in relation to their own health and well-being. Only one aspect of their caregiving experience went beyond existing domains: a new domain on support needs with relationship changes was identified to tailor the CSNAT better to MND carers.

Conclusions

The adapted CSNAT is an appropriate and relevant tool for use in clinical practice for assessment of support needs of carers of people with MND and potentially of carers in other longer-term caring contexts.

Strengths and limitations of this study

- Recruitment of carers from three major MND centres in the UK ensured a wide range of caregiving experiences and enhances transferability of findings
- Inclusion of both bereaved and current carers enabled reflection on the full duration of caregiving
- Enrolment of participants as subsequent advisors ensured strong, informed PPI involvement in CSNAT review and design, and may serve as a pragmatic model for PPI involvement in general
- The qualitative approach of the study which has a self-selecting sample limits generalisability of the study findings

Introduction

Motor Neurone Disease (MND) is a progressive, life limiting illness that is terminal at diagnosis. Life expectancy is usually between two to five years, though this can vary in individual cases. The disease is one of progressive muscle weakness affecting movement, speech, swallowing and eventually breathing. In the UK, it is estimated that there are 5,000 adults living with MND at any one time; six people diagnosed per day (1), in Australia about 2000 people: two people diagnosed daily (2) and in the USA, where it is more commonly known as Amyotrophic lateral sclerosis (ALS), up to 16,000 adults: 15 new cases per day (3).

The process of patient deterioration impacts greatly on family members, most often spouses/partners, who are the main sources of help and support for patients. Patients often progress to needing long term assistance with activities of daily living such as eating, bathing and toileting which can result in high levels of caregiver burden and a major impact on the physical health and well-being of family carers (4-6). Managing patients' loss of speech, swallowing and motor function further adds to caring responsibilities and concerns, but also to the distress of dealing with a devastating disease in a close family member. Unsurprisingly carers of people with MND suffer high levels of psychological morbidity, including anxiety and depression, and have reduced quality of life (7-10).

Better support has the potential to ameliorate negative impacts of taking on a caregiving role (7,9,11). However, reviews within the broader palliative care context have not shown such interventions to have major impact on carer outcomes (12-14). Carer interventions tested to date in an MND context have similarly reported limited effects (15,16) and none have been designed specifically for carers of people living with MND. To be more effective and provide the support carers need to prevent or reduce negative impacts, interventions must be individually tailored and consider their full range of support needs rather than be selective (12). Furthermore, they should address support that carers need to manage the carer role to reduce negative impacts (proactive approach), rather than address negative impacts once they occur (reactive approach).

One intervention which has been shown to improve carer support in end of life care is the Carer Support Needs Assessment Tool (CSNAT) intervention. The CSNAT intervention enables practitioners to provide comprehensive, person-centred carer assessment and support. For use in practice, the intervention comprises a comprehensive, evidence-based assessment tool (17) and a defined five-stage person-centred process (18), that together allow carers themselves to identify, consider and prioritise their support needs, discuss these with a practitioner and identify supportive input they would find helpful (action plan), with follow-up review. This represents a significant change in practice as support for carers of patients with life limiting illnesses is normally informal and unstructured with solutions proposed by practitioners (19). The CSNAT has good validity (20), the intervention is valued by practitioners and carers (19, 21, 22) and improves carer outcomes (23,24) within a palliative home care context. Thus a three-stage study sought to explore the suitability, acceptability and feasibility of the CSNAT intervention in MND caregiving. This paper presents data from the study's first two stages, with objectives (1) to explore the experiences of caregiving in the context of MND and use carer-identified support needs to assess suitability and acceptability of the CSNAT; and (2) to make any adaptions to the existing CSNAT for comprehensive assessment and support of family carers of people with MND.

Methods

Qualitative design using focus groups (FGs), interviews and workshops involving carers of people with MND.

Setting

The first two stages of the study were conducted December 2017-May 2018 at three MND specialist centres serving patients (and carers) from a wide range of areas. Both carers and practitioners were recruited from all three sites: practitioner data will be reported elsewhere.

Ethics approval was received from the North West – Greater Manchester West Research Ethics Committee (REC reference: 17/NW/0531). All participants provided written consent.

Stage 1: Focus groups and interviews with carers

Recruitment

Sites identified carers from patient databases using purposive sampling to ensure a balance between carer gender, relationship to the patient and type of MND. Both current and bereaved carers were included (see Table 1 for inclusion/exclusion criteria). Recruitment was through direct invitation at clinics by the MND Consultant/Clinical Nurse Specialist or by postal invitation from the MND consultant.

All carers received a recruitment pack (study invitation letter from the consultant, information leaflet, reply form and freepost return envelope). Carers interested in taking part responded directly to the study researcher (SC) who provided any further information and made arrangements for data collection.

The three sites identified 170 carers eligible to take part (126 current carers; 44 bereaved). 48 responded to the invitation (28% response rate); four later withdrew due to worsening patient health. Not all respondents were available to attend a group or interview. In total 33 carers (11 from each site) joined Stage 1. Table 2 summarises participants' characteristics.

Insert Tables 1 and 2 about here

Data collection

Nine focus groups were conducted (three at each site), December 2017-January 2018, facilitated by two researchers (GE/SC; GE/CR; CR/SC). Small groups were held with three to four carers each to maximise discussion: groups averaged 108 minutes. The topic guide covered three main areas: (1) a brief introduction about the carer and the person with MND; (2) their experience of key stages of caregiving starting with the time of diagnosis, what was challenging, what help/support they received or would have liked to have had, from whom and when; (3) carers were introduced to the CSNAT intervention and given a copy of the CSNAT (tool itself) and asked their reaction to the tool and its usefulness to carers of people with MND: anything not relevant; any type of support need missing.

Respite provision was offered to facilitate focus group participation. However, where carers felt unable to leave their home, because of caring or other reasons, an individual home interview was conducted by the study researcher (SC) to enable their participation. Four interviews were conducted, each lasting just over an hour, following the same format and topic guide as the focus groups.

Analysis

Sessions were audio-recorded and field notes were written. Recordings were fully transcribed, then checked and anonymised by a researcher (SC). Transcripts were read by all researchers for familiarisation. Qualitative content analysis was conducted (25): 1) Conventional content analysis was used to analyse the experience of caregiving in MND allowing codes to emerge from the data to develop an initial coding scheme which was then used to index the data; codes were then clustered into categories. 2) A directed content analysis considered carers' support needs in relation to CSNAT as the tool already provided a framework, mapping data to the existing 14 CSNAT domains. Support needs/supportive input not captured by the CSNAT domain coding scheme were coded separately.

The research team discussed and agreed the coding process which was used by GE to index the transcripts. Atlas/ti was used to facilitate data management. Verification of the indexing process was conducted by a second researcher (CR) and a process of checking and agreeing emergent domains and interpretations was conducted by the whole research team.

Stage 2: Workshops with carer advisors

Recruitment

FG/interview participants from Stage 1 were invited to become carer advisors for Stage 2 workshops. Those interested provided contact details to the research team and agreed to further contact.

There were 19 carer advisors: 10 bereaved; 9 current carers. Three of these were carers who had shown interest in Stage 1 but then were unable to participate at that time. Table 3 summarises the characteristics of the carer advisors.

Insert Table 3 about here

Data collection

Three workshops were conducted in May 2018, one at each site. They lasted just under two hours, were facilitated by two researchers (CR/SC) with five to eight carers in each. A workshop guide was used to structure the discussions: (1) a brief background to the study; (2) a reminder about the two-part CSNAT intervention; (3) an overview of Stage 1 findings. Then carer participants were asked to review the findings on the content of the CSNAT: was there anything missing, focusing specifically on any additional domain(s) needed (reported below) and the process of using the CSNAT intervention in practice (to be reported in a subsequent paper on implementation).

At the end of the workshops, 10 participants agreed to help finalise the wording of an additional domain for the CSNAT in the context of MND by email/telephone contact.

Analysis

Workshops were audio-recorded and field notes written. Data processing was the same as Stage 1. As the workshops focussed on refining the CSNAT content for the context of MND, directed content analysis using the existing framework of the CSNAT domains was used. At all stages, the coding was shared within the research team, interpretations discussed and agreed.

PPI involvement

At the study outset, two researchers (GE & SC) attended a regional MNDA meeting, to introduce the study and have informal discussions with family carers. This led to two follow-up telephone conversations (GE) that provided a wider perspective and understanding of caring for someone with MND, which was used to enhance the sensitivity of subsequent data collection. Additionally, use of carer advisors in Stage 2 provided a strong PPI element to the CSNAT review and design.

Findings

The findings are in three main sections: (1) the context of caregiving in MND; (2) the support needs and supportive input derived from the experience of MND caregiving that relate to CSNAT domains that; and (3) an additional domain of support needs identified within the study. Italics indicate verbatim quotations.

The context of caregiving in MND

With any life limiting illness there is a significant emotional impact on the family. MND carers expressed that beyond the '*shock*' of diagnosis, they were dealing with an illness that is terminal from the outset: *"Well, it is a death sentence, isn't it, […] but most people with cancer, they've got a little...they've got hope that something...there's very few that actually they get to the stage where it's diagnosed and they say there's absolutely nothing that we can do for you"* (SRB017). The great majority of carers in the study were partners/spouses of the person with MND whose own lives were "*on hold"* (SHC059) during caregiving. "*We've got the illness together*" (SHC052) expressed their experience and influenced the support needs they had.

Maintaining normality

A strong feature in early caregiving was of actively promoting patient independence for as long as possible, to enable patients to retain some normality in the face of their illness. This involved encouraging them to carry on with previous activities, even if this took much longer, for a sense of satisfaction. Tact and diplomacy was often required in making adjustments to activities of daily living (ADLs) to maintain independence. It was hard for carers to know how long to hold back: *"It's difficult for him to accept that he is not as active as he used to be. And for me to have the balance between helping where it's needed and not giving help where it's not. […] How long should I hover there*" (SCH041). Carers were keen to avoid 'taking over' and enabling patients feel that they were still living a normal life. This had to be tempered with an awareness that some aspects of maintaining independence could also be hazardous. Getting the balance right was an important aspect of early caregiving.

Relationship changes because of MND

Carers described how the illness and caregiving influenced their relationship with the patient. Patients could be '*stubborn'*, '*demanding'*, '*angry'*. They fully acknowledged the difficult situation for patients, but certain responses greatly affected carers. As many were couples, there was a changed relationship, for some from the point of diagnosis, with tensions or petty arguments. The disease blurred role boundaries: as husband/wife/partner and as carer, affecting all aspects of their relationship, particularly when providing personal care. Some talked openly about loss of intimacy due to illness, though others reflected that it was not "*top of my list*" of concerns (SRC030) as long as closeness remained. But for others, "*the affection is taken over by the pressure of caring*" (SRC002).

Chasing the disease

The progressive nature of MND meant that carers found themselves managing a situation that was never static: "*because it never plateaued, it just kept going downwards.*" (SHB015) They stepped in to compensate for the deterioration in the patient: *"You're on a roll, aren't you? […] You're like a hamster on a wheel, and each day or each week or each month, you do that little bit more and a little bit more"* (SRB013). Carers found themselves managing one set of limitations when another deterioration happened: something new to deal with, whilst also coping with the psychological impact of further deterioration. Speed of progression meant there was an immediacy to patients' needs that was often at odds with time taken to get supportive input in place. [Referring to the need for changes to a bathroom] "*we were told we might wait between four and six months to be assessed. And then you've got to wait for the work to be done. Well, we needed it doing there and then*." (SHC055). Many times they arranged for equipment to be provided at their own expense, so that it was in place at the time it was needed.

Intensity of caregiving

Caregiving experiences were unique, but there was a commonality in terms of the intense nature of their role which in part related to being partner/spouse of the person with MND: someone with whom they had a close personal relationship. A strong sense of responsibility for caregiving was combined with sadness and emotional vulnerability: "*because you feel so inadequate, you want to make it better for them, you can't*." (SHC055). As MND quickly affected patients' abilities to manage ADLs, carers often became 'hands on' at an early stage. Dependency on the carer was 24/7, including providing care at night, because there was no one else. Complexity of caregiving and constant vigilance required were also factors in this intensity.

(2) Domains of support for carers of people with MND

Carers spoke in positive terms about support from healthcare professionals, but this was for the patient, less so about separate support for themselves as carers: "*Individually, they've not provided that support, because that's not their brief, it's to look after [the patient]"* (SCH037). Commonly carers were asked 'are you alright'? *"And, of course, you say, yes, you are alright, because you've got to be alright, you've got no option, have you?"* (WB002). But others felt 'abandoned' or 'invisible' within patient consultations with healthcare teams, despite having many support needs.

Insert Table 4 about here

Direct domains: carers' own health and well-being needs

Carers' discussions revealed the extent of 'direct' support needs: support required to preserve their own health and well-being in their role as 'clients'. Table 4 provides illustrative examples of the range of support needs (both met and unmet) and input required to meet those needs.

Getting a break from caregiving depended on stage of illness. Initially, carers were able to get short periods away but only if patients could be left comfortably and safely, e.g. with food/drinks; able to access the toilet. Availability of professional carers varied greatly: some carers only had support from family or paid for private respite. It was much more difficult to leave patients in later stage MND where symptoms needed constant attention. However, most breaks were to do tasks like shopping or housework rather than actual time for themselves, though carers recognised that it was important to create some separate space for themselves: "*It's snatching time*" (SRC030).

Being a carer overnight was exhausting: requiring constant vigilance. Carers were aware of limited respite services but lack of discussion by healthcare practitioners about this in itself was difficult. A common dilemma carers faced was of needing a break but having feelings of guilt and ambivalence with regard to having their own needs met. The impact of overnight caregiving on physical health was substantial: "*I was rocking with exhaustion*" (SCH041). Carers were aware of the effects, but had little help to do anything about it.

With financial, legal and work issues, carers accessed help/advice from many sources, but a recurrent theme was input needed earlier in the illness: pro-active or anticipatory advice/information and signposting on. Many carers went through an *ad hoc* process of discovering benefits/allowances often missing out on certain entitlements. Need for practical help within the context of MND, extended beyond the home to the garden and to transport issues from the home, including parking, but they were rarely asked about this: *"actually sometimes it's just for them to say 'No, I can see you're struggling'"* (SHC047). Carers often had difficulties accepting help, but this was true across all the support domains, not just practical help.

The emotional impact of caregiving was harder to deal with for some carers, than physical effects, and they didn't always have an outlet for their feelings. They needed support to deal with their own reactions to the illness but also the patient's response. A worry commonly voiced was what would happen if they became ill, or worst-case scenario, they died while caregiving: "*If something happens to me, then we're in trouble because I do everything for [patient] "* (SCH037). The diagnosis of MND challenged the belief systems of both patients and carers and raised needs about information and discussions about assisted dying.

Insert Table 5 about here

'Enabling' domains: support needs in caring for the patient

Carers also had a range of support needs to enable them to carer for the person with MND in their role as 'co-workers' (see Table 5). They provided an extensive range of support, including assisting with all ADLs. Carers received help from different professional care teams, but these were time-limited visits, leaving carers to manage for the remaining hours. Managing ADLs necessitated not just advice, but 'training': "*I had to learn as I was going along. [..] You need somebody really that could take you to one side and show you how to do it*" (SRB003). "*Yeah. Well, it's basic things like learning how to lift them up out of the chair or things like that, or help them out of bed, to roll over and that kind of thing"* (SRB017).

Carers needed to know about, access and be able to use many different pieces of equipment to manage ADLs. Although equipment was for the patient, carers were clear that it supported them in caregiving: *"I don't need support particularly for me, but I do need equipment to help me do what I do"* (SHC045) and they also needed training to use this equipment. Dealing with MND symptoms involved managing complex medical devices in addition to medicines, again requiring advice/information, but importantly training in their use. Some found this worrying, others were fine: *"Once I got the confidence I was fine and it suited [partner] because she didn't want any help […] so it was just me and her right until the end really"* (WB009). As a result, carers became expert in managing patients' needs.

Carers needed to be able to contact services if concerned and at its most basic that meant 24-hour phone services. It was also about having a key contact person, and different professionals took on this role including occupational therapists, community matrons, district nurses, GPs and MND specialist nurses. However, in the context of MND, carers were very concerned about patients'

ability to summon help if carers themselves became ill, identifying the importance of a contact to check on carers of patients in the later stages of MND.

Support needs in understanding the illness were time related: *"I don't particularly need any more information at the moment about understanding my relative's illness, but I would have done [earlier]"* (SHC014), particularly around diagnosis. General information was needed then but also someone with knowledge of MND to answer specific questions. Talking with their relative about his/her illness was difficult for many carers, needing support with managing issues of denial from both sides and for some also suggestions of suicide. Carers also experienced considerable difficulties in accessing any support for themselves when patients refused to talk about their illness or let anyone know about the diagnosis.

Regarding knowing what to expect in the future, some carers preferred not to know, living each day at a time, though they also acknowledged that 'not knowing' was hard. Where carers wanted this support, they found some healthcare professionals reluctant to talk about dying: "*vague talk*" (WB003D) wasn't helpful in making preparations for the further decline and death.

An additional domain of support needs in MND

Stage 1 FGs and interviews identified that support needs in MND mapped well to the existing 14 CSNAT domains and this was later confirmed by carer advisors in Stage 2 workshops. These workshops also sought to identify any aspects that didn't map or suggested missing domains. One aspect of caregiving, dealing with relationship changes as a result of MND, was further explored to determine whether support needs arising from these changes were encompassed by existing CSNAT domains or an additional, separate, domain was needed.

MND affected relationships in different ways for different people. Some felt that difficulties related to frustrations from the loss of control and role changes patients experienced, and this was difficult to talk about. Relationship issues could be part of the 'feelings and worries' domain, but depended on circumstances. An alternative domain was 'talking to your relative about his/her illness', though this could be perceived as having a narrower, physical focus: "*As I say, I think the physical things sometimes are easy [..], but it's the mental thing with your relationship and everything*" (F1 CaW1). Overall, the consensus was that it was important to add a separate domain about relationships, one that was more specific: ".. *because, whilst yes, it does fit into these two categories really well, but then it's that, happy to verbalise it, which is sometimes the hardest part isn't it? Getting people to say, this is actually what's bothering me*" (F5 CaW1).

Carers identified several reasons for having a separate relationship domain. It could prepare new carers for something that might affect them in the future. Just as carers may not have support needs within some of the CSNAT domains in the early stages but these arise later, so too with the relationship domain. Changes in relationships usually evolved over the course of the illness, and were not necessarily present at the start. What was important to carers was that there was a choice in being able to discuss support with relationships issues, should they arise. Recognising the conservative nature of most people about talking about relationship changes such as intimacy, a separate domain was felt to give *"permission to talk about something very private"* (F3 CaW1), if they wished to.

Workshop discussions further revealed that carers' support needs with relationship issues extended beyond spousal relationships: *"there's all sorts of relationship groups that are affected because of the illness. Friendship groups, work colleagues, social groups. Relationships with healthcare*

professionals as well, there might be a conflict with who your current healthcare professionals are. [..] So perhaps having that extra domain that actually bring out some of those issues" (M2 CaW3). Wording of the domain thus needed to reflect support needs within more wide ranging relationships. Different options were explored initially in the workshops, with email and telephone follow up iterations. "Do you need more support with managing relationships" was finally agreed and added to the existing CSNAT questions to be piloted in Stage 3 of the study (to be reported elsewhere).

Discussion

This paper examines experiences of caregiving in the context of MND. Carers' lives were significantly impacted by the disease. Study findings suggest that adapting the existing CSNAT through the addition of a new domain on support needs with relationship changes will enable identification of the wide range of support needs experienced by carers of people with MND.

Overall, support needs in MND caregiving mapped well to existing 'enabling' and 'direct' CSNAT domains and carers found the domains appropriate and relevant: a finding supported by a pilot study using the CSNAT intervention in the context of MND in Australia (26). However, our in-depth exploration of carers' support needs also identified that a further assessment domain was required to address role and relationship changes due to MND, commonly reported aspects of the experience of MND caregiving (4,6,27). However, the need for such an additional domain may not be required for MND *per se,* but may be reflective of support needs arising from prolonged intensive caregiving. Farquhar et al (28) reported similar role changes experienced by carers of patients with breathlessness in advanced COPD. More recently, a systematic review of support needs of carers of patients with COPD identified difficulties within patient-carer relationships and carer-clinician relationships and also recommended an additional CSNAT domain to encompass the full range of support needs of these carers (29). The original study to develop CSNAT (17) mainly involved carers in a cancer context where intensive caregiving was much shorter term. It furthermore included only bereaved carers, many of whom reflected back on the uncomplaining nature of those they cared for and not on the tensions expressed in the current study.

The extent of carers' support needs in MND in this study evidences the necessity of a separate process of assessment and support for MND carers. Carers furthermore required support to enable them to support the patient as 'co-workers' and direct support to look after their own health and well-being as 'clients'. Current guidance, such as from NICE (30) recommends advising carers of their legal right to a Carer's Assessment but this fails to take account of this dual role carers play and their support needs in both roles. Whilst some needs for carers as 'clients' may be addressed by the statutory carer assessment, these assessments do not identify the needs carers have as 'co-workers', where they rather need healthcare professional input to enable them to provide care for the person with MND. The extent of support needs within these 'enabling' domains and the burden they experience from caregiving evidences a need for a more comprehensive assessment process. The broad domains of the CSNAT are intended to help open conversations with carers by providing visibility about aspects of support others in their situation have found helpful. Which individual needs are discussed within domains depends on how those domains resonate with individual carers: what is key is that they facilitate a conversation to uncover the carer's individual needs which can then be supported.

Whilst there is a wide literature on carers' needs in MND, a strength of this study is that our findings specify in detail many different types of support carers needed or found helpful from health/social

care professionals. 'Pro-active' input was identified as particularly important across many domains, i.e. guidance ahead of need, not just 'reactive' input to a problem or crisis, which resonates with findings from a meta-analysis of carers' educational needs (31). Certain types of input that may be delivered directly by professionals were common across domains: particularly advice and information (ranging from very general to highly tailored); training in different care activities; or directly delivered help. Family and friends may also provide some direct help. However, some support needs may necessitate signposting and referral by health/social care professionals to other support agencies. These common themes and detailed analysis of needs experienced offer practical guidance to assist healthcare professionals in ensuring help is tailored to carers' individual needs.

Limitations of the study

This study was qualitative with a self-selecting sample, so findings may not be fully generalisable. However, the three studies sites where recruitment took place had very different MND management protocols which adds validity in terms of transferability of findings to other centres and practitioners working with MND patients and their carers. We also believe that the findings will have relevance for practitioners and carers managing all stages of the illness as we were able to conduct interviews with carers from throughout the illness trajectory from newly diagnosed MND to advanced disease and into bereavement.

Implications for practice

In the first two stages of this study an adapted version of the Carer Support Needs Assessment Tool, comprising the existing 14 domains plus a new domain on support with managing relationships was developed for implementation as part of a practice intervention for MND carers (Stage 3 study findings to be reported elsewhere). The adapted CSNAT is an appropriate and relevant tool for use in clinical practice for the assessment of support needs of carers of people with MND and potentially of carers in other longer term caring contexts. Furthermore, the detailed exploration of the input carers themselves have identified as important in meeting their different support needs provides a valuable training resource to assist healthcare professionals in tailoring support provision to carers in the context of MND.

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Declarations

Contributors: GE, SC, CR, GG all contributed towards data collection, data analysis, drafting and critically revising the paper. All authors gave final approval of the version to be published.

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Accessing the CSNAT.

The CSNAT is a copyright tool available free of charge to the NHS and not for profit organisations. Training and a licence are required for its use as a practice intervention. For further details go to http://csnat.org

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Table 1: Inclusion/Exclusion criteria for Stage 1 and 2 recruitment

	Current carers	Bereaved carers
Inclusion	Patient at least 3 months post-diagnosis	6-12 months post-bereavement
Exclusion	Younger than 18 years	Younger than 18 years
	Clinician concerns about psychological/physical ability to cope with study participation	Clinician concerns about psychological/physical ability to cope with study participation
	Unable to give informed consent	Unable to give informed consent

Table 2: Stage 1 Carer participants.

	Bereaved carers (14)	Current carers (19)
Relationship to patient		
Spouse/partner	13	17
Daughter/son	1	1
Other	0	1
Age range		
<45	0	2
46-55	2	2
56-65	1	6
66-75	8	6
>75	3	2
Missing	0	1
Carer description of type of MND		
ALS	5	8
MND only	6	1
Bulbar	3	3
PLS	0	2
PMA	0	1
Not known	0	4
Duration of caring		
Less than 1 year	3	1
1-2 years	8	9
3-4 years	2	6
5-10 years	1	1
More than 10 years	0	2

Table 3: Stage 2 Carer advisors

	Bereaved carers (10)	Current carers (9)
Relationship to patient		
Spouse/partner	9	8
Daughter/son	1	0
Other	0	1
Age range		
<45	0	2
46-55	2	1
56-65	1	3
66-75	5	2
>75	2	0
Missing	0	1
Carer description of type of MND		
ALS	5	5
MND only	3	1
Bulbar	1	1
PLS	0	1
PMA	0	0
Not known	1	1
Duration of caring		
Less than 1 year	3	1
1-2 years	5	4
3-4 years	2	3
5-10 years	0	1
More than 10 years	0	0

Table 4: Direct domains: direct support to carers to preserve their own health and well-being as 'clients'.

Each domain comprises individual needs (both met and unmet) but also supportive input provided to meet those needs.

Domains of support needs	Key aspects of support identified in interviews/focus groups with carers	
	Met needs/unmet needs with ..	Supportive input (received or needed)

Having time for yourself in the day	.. patient refusing to have help from anyone other than carer
	
	.. managing the patient who is frightened to be alone without the carer even for short periods eg to visit own GP
	
	.. dealing with not being able to get out because patient cannot be left
	
	.. getting away from the 'unfairness' of MND
	
	.. feeling that they should be there and doing things 24/7 particularly if a spouse/partner well as a carer
	
	.. thinking it is legitimate to get a break (carers tend not to think about a break for themselves)
	
	.. getting a few hours in the week to do a range of necessary tasks: food shopping, going to bank, going to post office, changing library books, getting housework done, attending appointments
	
	.. dealing with healthcare professionals who consider that carers need time, not for self, but only to go to Post Office, buy food
	
	.. having some time just for themselves/what they want to do: carers talked about doing something relaxing, being able to unwind, something for their own health/fitness, to go driving as a stress release, going for a coffee, going for a walk, meeting a friend, doing some voluntary work
		Advice and information:
		• about services locally that would provide a break for the carer
		
		Directly delivered input:
		• advance booking of short period of respite, eg through MNDA
		• specific breaks from health and care services/charities:
		  ○ care-team provided via local authority personal budget
		  ○ professional carers from an early stage to build a relationship with the patient and confidence to be left with them
		  ○ sitters for some respite hours from charity or from hospice
		  ○ team providing set hours per week for personal care for the patient
		• family help
		  ○ family events providing a break-because more people around to help
		  ○ direct care help from family members, though carers often reluctant to accept
		• private care teams (at a cost to the patient and carer)
		  ○ agency sitting services; private care team two afternoons a week
		
		Opportunistic breaks
		• when patient attending hospice or day services
		• during DN team visits to the patient – potential cover for the carer to go out
		• reliance on friends/neighbours to sit with patient
		• by having Macmillan Transport to take patient to hospice appointments
		
		Identified 'downtime' for the carer even if unable to leave the home: eg
		• in the late evening when patient is safely in bed
		• in the early morning before the patient is up

Getting a break from caring overnight	.. being up several times during the night because caring involves helping with toileting, managing falls, turning the patient in bed, listening out for the patient
	
	.. difficulty of raising need for a break in front of the patient
	
	.. feelings about respite
	• guilt about wanting respite
	• ambivalence – whether wanted /reluctance to leave patient
	• knowing that patient prefers carer/family to do overnight
	• having night respite available but patient not wanting it
	
	.. being able to 'let go' when care worker is providing respite
		Advice and information:
		• availability of respite services
		
		Directly delivered input:
		• night care in the patient's own home
		  ○ arranged by Macmillan
		  ○ care worker from the hospice
		  ○ by family members/shared care overnight
		  ○ by private arrangement
		• patient admission for a period of respite: to hospital or hospice
		
		Signposting/referral to:
		• joint patient and carer break at a respite centre where patient needs met by centre staff overnight as well as in the daytime
		• a holiday break with time in the day for the carer to catch up on sleep

Looking after your own health (physical problems)	.. physical effects of caring, through providing overnight care: fatigue and tiredness due to lack of sleep; weight loss .. direct impact of lifting patients: back problems, bad shoulder, hernias .. understanding the impact of caring on carer from the start .. knowing who to talk to about physical effects from the stress of caring role .. carer's own health problems: high blood pressure, illnesses / injuries/ symptoms experienced .. loss/lack of time for physical exercise .. tiredness from doing both caring and working	[Little advice on carers' own health] Directly delivered input: • someone to look after patient to give carer time to do exercise / go for a walk • a person to look after patient to allow carer to go to hospital for treatment • physical therapy sessions delivered in the home as carer unable to leave the patient for time to attend clinic • prescribed medication for health problems • strengthening exercises at a gym to help with lifting the patient when he falls (because no other help offered)
Your financial, legal or work issues	.. applying for benefits /allowances • understanding which benefits carers are entitled to • feeling confused by online information • dealing with social security phone lines	Advice and information: • on entitlements/benefits available from hospital, telephone helpline, Age UK, social workers, MNDA carers' voluntary group, Citizen's Advice Bureau: • on working rights

	• the lack of awareness of people on phone lines about MND • the costs of ringing benefit lines • being given incorrect advice • completing the lengthy claim forms • persistence in making claims .. dealing with loss of income • when patient unable to continue to work • when carer has to give up working • when managing on a reduced income .. getting help with extra costs because of the illness: heating; prescriptions; prescription exemptions .. lengthy waiting period for assessment for financial assistance with bathroom adaptations (leaving patient unable to shower)	• reduction in council tax if house adapted for MND • free car tax • no VAT on equipment to manage MND • MNDA grant for adaptations to home • MNDA grants for carers • reduced price cinema and theatre tickets for carers accompanying patient • Wills and Power of attorney on MNDA website about Directly delivered input: • help to complete application for financial assistance, from Age UK, family members • reduced working hours enabled by employer /supportive line manager • part time working and flexible working from home supported by employer • completion of a Will at home by solicitor
Practical help in the home	.. fitting in all the household tasks whilst caring including washing, ironing, cleaning, shopping, preparing meals .. garden work as patient becomes less able to do it .. practicalities of getting to hospital appointments .. patient's refusal to have anyone in the home to help the carer .. cost of having a cleaner to provide some help in the home .. accepting help offered/provided	Directly delivered input: • family sharing some of the duties like cleaning, ironing and shopping • help with garden from friends/family • paid help: in the home; in the garden • GP signing carer off sick from work when struggling to manage – to give time to do practical tasks • Having a 'blue badge' to help with parking

Dealing with your feelings and worries	.. carers' own specific feelings and worries: • guilt - if carer gets irritable with the patient or for wanting help for self as a carer when the patient has the illness • having to put on a 'front' of coping because the patient needs to see carer as dealing with things. • anxiety about new symptoms of progression of the illness • fear of what lies ahead with the illness • sadness at patient's deterioration • isolation and mental health issues • grieving which began at diagnosis • worry about becoming ill themselves while caregiving .. patients' reaction to the illness which impact carers' own mental health • patient not wanting to tell family how he is – carer has the load on his/her own • denial by the patient • too much openness by the patient in discussions about dying causing carer distress .. knowing who to go to for help with feelings	Directly delivered input: • Someone to talk to ○ soon after diagnosis ○ from the medical team to talk with the carer alone about how they were managing MND as a couple ○ at a regular appointment following referral – an hour of talking ○ in the middle of the night when frightened – a helpline ○ someone to call the carer regularly – to just listen Range of people provide this support: family members, a network/circle of friends, friends in the church, from MNDA carers' meeting to talk openly, away from the patient Directly delivered input (in addition to talking): • getting out to do gym sessions • medications for anxiety/depression Signposting/referral • to more specific mental health input where needed
Your beliefs and spiritual concerns	.. dealing with the effect of disease on personal beliefs, including challenges to those beliefs .. understanding issues and feelings around assisted dying	Advice and information: • about Dignitas (where requested by the carer) Directly delivered input: • an offer to talk about beliefs, in privacy • time to talk when carer ready

Table 5: 'Enabling' domains: support for carer to care for the patient in their role as 'co-workers'

Domains of support needs	Key aspects of support identified in the interviews/focus groups with carers	
	Met needs/unmet needs with ..	Supportive input (received or needed)
Providing personal care for your relative ..	.. managing/helping patient with ADLs: • getting up in morning/to bed at night • dressing and undressing • washing /bathing/showering • toileting – both in day and at night, • managing incontinence, dealing with soiling, managing catheters • all aspects of mobility: lifting or moving including in bed, managing patient falls • feeding the patient, including avoiding loss of weight .. understanding changes in mobility /movement as disease progresses .. strain of being the only person the patient permits to help with ADLs .. being able to give carer perspective when patient is not being fully honest about how he/she is managing. .. managing the cost of paying for private carers	Advice and information: • anticipatory guidance on how to manage ADLs • pro-active advice on getting carer team input with personal care and how to access care services • on completing forms for continuing health care • from continence service • practical tips for managing outside the home eg how to access a radar key for disabled toilets Education / training – needed from 'day one' • lifting and handling • how to do a bedbath; washing/cleansing to deal with incontinence and soiling • hygiene requirements for managing catheters • individualised dietary advice appropriate to the carer's situation Directly delivered input: • provision of equipment by different agencies (local councils, MNDA) and professionals (such as OTs) enabling carers to provide personal care, eg sliding boards, hoists, commodes etc • help from professional care team with showering and getting patient up/to bed but requires continuity and reliable timing • private care assistants to do personal care • care packages from continuing health care • DN assistance with changing catheters • Regular contact from DN team to see how carer was managing • help from neighbours when patient falls • help from ambulance service with lifting • Short term 'emergency' care team four times/day for one week on leaving hospital
Equipment to help care for your relative	..understanding and using different types of equipment to help manage the patient's illness	Advice and information: • anticipatory guidance from HCPs on types of equipment likely to be needed during the illness course

	.. accessing specific pieces of equipment/aids including walking aids, seat raisers, wheelchairs, commodes, shower stools, perching stools, manger air cushions, fold up chairs that goes in car, hoists, hospital beds, special cups, special cutlery, zimmers, walking trolleys, walking sticks, hand rails, boogie board, iPads with predictive text. ..making adaptations to the home to help with managing the needs of the person with MND: including putting in showers, wet rooms, raised toilets, full lifts, stair lifts, outside ramps ..managing cost implications of paying for equipment/adaptations to respond to immediacy of the patients' needs	• agencies providing different equipment (locally): therapy services, local councils, MNDA • website for ordering equipment accessible by carers • MNDA grants to help with the cost of equipment Education/training in use of a range of equipment: • such as hoists, sliding mats Directly delivered input: • Timely referral by MND nurse to OT at local council for input • A named OT visiting regularly to review equipment needed • Services taking account of patient/carer preferences in equipment provided • Equipment actually *wanted*: e.g. a hospital bed may not be supportive input for all carers; • Equipment actually *needed* eg iPad may not help when family already has one.
Managing your relative's symptoms including giving medicines	.. managing patient symptoms: • difficulties swallowing • choking • excess secretions/saliva • breathing difficulties/shallow breathing • panic attacks • terminal agitation in the end stages .. using different machines to manage symptoms including PEG/RIG, Cough Assist, Suction, Respirators .. dealing with responsibility for managing RIG .. feeling helpless during a choking episode .. managing reluctance of patient to take drugs to help with panic attacks .. administering medicines down the feeding tube .. accessing specialist nutrition for patient each month	Advice and information: • how to manage a choking episode • breathing problems in an emergency from Ambulance service /paramedics • how to handle better a panic attack • managing communication difficulties • contacting the feeding company if any problems Education/training: • managing PEG/RIG including using it to provide patient's nutrition, cleaning it/preventing infection, clearing any blocking of the tube • fitting of a feeding tube prior to start of choking episodes • managing the patient's respirator • using Cough Assist Directly delivered input: • Provision of oxygen in the home • Having an efficient delivery system of specialist nutrition so that correct prescription is supplied • Initial supervision of carer managing PEG/RIG, including when the patient returned home

		• GP help in getting medication in liquid form • Drugs to assist carer dealing with patient's panic attacks • Local administration of Botox injections to dry up saliva rather than a five hour round trip to main hospital • Setting up syringe driver to settle patient at end stage
Knowing who to contact if you are concerned about your relative ..	.. confusion over which professional does what and which part of the NHS they are from .. ensuring correct details for night time contacts .. dealing with changes that occur and help that is needed .. accessing MND expertise in an emergency situation .. potential situation of carer becoming ill/has an accident/dying and patient being unable to raise alarm	Advice and information: Most basic – a contact number • available 24/7, not just office hours • in primary care/GP surgery • If an answer-machine – a timely response to the message A 'contacts' book – of numbers of HCPs including who does what An emergency contact eg 'Carers First' - provides a number the patient can ring if something happens to the carer and they organise a care team to come in Having responsive contact: • A person to talk to/have a conversation • who understands the caring situation in MND • who knows how to access help • to visit at home to facilitate further support and provide continuity Pro-active contacts: • at regular times along the caring journey • a checking system in late stages of MND to ensure carer is alright
Talking to your relative about his/her illness	.. dealing with the patient's reaction to the diagnosis eg denial, threats of suicide .. patient's refusal to let people know about the illness .. patient's refusal to talk about their (joint) situation of living with the disease .. understanding the patient's situation/mental well-being separate from the clinical condition	Directly delivered input: • An opportunity to talk about their situation as a carer • Regular visit by MND nurse just to talk with patient and carer about their situation Referral • to a counselling/support group for patient and carer • of the patient for counselling (was a support for the carer)

	.. being able to discuss with the patient, the carer's role in providing care .. with carer's own denial of the diagnosis	
Understanding your relative's illness	.. understanding the different stages of the illness including which stage the patient is currently at .. understanding the speed of progression of the illness .. knowing the restrictions of the disease	Advice and information: • initial general information about MND (usually from MNDA) Directly delivered input • an early (pro-active) contact by HCP for discussion following shock of the diagnosis • consultations with a person who understands MND to answer questions: specialist nurses, GPs, Community Matrons • a separate explanation to the carer about the disease they are dealing with to sensitise them to the changes • carer/consultant consultation to ask questions *without* patient present
Knowing what to expect in the future ..	.. fears/worries about managing next stage of deterioration .. ambivalence of wanting to know about the future .. talking about the dying process .. preferred place of care discussions .. treatment decisions • DNR – with patient and carer and their situation as a couple • patient's decision on DNR/or not • refusing treatment • respect from hospital about DNR signed by the patient .. dealing with the unpredictability of prognosis .. understanding the proximity of death .. issues arising after the death • moving the body after death • funeral arrangements	Advice and information: • symptoms to expect as patient deteriorates • illness trajectory (some relied on discussion of patient symptoms in clinics as a clue to progression) • realistic prognosis including preparing for a short prognosis • signs of dying • services providing support like hospice at home • Directly delivered input – pro-actively • revisiting what to expect over the course of the illness, not just a one off. • Advance care planning discussions to put support in place when needed: • DNR and Advance refusal of treatment discussions as part of care from GP • From OT service on equipment likely to be needed • visits from the Carers' Centre to discuss 'what the future holds' Openness by HCPs to talk when family ask • Honesty about what death involves • That time of death is close so family can prepare and be present

Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study. Ewing, Croke, Rowland, Grande.

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Noted in the paper, p5,6
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	All researchers have PhDs, noted on p1
3.	Occupation	What was their occupation at the time of the study?	Noted on p1
4.	Gender	Was the researcher male or female?	Female. Not noted in the paper
5.	Experience and training	What experience or training did the researcher have?	Evident in author credentials on p1
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	SC the study researcher established relationships with participants through telephone contacts to set up data collection. Not included in the paper.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Full introduction given to participants at the start of interviews/focus groups/workshops.

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	As above
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Content analysis - p6
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Included in Methods section – p5 and Table 1 p15
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Included in Methods section - p5
12.	Sample size	How many participants were in the study?	Included in Methods section – p5
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	We include how many people were invited and how many took part. We do not have information on reasons for not

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
			participating because we did not have access to the NHS database of eligible participants
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Included in Methods section – p5,6
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	In one home interview with a carer, the patient with MND they were caring for was present.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Reported in the paper – p16,17
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The topic guide for focus groups/interviews comprised three broad question areas. These broad areas are included in the paper – p5. The topic guide was informed by PPI work, it was not pilot tested. In qualitative studies 'all is data' and it is usual practice to refine questions asked/areas explored.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording: as detailed in the paper – p6
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, as detailed in the paper – p6
21.	Duration	What was the duration of the interviews or focus group?	Detailed in the paper – p5,6
22.	Data saturation	Was data saturation discussed?	No as this is only really pertinent to grounded theory which was not used in this study. Recurrent themes emerged throughout and there were no 'disconfirming cases'.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were not returned to participants. Feedback of Stage 1 findings took place during Stage 2 workshops sessions, as detailed in the paper – p6.
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Included in the paper – p6
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Not in the paper

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes on experience of caregiving were derived from the data, as included in the paper – p6. For identification of domains of support needs the existing framework of CSNAT support domains was used which is usual practice with the directed content analysis approach used – p6.
27.	Software	What software, if applicable, was used to manage the data?	Atlas/ti – p6
28.	Participant checking	Did participants provide feedback on the findings?	Feedback on the findings formed part of the Stage 2 workshop discussion sessions and these were included as data. This is reported in the paper – p6.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Yes, included in the paper – pp 7-11
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	pp 7-11

No	Item	Guide questions/description	Are the CORE-D items addressed/in what way?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	pp 8-10 plus tables 4 and 5

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Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study

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Abstract

Objectives

Motor Neurone Disease (MND) is a progressive, life-limiting illness. Caregiving impacts greatly on family carers with few supportive interventions for carers. We report Stages 1 and 2 of a study to:

(1) explore experiences of MND caregiving and use carer-identified support needs to determine suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT);

(2) adapt the CSNAT as necessary for comprehensive assessment and support of MND carers, prior to (Stage 3) feasibility testing.

Design

Qualitative: focus groups, interviews and carer workshops.

Setting

Three UK MND specialist centres serving a wide range of areas.

Participants

Stage 1: 33 carers, 11 from each site: 19 current carers, 14 bereaved. Stage 2: 19 carer advisors: 10 bereaved, nine current carers. Majority were spouses/partners ranging in age from under 45 to over 75 years. Duration of caring: four months-12.5 years.

Results

Carers described challenges of a disease that was terminal from outset, of 'chasing' progressive deterioration, trying to balance normality and patient independence against growing dependence, and intensive involvement in caregiving. Carers had extensive support needs which could be mapped to existing CSNAT domains: both 'enabling' domains which identify carers' needs as co-workers as well as carers' 'direct' needs as clients in relation to their own health and well-being. Only one aspect of their caregiving experience went beyond existing domains: a new domain on support needs with relationship changes was identified to tailor the CSNAT better to MND carers.

Conclusions

Carers of people with MND found the adapted CSNAT to be an appropriate and relevant tool for assessment of their support needs. The revised version has potential for assessment of carers in other longer-term caring contexts. A further paper will report the Stage 3 study on feasibility of using the adapted CSNAT in routine practice.

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Strengths and limitations of this study

- Recruitment of carers from three major MND centres in the UK ensured a wide range of caregiving experiences and enhances transferability of findings.
- Inclusion of both bereaved and current carers enabled reflection on the full duration of caregiving.
- Enrolment of participants as subsequent advisors ensured strong, informed Patient and Public Involvement (PPI) in CSNAT review and design, and may serve as a pragmatic model for PPI involvement in general.
- The qualitative approach of the study which has a self-selecting sample limits generalisability of the study findings.

Introduction

Motor Neurone Disease (MND) is a progressive, life limiting illness that is terminal at diagnosis. Life expectancy is usually between two to five years, though this can vary in individual cases. The disease is one of progressive muscle weakness affecting movement, speech, swallowing and eventually breathing. In the UK, there are estimated to be 5,000 adults living with MND at any one time with six people diagnosed per day (1), in Australia about 2000 people are living with MND with two people diagnosed daily (2) and in the USA, where MND is more commonly known as Amyotrophic Lateral Sclerosis (ALS), up to 16,000 adults have ALS with 15 new cases diagnosed each day (3).

The process of patient deterioration impacts greatly on family members, most often spouses/partners (hereafter referred to as carers), who are the main sources of help and support for patients. Patients often progress to needing long term assistance with activities of daily living such as eating, bathing and toileting which can result in high levels of caregiver burden and a major impact on the physical health and well-being of carers (4-6). Managing patients' loss of speech, swallowing and motor function further adds to caring responsibilities and concerns, but also to the distress of dealing with a devastating disease in a close family member. Unsurprisingly carers of people with MND suffer high levels of psychological morbidity, including anxiety and depression, and have reduced quality of life (7-10).

Better support has the potential to ameliorate negative impacts of taking on a caregiving role (7,9,11). However, reviews within the broader palliative care context have not shown such interventions to have major impact on carer outcomes (12-14). In an MND context, although reviews show carer well-being to be compromised (15) carer interventions tested to date have reported limited effects (16,17) and none have been designed specifically for carers of people living with MND. The Carers' Alert Thermometer (CAT) has been used with family carers of people with MND (18). The CAT was designed originally as an alert tool in a more general care context and to date it has not undergone testing as a practice intervention in any trial. For MND, its instructions were modified to enable use by MNDA volunteers instead of healthcare staff: there was no involvement of carers themselves to review suitability or relevance of the CAT questions prior to its use with MND carers.

To be more effective and provide the support carers need to prevent or reduce negative impacts, interventions must be individually tailored and consider their full range of support needs rather than be selective (12). Furthermore, they should address support that carers need to manage the carer role to reduce negative impacts (proactive approach), rather than address negative impacts once they occur (reactive approach).

One intervention which has been shown to improve carer support in end of life care is the Carer Support Needs Assessment Tool (CSNAT) intervention. The CSNAT intervention enables practitioners to provide comprehensive, person-centred carer assessment and support. For use in practice, the intervention comprises a comprehensive, evidence-based assessment tool (19) and a defined five-stage person-centred process (20), that together allow carers themselves to identify, consider and prioritise their support needs, discuss these with a practitioner and identify supportive input they would find helpful (action plan), with follow-up review. This represents a significant change in practice as support for carers of patients with life limiting illnesses is normally informal and unstructured with solutions proposed by practitioners (21). The CSNAT has good validity (22), the intervention is valued by practitioners and carers (21, 23, 24) and improves carer outcomes (25,26) within a palliative home care context. Thus a three-stage study sought to explore the suitability, acceptability and feasibility of the CSNAT intervention in MND caregiving. This paper presents data from the study's first two stages, with objectives (1) to explore the experiences of caregiving in the

context of MND and use carer-identified support needs to assess suitability and acceptability of the CSNAT; and (2) to make any adaptions to the existing CSNAT for comprehensive assessment and support of carers of people with MND. A further paper will report the third stage feasibility study from the perspective of carers and healthcare professionals.

Methods

Qualitative design using focus groups (FGs), interviews and workshops involving carers of people with MND.

Setting

The first two stages of the study were conducted December 2017-May 2018 at three MND specialist centres serving patients (and carers) from a wide range of areas. Carers were recruited from all three sites.

Ethics approval was received from the North West – Greater Manchester West Research Ethics Committee (REC reference: 17/NW/0531). All participants provided written consent.

Stage 1: Focus groups and interviews with carers

Recruitment

Sites identified carers from patient databases using purposive sampling to ensure a balance between carer gender, relationship to the patient and type of MND. Both current and bereaved carers were included (see Table 1 for inclusion/exclusion criteria). Recruitment was through direct invitation at clinics by the MND Consultant/Clinical Nurse Specialist or by postal invitation from the MND consultant.

All carers received a recruitment pack (study invitation letter from the consultant, information leaflet explaining the study, confidentiality of data handling and data protection, reply form and freepost return envelope). Carers interested in taking part responded directly to the study researcher (SC) who provided any further information and made arrangements for data collection.

The three sites identified 170 carers eligible to take part (126 current carers; 44 bereaved). 48 responded to the invitation (28% response rate); four later withdrew due to worsening patient health. Not all respondents were available to attend a group or interview. In total 33 carers (11 from each site) joined Stage 1. Table 2 summarises participants' characteristics.

Insert Tables 1 and 2 about here

Data collection

Nine focus groups were conducted (three at each site), December 2017-January 2018, facilitated by two researchers (GE/SC; GE/CR; CR/SC). Focus groups were chosen to enable participants to 'share and compare' experiences, allowing observation of both consensus and diversity of views (27). Small groups were held with three to four carers each to maximise discussion: groups averaged 108 minutes. A distress protocol which identified support contacts at each site was employed to ensure any upset participants were supported. The introduction to the session by the main facilitator recognised the sensitivity of the discussion and assured participants that they could take a break, leave the session or withdraw at any time if they so wished. The confidential nature of the discussion was reiterated. At the end of each session, facilitators checked on whether any participants were

upset and that they had contact details for further support if needed. There was a period after each FG where carers could chat and have further refreshments before leaving. None of the participants required additional support as a result of taking part in the FGs/interviews.

The topic guide covered three main areas: (1) a brief introduction about the carer and the person with MND; (2) their experience of key stages of caregiving starting with the time of diagnosis, what was challenging, what help/support they received or would have liked to have had, from whom and when; (3) carers were introduced to the CSNAT intervention and given a copy of the CSNAT (tool itself) and asked their reaction to the tool and its usefulness to carers of people with MND: anything not relevant; any type of support need missing.

Respite provision was offered to facilitate focus group participation. However, where carers felt unable to leave their home, because of caring or other reasons, an individual home interview was conducted by the study researcher (SC) to enable their participation. Four interviews were conducted, each lasting just over an hour, following the same format and topic guide as the focus groups. As the interviews were conducted after the majority of FGs were completed, the researcher (SC) was able to share aspects of the FG discussions at individual interviews to have some elements of the 'share and compare' discussion in the groups. As such, there was no substantial difference in the findings between the two approaches. The main benefit of the FG discussions was a personal one of communality of experience and mutual support.

Analysis

Sessions were audio-recorded and field notes were written. Recordings were fully transcribed, then checked and anonymised by a researcher (SC). Transcripts were read by all researchers for familiarisation. Qualitative content analysis was conducted (28): 1) Conventional content analysis was used to analyse the experience of caregiving in MND allowing codes to emerge from the data to develop an initial coding scheme which was then used to index the data; codes were then clustered into categories. 2) A directed content analysis considered carers' support needs in relation to CSNAT as the tool already provided a framework, mapping data to the existing 14 CSNAT domains. Support needs/supportive input not captured by the CSNAT domain coding scheme were coded separately.

The research team discussed and agreed the coding process which was used by GE to index the transcripts. Atlas/ti was used to facilitate data management. Verification of the indexing process was conducted by a second researcher (CR) and a process of checking and agreeing emergent domains and interpretations was conducted by the whole research team.

Stage 2: Workshops with carer advisors

Recruitment

FG/interview participants from Stage 1 were invited to become carer advisors for Stage 2 workshops. Those interested provided contact details to the research team and agreed to further contact.

There were 19 carer advisors: 10 bereaved; 9 current carers. Three of these were carers who had shown interest in Stage 1 but then were unable to participate at that time. Table 3 summarises the characteristics of the carer advisors.

Insert Table 3 about here

Data collection

Three workshops were conducted in May 2018, one at each site. They lasted just under two hours, were facilitated by two researchers (CR/SC) with five to eight carers in each. A workshop guide was used to structure the discussions: (1) a brief background to the study; (2) a reminder about the two-part CSNAT intervention; (3) an overview of Stage 1 findings. Then carer participants were asked to review the findings on the content of the CSNAT: was there anything missing, focusing specifically on any additional domain(s) needed (reported below) and the process of using the CSNAT intervention in practice (to be reported in a subsequent paper on implementation).

At the end of the workshops, 10 participants agreed to help finalise the wording of an additional domain for the CSNAT in the context of MND by email/telephone contact.

Analysis

Workshops were audio-recorded and field notes written. Data processing was the same as Stage 1. As the workshops focussed on refining the CSNAT content for the context of MND, directed content analysis using the existing framework of the CSNAT domains was used. At all stages, the coding was shared within the research team, interpretations discussed and agreed.

Patient and Public Involvement

At the study outset, two researchers (GE & SC) attended a regional Motor Neurone Disease Association (MNDA) meeting, to introduce the study and have informal discussions with family carers. This led to two follow-up telephone conversations (GE) that provided a wider perspective and understanding of caring for someone with MND, which was used to enhance the sensitivity of subsequent data collection. Additionally, use of carer advisors in Stage 2 provided a strong PPI element to the CSNAT review and design.

Findings

The findings are in three main sections: (1) the context of caregiving in MND; (2) the support needs and supportive input derived from the experience of MND caregiving that relate to existing CSNAT domains; and (3) an additional domain of support needs identified within the study. Italics indicate verbatim quotations. To preserve anonymity participant quotes are identified by alphanumeric codes: the letter(B) indicates the respondent was bereaved and the letter (C) a current carer.

(1) The context of caregiving in MND

With any life limiting illness there is a significant emotional impact on the family. MND carers expressed that beyond the '*shock*' of diagnosis, they were dealing with an illness that is terminal from the outset: *"Well, it is a death sentence, isn't it, […] but most people with cancer, they've got a little...they've got hope that something...there's very few that actually they get to the stage where it's diagnosed and they say there's absolutely nothing that we can do for you"* (BSR017). The great majority of carers in the study were partners/spouses of the person with MND whose own lives were "*on hold"* (CSH059) during caregiving. "*We've got the illness together*" (CSH052) expressed their experience and influenced the support needs they had.

Maintaining normality

A strong feature in early caregiving was of actively promoting patient independence for as long as possible, to enable patients to retain some normality in the face of their illness. This involved encouraging them to carry on with previous activities, even if this took much longer, for a sense of satisfaction. Tact and diplomacy was often required in making adjustments to activities of daily living (ADLs) to maintain independence. It was hard for carers to know how long to hold back: *"It's difficult for him to accept that he is not as active as he used to be. And for me to have the balance between helping where it's needed and not giving help where it's not. […] How long should I hover there*" (CSH041). Carers were keen to avoid 'taking over' and enabling patients feel that they were still living a normal life. This had to be tempered with an awareness that some aspects of maintaining independence could also be hazardous. Getting the balance right was an important aspect of early caregiving.

Relationship changes because of MND

Carers described how the illness and caregiving influenced their relationship with the patient. Patients could be '*stubborn'*, '*demanding'*, '*angry'*. They fully acknowledged the difficult situation for patients, but certain responses greatly affected carers. As many were couples, there was a changed relationship, for some from the point of diagnosis, with tensions or petty arguments. The disease blurred role boundaries: as husband/wife/partner and as carer, affecting all aspects of their relationship, particularly when providing personal care. Some talked openly about loss of intimacy due to illness, though others reflected that it was not "*top of my list*" of concerns (CSR030) as long as closeness remained. But for others, "*the affection is taken over by the pressure of caring*" (CSR002).

Chasing the disease

The progressive nature of MND meant that carers found themselves managing a situation that was never static: "*because it never plateaued, it just kept going downwards.*" (BSH015) They stepped in to compensate for the deterioration in the patient: *"You're on a roll, aren't you? […] You're like a hamster on a wheel, and each day or each week or each month, you do that little bit more and a little bit more"* (BSR013). Carers found themselves managing one set of limitations when another deterioration happened: something new to deal with, whilst also coping with the psychological impact of further deterioration. Speed of progression meant there was an immediacy to patients' needs that was often at odds with time taken to get supportive input in place. [Referring to the need for changes to a bathroom] "*we were told we might wait between four and six months to be assessed. And then you've got to wait for the work to be done. Well, we needed it doing there and then*." (CSH055). Many times they arranged for equipment to be provided at their own expense, so it was in place at the time it was needed.

Intensity of caregiving

Caregiving experiences were unique, but there was a commonality in terms of the intense nature of their role which in part related to being partner/spouse of the person with MND: someone with whom they had a close personal relationship. A strong sense of responsibility for caregiving was combined with sadness and emotional vulnerability: "*because you feel so inadequate, you want to make it better for them, you can't*." (CSH055). As MND quickly affected patients' abilities to manage ADLs, carers often became 'hands on' at an early stage. Dependency on the carer was 24/7, including providing care at night, because there was no one else. Complexity of caregiving and constant vigilance required were also factors in this intensity.

(2) Domains of support for carers of people with MND

Carers spoke in positive terms about support from healthcare professionals, but this was for the patient, less so about separate support for themselves as carers: "*Individually, they've not provided that support, because that's not their brief, it's to look after [the patient]"* (CSH037). Commonly carers were asked 'are you alright'? *"And, of course, you say, yes, you are alright, because you've got to be alright, you've got no option, have you?"* (BW002). But others felt 'abandoned' or 'invisible' within patient consultations with healthcare teams, despite having many support needs.

Insert Table 4 about here

Direct domains: carers' own health and well-being needs

Carers' discussions revealed the extent of 'direct' support needs: support required to preserve their own health and well-being in their role as 'clients'. Table 4 provides illustrative examples of the range of support needs (both met and unmet) and input required to meet those needs.

Getting a break from caregiving depended on stage of illness. Initially, carers were able to get short periods away but only if patients could be left comfortably and safely, e.g. with food/drinks; able to access the toilet. Availability of professional carers varied greatly: some carers only had support from family or paid for private respite. It was much more difficult to leave patients in later stage MND where symptoms needed constant attention. However, most breaks were to do tasks like shopping or housework rather than actual time for themselves, though carers recognised that it was important to create some separate space for themselves: "*It's snatching time*" (CSR030).

Being a carer overnight was exhausting: requiring constant vigilance. Carers were aware of limited respite services but lack of discussion by healthcare practitioners about this in itself was difficult. A common dilemma carers faced was of needing a break but having feelings of guilt and ambivalence with regard to having their own needs met. The impact of overnight caregiving on physical health was substantial: "*I was rocking with exhaustion*" (CSH041). Carers were aware of the effects, but had little help to do anything about it.

With financial, legal and work issues, carers accessed help/advice from many sources, but a recurrent theme was input needed earlier in the illness: pro-active or anticipatory advice/information and signposting on. Many carers went through an *ad hoc* process of discovering benefits/allowances often missing out on certain entitlements. Need for practical help within the context of MND, extended beyond the home to the garden and to transport issues from the home, including parking, but they were rarely asked about this: *"actually sometimes it's just for them to say 'No, I can see you're struggling'"* (CSH047). Carers often had difficulties accepting help, but this was true across all the support domains, not just practical help.

The emotional impact of caregiving was harder to deal with for some carers, than physical effects, and they didn't always have an outlet for their feelings. They needed support to deal with their own reactions to the illness but also the patient's response. A worry commonly voiced was what would happen if they became ill, or worst-case scenario, they died while caregiving: "*If something happens to me, then we're in trouble because I do everything for [patient]"* (CSH037). The diagnosis of MND challenged the belief systems of both patients and carers and raised needs about information and discussions about assisted dying.

Insert Table 5 about here

'Enabling' domains: support needs in caring for the patient

Carers also had a range of support needs to enable them to care for the person with MND in their role as 'co-workers' (see Table 5). They provided an extensive range of support, including assisting with all ADLs. Carers received help from different professional care teams, but these were time-limited visits, leaving carers to manage for the remaining hours. Managing ADLs necessitated not just advice, but 'training': "*I had to learn as I was going along. [..] You need somebody really that could take you to one side and show you how to do it*" (BSR003). "*Yeah. Well, it's basic things like learning how to lift them up out of the chair or things like that, or help them out of bed, to roll over and that kind of thing"* (BSR017).

Carers needed to know about, access and be able to use many different pieces of equipment to manage ADLs. Although equipment was for the patient, carers were clear that it supported them in caregiving: *"I don't need support particularly for me, but I do need equipment to help me do what I do"* (CSH045) and they also needed training to use this equipment. Dealing with MND symptoms involved managing complex medical devices in addition to medicines, again requiring advice/information, but importantly training in their use. Some found this worrying, others were fine: *"Once I got the confidence I was fine and it suited [partner] because she didn't want any help […] so it was just me and her right until the end really"* (BW009). As a result, carers became expert in managing patients' needs.

Carers needed to be able to contact services if concerned and at its most basic that meant 24-hour phone services. It was also about having a key contact person, and different professionals took on this role including occupational therapists, community matrons, district nurses, GPs and MND specialist nurses. However, in the context of MND, carers were very concerned about patients' ability to summon help if carers themselves became ill, identifying the importance of a contact to check on carers of patients in the later stages of MND.

Support needs in understanding the illness were time related: *"I don't particularly need any more information at the moment about understanding my relative's illness, but I would have done [earlier]"* (CSH014), particularly around diagnosis. General information was needed then but also someone with knowledge of MND to answer specific questions. Talking with their relative about his/her illness was difficult for many carers, needing support with managing issues of denial from both sides and for some also suggestions of suicide. Carers also experienced considerable difficulties in accessing any support for themselves when patients refused to talk about their illness or let anyone know about the diagnosis.

Regarding knowing what to expect in the future, some carers preferred not to know, living each day at a time, though they also acknowledged that 'not knowing' was hard. Where carers wanted this support, they found some healthcare professionals reluctant to talk about dying: "*vague talk*" (BW003D) wasn't helpful in making preparations for the further decline and death.

(3) An additional domain of support needs in MND

Stage 1 FGs and interviews identified that support needs in MND mapped well to the existing 14 CSNAT domains and this was later confirmed by carer advisors in Stage 2 workshops. These workshops also sought to identify any aspects that didn't map or suggested missing domains. One aspect of caregiving, dealing with relationship changes as a result of MND, was further explored to determine whether support needs arising from these changes were encompassed by existing CSNAT domains or an additional, separate, domain was needed.

MND affected relationships in different ways for different people. Some felt that difficulties related to frustrations from the loss of control and role changes patients experienced, and this was difficult to talk about. Relationship issues could be part of the 'feelings and worries' domain, but depended on circumstances. An alternative domain was 'talking to your relative about his/her illness', though this could be perceived as having a narrower, physical focus: "*As I say, I think the physical things sometimes are easy [..], but it's the mental thing with your relationship and everything*" (CSH034). Overall, the consensus was that it was important to add a separate domain about relationships, one that was more specific: ".. *because, whilst yes, it does fit into these two categories really well, but then it's that, happy to verbalise it, which is sometimes the hardest part isn't it? Getting people to say, this is actually what's bothering me*" (CSH047).

Carers identified several reasons for having a separate relationship domain. It could prepare new carers for something that might affect them in the future. Just as carers may not have support needs within some of the CSNAT domains in the early stages but these arise later, so too with the relationship domain. Changes in relationships usually evolved over the course of the illness, and were not necessarily present at the start. What was important to carers was that there was a choice in being able to discuss support with relationships issues, should they arise. Recognising the conservative nature of most people about talking about relationship changes such as intimacy, a separate domain was felt to give *"permission to talk about something very private"* (CSH055), if they wished to.

Workshop discussions further revealed that carers' support needs with relationship issues extended beyond spousal relationships: *"there's all sorts of relationship groups that are affected because of the illness. Friendship groups, work colleagues, social groups. Relationships with healthcare professionals as well, there might be a conflict with who your current healthcare professionals are. [..] So perhaps having that extra domain that actually bring out some of those issues"* (CSR048). Wording of the domain thus needed to reflect support needs within more wide ranging relationships. Different options were explored initially in the workshops, with email and telephone follow up iterations. "Do you need more support with managing relationships" was finally agreed and added to the existing CSNAT questions to be piloted in Stage 3 of the study (to be reported elsewhere).

Discussion

This paper examines experiences of caregiving in the context of MND. Carers' lives were significantly impacted by the disease. Study findings suggest that adapting the existing CSNAT through the addition of a new domain on support needs with relationship changes will enable identification of the wide range of support needs experienced by carers of people with MND.

Overall, support needs in MND caregiving mapped well to existing 'enabling' and 'direct' CSNAT domains and carers found the domains appropriate and relevant: a finding supported by a pilot study using the CSNAT intervention in the context of MND in Australia (29). However, our in-depth exploration of carers' support needs also identified that a further assessment domain was required to address role and relationship changes due to MND, commonly reported aspects of the experience of MND caregiving (4,6, 30, 31, 32). However, the need for such an additional domain may not be required for MND *per se,* but may be reflective of support needs arising from prolonged intensive caregiving. Farquhar et al (33) reported similar role changes experienced by carers of patients with breathlessness in advanced COPD. More recently, two systematic reviews of support needs of carers of patients with COPD (34) and of people living with pulmonary fibrosis and their caregivers (35) identified similar difficulties within patient-carer relationships. The COPD review also identified

support needs with carer-clinician relationships, recommending an additional CSNAT domain to encompass the full range of support needs of these carers (34). The original study to develop CSNAT (19) mainly involved carers in a cancer context where intensive caregiving was much shorter term. It furthermore included only bereaved carers, many of whom reflected back on the uncomplaining nature of those they cared for and not on the tensions expressed in the current study.

The extent of carers' support needs in MND in this study evidences the necessity of a separate process of assessment and support for MND carers. Carers furthermore required support to enable them to support the patient as 'co-workers' and direct support to look after their own health and well-being as 'clients'. Current guidance, such as from NICE (36) recommends advising carers of their legal right to a Carer's Assessment but this fails to take account of this dual role carers play and their support needs in both roles. Whilst some needs for carers as 'clients' may be addressed by the statutory carer assessment, these assessments do not identify the needs carers have as 'co-workers', where they rather need healthcare professional input to enable them to provide care for the person with MND. The extent of support needs within these 'enabling' domains and the burden they experience from caregiving evidences a need for a more comprehensive assessment process. The broad domains of the CSNAT are intended to help open conversations with carers by providing visibility about aspects of support others in their situation have found helpful. Which individual needs are discussed within domains depends on how those domains resonate with individual carers: what is key is that they facilitate a conversation to uncover the carer's individual needs which can then be supported.

Whilst there is a wide literature on carers' needs in MND, a strength of this study is that our findings specify in detail many different types of support carers needed or found helpful from health/social care professionals. 'Pro-active' input was identified as particularly important across many domains, i.e. guidance ahead of need, not just 'reactive' input to a problem or crisis, which resonates with findings from a meta-analysis of carers' educational needs (37). Certain types of input that may be delivered directly by professionals were common across domains: particularly advice and information (ranging from very general to highly tailored); training in different care activities; or directly delivered help. Family and friends may also provide some direct help. However, some support needs may necessitate signposting and referral by health/social care professionals to other support agencies. These common themes and detailed analysis of needs experienced offer practical guidance to assist healthcare professionals in ensuring help is tailored to carers' individual needs.

Limitations of the study

This study was qualitative with a self-selecting sample, so findings may not be fully generalisable. However, the three study sites where recruitment took place had very different MND management protocols which adds validity in terms of transferability of findings to other centres and practitioners working with MND patients and their carers. We also believe that the findings will have relevance for practitioners and carers managing all stages of the illness as we were able to conduct interviews with carers from throughout the illness trajectory from newly diagnosed MND to advanced disease and into bereavement.

Implications for practice

In the first two stages of this study an adapted version of the Carer Support Needs Assessment Tool, comprising the existing 14 domains plus a new domain on support with managing relationships was developed for implementation as part of a practice intervention for MND carers (Stage 3 study findings to be reported elsewhere). Carers found the adapted CSNAT to be an appropriate and

relevant tool for assessment of their support needs. The revised version also has potential for assessment of carers in other longer term caring contexts. Furthermore, the detailed exploration of the input carers themselves have identified as important in meeting their different support needs provides a valuable training resource to assist healthcare professionals in tailoring support provision to carers in the context of MND.

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Declarations

Contributor statement:
GE: co-lead, designed the study, acquisition of funding, data collection, analysis and interpretation of data, drafted the article; SC: data collection, interpretation of data and revised article critically for important intellectual content; CR: designed the study, data collection, analysis and interpretation of data and revised article critically for important intellectual content; GG: project lead, designed the study, acquisition of funding, data collection, analysis and interpretation of data and revised article critically for important intellectual content**.** All authors gave final approval of the version to be published.

Competing interests:
None declared

Data availability statement:
All data relevant to the study are included in the article or uploaded as supplementary information. No additional data available.

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Accessing the CSNAT.

The CSNAT is a copyright tool available free of charge to the NHS and not for profit organisations. Training and a licence are required for its use as a practice intervention. For further details go to http://csnat.org

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Table 1: Inclusion/Exclusion criteria for Stage 1 and 2 recruitment

	Current carers	Bereaved carers
Inclusion	Patient at least 3 months post-diagnosis	6-12 months post-bereavement
Exclusion	Younger than 18 years	Younger than 18 years
	Clinician concerns about psychological/physical ability to cope with study participation	Clinician concerns about psychological/physical ability to cope with study participation
	Unable to give informed consent	Unable to give informed consent

Table 2: Stage 1 Carer participants.

	Bereaved carers (14)	Current carers (19)
Relationship to patient		
Spouse/partner	13	17
Daughter/son	1	1
Other	0	1
Age range		
<45	0	2
46-55	2	2
56-65	1	6
66-75	8	6
>75	3	2
Missing	0	1
Carer description of type of MND		
ALS	5	8
MND only	6	1
Bulbar	3	3
Primary Lateral Sclerosis	0	2
Progressive Muscular Atrophy	0	1
Not known	0	4
Duration of caring		
Less than 1 year	3	1
1-2 years	8	9
3-4 years	2	6
5-10 years	1	1
More than 10 years	0	2

Table 3: Stage 2 Carer advisors

	Bereaved carers (10)	Current carers (9)
Relationship to patient		
Spouse/partner	9	8
Daughter/son	1	0
Other	0	1
Age range		
<45	0	2
46-55	2	1
56-65	1	3
66-75	5	2
>75	2	0
Missing	0	1
Carer description of type of MND		
ALS	5	5
MND only	3	1
Bulbar	1	1
Primary Lateral Sclerosis	0	1
Progressive Muscular Atrophy	0	0
Not known	1	1
Duration of caring		
Less than 1 year	3	1
1-2 years	5	4
3-4 years	2	3
5-10 years	0	1
More than 10 years	0	0

Table 4: Direct domains: direct support to carers to preserve their own health and well-being as 'clients'.

Each domain comprises individual needs (both met and unmet) but also supportive input to meet those needs.

Domains of support needs	Key aspects of support identified in interviews/focus groups with carers	
	Met needs/unmet needs with ..	Supportive input (received or needed)

Having time for yourself in the day	.. patient refusing to have help from anyone other than carer
	
	.. managing the patient who is frightened to be alone without the carer even for short periods eg to visit own GP
	
	.. dealing with not being able to get out because patient cannot be left
	
	.. getting away from the 'unfairness' of MND
	
	.. feeling that they should be there and doing things 24/7 particularly if a spouse/partner well as a carer
	
	.. thinking it is legitimate to get a break (carers tend not to think about a break for themselves)
	
	.. getting a few hours in the week to do a range of necessary tasks: food shopping, going to bank, going to post office, changing library books, getting housework done, attending appointments
	
	.. dealing with healthcare professionals who consider that carers need time, not for self, but only to go to Post Office, buy food
	
	.. having some time just for themselves/what they want to do: carers talked about doing something relaxing, being able to unwind, something for their own health/fitness, to go driving as a stress release, going for a coffee, going for a walk, meeting a friend, doing some voluntary work
		Advice and information:
		• about services locally that would provide a break for the carer
		
		Directly delivered input:
		• advance booking of short period of respite, eg through MNDA
		• specific breaks from health and care services/charities:
		  ○ care-team provided via local authority personal budget
		  ○ professional carers from an early stage to build a relationship with the patient and confidence to be left with them
		  ○ sitters for some respite hours from charity or from hospice
		  ○ team providing set hours per week for personal care for the patient
		• family help
		  ○ family events providing a break-because more people around to help
		  ○ direct care help from family members, though carers often reluctant to accept
		• private care teams (at a cost to the patient and carer)
		  ○ agency sitting services; private care team two afternoons a week
		
		Opportunistic breaks
		• when patient attending hospice or day services
		• during District Nurse (DN) team visits to the patient – potential cover for the carer to go out
		• reliance on friends/neighbours to sit with patient
		• by having Macmillan Transport to take patient to hospice appointments
		
		Identified 'downtime' for the carer even if unable to leave the home: eg
		• in the late evening when patient is safely in bed
		• in the early morning before the patient is up

Getting a break from caring overnight	.. being up several times during the night because caring involves helping with toileting, managing falls, turning the patient in bed, listening out for the patient
	
	.. difficulty of raising need for a break in front of the patient
	
	.. feelings about respite
	• guilt about wanting respite
	• ambivalence – whether wanted /reluctance to leave patient
	• knowing that patient prefers carer/family to do overnight
	• having night respite available but patient not wanting it
	
	.. being able to 'let go' when care worker is providing respite
		Advice and information:
		• availability of respite services
		
		Directly delivered input:
		• night care in the patient's own home
		  ○ arranged by Macmillan
		  ○ care worker from the hospice
		  ○ by family members/shared care overnight
		  ○ by private arrangement
		• patient admission for a period of respite: to hospital or hospice
		
		Signposting/referral to:
		• joint patient and carer break at a respite centre where patient needs met by centre staff overnight as well as in the daytime
		• a holiday break with time in the day for the carer to catch up on sleep

Looking after your own health (physical problems)	.. physical effects of caring, through providing overnight care: fatigue and tiredness due to lack of sleep; weight loss .. direct impact of lifting patients: back problems, bad shoulder, hernias .. understanding the impact of caring on carer from the start .. knowing who to talk to about physical effects from the stress of caring role .. carer's own health problems: high blood pressure, illnesses / injuries/ symptoms experienced .. loss/lack of time for physical exercise .. tiredness from doing both caring and working	[Little advice on carers' own health] Directly delivered input: • someone to look after patient to give carer time to do exercise / go for a walk • a person to look after patient to allow carer to go to hospital for treatment • physical therapy sessions delivered in the home as carer unable to leave the patient for time to attend clinic • prescribed medication for health problems strengthening exercises at a gym to help with lifting the patient when he falls (because no other help offered)
Your financial, legal or work issues	.. applying for benefits /allowances • understanding which benefits carers are entitled to • feeling confused by online information • dealing with social security phone lines	Advice and information: • on entitlements/benefits available from hospital, telephone helpline, Age UK, social workers, MNDA carers' voluntary group, Citizen's Advice Bureau: • on working rights

	• the lack of awareness of people on phone lines about MND • the costs of ringing benefit lines • being given incorrect advice • completing the lengthy claim forms • persistence in making claims .. dealing with loss of income • when patient unable to continue to work • when carer has to give up working • when managing on a reduced income .. getting help with extra costs because of the illness: heating; prescriptions; prescription exemptions .. lengthy waiting period for assessment for financial assistance with bathroom adaptations (leaving patient unable to shower)	• reduction in council tax if house adapted for MND • free car tax • no VAT on equipment to manage MND • MNDA grant for adaptations to home • MNDA grants for carers • reduced price cinema and theatre tickets for carers accompanying patient • Wills and Power of attorney on MNDA website about Directly delivered input: • help to complete application for financial assistance, from Age UK, family members • reduced working hours enabled by employer /supportive line manager • part time working and flexible working from home supported by employer • completion of a Will at home by solicitor
Practical help in the home	.. fitting in all the household tasks whilst caring including washing, ironing, cleaning, shopping, preparing meals .. garden work as patient becomes less able to do it .. practicalities of getting to hospital appointments .. patient's refusal to have anyone in the home to help the carer .. cost of having a cleaner to provide some help in the home .. accepting help offered/provided	Directly delivered input: • family sharing some of the duties like cleaning, ironing and shopping • help with garden from friends/family • paid help: in the home; in the garden • GP signing carer off sick from work when struggling to manage – to give time to do practical tasks • Having a 'blue badge' to help with parking

Dealing with your feelings and worries	.. carers' own specific feelings and worries: • guilt - if carer gets irritable with the patient or for wanting help for self as a carer when the patient has the illness • having to put on a 'front' of coping because the patient needs to see carer as dealing with things. • anxiety about new symptoms of progression of the illness • fear of what lies ahead with the illness • sadness at patient's deterioration • isolation and mental health issues • grieving which began at diagnosis • worry about becoming ill themselves while caregiving .. patients' reaction to the illness which impact carers' own mental health • patient not wanting to tell family how he is – carer has the load on his/her own • denial by the patient • too much openness by the patient in discussions about dying causing carer distress .. knowing who to go to for help with feelings	Directly delivered input: • Someone to talk to ○ soon after diagnosis ○ from the medical team to talk with the carer alone about how they were managing MND as a couple ○ at a regular appointment following referral – an hour of talking ○ in the middle of the night when frightened – a helpline ○ someone to call the carer regularly – to just listen Range of people provide this support: family members, a network/circle of friends, friends in the church, from MNDA carers' meeting to talk openly, away from the patient Directly delivered input (in addition to talking): • getting out to do gym sessions • medications for anxiety/depression Signposting/referral • to more specific mental health input where needed
Your beliefs and spiritual concerns	.. dealing with the effect of disease on personal beliefs, including challenges to those beliefs .. understanding issues and feelings around assisted dying	Advice and information: • about Dignitas (where requested by the carer) Directly delivered input: • an offer to talk about beliefs, in privacy • time to talk when carer ready

Table 5: 'Enabling' domains: support for carer to care for the patient in their role as 'co-workers'

Domains of support needs	Key aspects of support identified in the interviews/focus groups with carers	
	Met needs/unmet needs with ..	Supportive input (received or needed)
Providing personal care for your relative ..	.. managing/helping patient with ADLs: • getting up in morning/to bed at night • dressing and undressing • washing /bathing/showering • toileting – both in day and at night, • managing incontinence, dealing with soiling, managing catheters • all aspects of mobility: lifting or moving including in bed, managing patient falls • feeding the patient, including avoiding loss of weight .. understanding changes in mobility /movement as disease progresses .. strain of being the only person the patient permits to help with ADLs .. being able to give carer perspective when patient is not being fully honest about how he/she is managing. .. managing the cost of paying for private carers	Advice and information: • anticipatory guidance on how to manage ADLs • pro-active advice on getting carer team in/out with personal care and how to access care services • on completing forms for continuing health care • from continence service • practical tips for managing outside the home eg how to access a radar key for disabled toilets Education / training – needed from 'day one' • lifting and handling • how to do a bedbath; washing/cleansing to deal with incontinence and soiling • hygiene requirements for managing catheters • individualised dietary advice appropriate to the carer's situation Directly delivered input: • provision of equipment by different agencies (local councils, MNDA) and professionals (such as OTs) enabling carers to provide personal care, eg sliding boards, hoists, commodes etc • help from professional care team with showering and getting patient up/to bed but requires continuity and reliable timing • private care assistants to do personal care • care packages from continuing health care • DN assistance with changing catheters • Regular contact from DN team to see how carer was managing • help from neighbours when patient falls • help from ambulance service with lifting • Short term 'emergency' care team four times/day for one week on leaving hospital
Equipment to help care for your relative	..understanding and using different types of equipment to help manage the patient's illness	Advice and information: • anticipatory guidance from HCPs on types of equipment likely to be needed during the illness course

	.. accessing specific pieces of equipment/aids including walking aids, seat raisers, wheelchairs, commodes, shower stools, perching stools, manger air cushions, fold up chairs that goes in car, hoists, hospital beds, special cups, special cutlery, zimmers, walking trolleys, walking sticks, hand rails, boogie board, iPads with predictive text. ..making adaptations to the home to help with managing the needs of the person with MND: including putting in showers, wet rooms, raised toilets, full lifts, stair lifts, outside ramps ..managing cost implications of paying for equipment/adaptations to respond to immediacy of the patients' needs	• agencies providing different equipment (locally): therapy services, local councils, MNDA • website for ordering equipment accessible by carers • MNDA grants to help with the cost of equipment Education/training in use of a range of equipment: • such as hoists, sliding mats Directly delivered input: • Timely referral by MND nurse to Occupational Therapist (OT) at local council for input • A named OT visiting regularly to review equipment needed • Services taking account of patient/carer preferences in equipment provided • Equipment actually *wanted*: e.g. a hospital bed may not be supportive input for all carers; • Equipment actually *needed* eg iPad may not help when family already has one.
Managing your relative's symptoms including giving medicines	.. managing patient symptoms: • difficulties swallowing • choking • excess secretions/saliva • breathing difficulties/shallow breathing • panic attacks • terminal agitation in the end stages .. using different appliances to manage symptoms including Cough Assist, Suction, Respirators, Percutaneous Endoscopic Gastrostomy (PEG) or Radiologically Inserted Gastrostomy (RIG) tubes .. dealing with responsibility for managing RIG .. feeling helpless during a choking episode .. managing reluctance of patient to take drugs to help with panic attacks	Advice and information: • how to manage a choking episode • breathing problems in an emergency from Ambulance service /paramedics • how to handle better a panic attack • managing communication difficulties • contacting the feeding company if any problems Education/training: • managing PEG/RIG including using it to provide patient's nutrition, cleaning it/preventing infection, clearing any blocking of the tube • fitting of a feeding tube prior to start of choking episodes • managing the patient's respirator • using Cough Assist Directly delivered input: • Provision of oxygen in the home • Having an efficient delivery system of specialist nutrition so that correct prescription is supplied

	.. administering medicines down the feeding tube .. accessing specialist nutrition for patient each month	• Initial supervision of carer managing PEG/RIG, including when the patient returned home • GP help in getting medication in liquid form • Drugs to assist carer dealing with patient panic attacks • Local administration of Botox injections to dry up saliva rather than a five hour round trip to main hospital • Setting up syringe driver to settle patient at end stage
Knowing who to contact if you are concerned about your relative ..	.. confusion over which professional does what and which part of the NHS they are from .. ensuring correct details for night time contacts .. dealing with changes that occur and help that is needed .. accessing MND expertise in an emergency situation .. potential situation of carer becoming ill/has an accident/dying and patient being unable to raise alarm	Advice and information: Most basic – a contact number • available 24/7, not just office hours • in primary care/GP surgery • If an answer-machine – a timely response to the message A 'contacts' book – of numbers of HCPs including who does what An emergency contact eg 'Carers First' - provides a number the patient can ring if something happens to the carer and they organise a care team to come in Having responsive contact: • A person to talk to/have a conversation • who understands the caring situation in MND • who knows how to access help • to visit at home to facilitate further support and provide continuity Pro-active contacts: • at regular times along the caring journey • a checking system in late stages of MND to ensure carer is alright
Talking to your relative about his/her illness	.. dealing with the patient's reaction to the diagnosis eg denial, threats of suicide .. patient's refusal to let people know about the illness .. patient's refusal to talk about their (joint) situation of living with the disease	Directly delivered input: • An opportunity to talk about their situation as a carer • Regular visit by MND nurse just to talk with patient and carer about their situation Referral • to a counselling/support group for patient and carer • of the patient for counselling (was a support for the carer)

	.. understanding the patient's situation/mental well-being separate from the clinical condition .. being able to discuss with the patient, the carer's role in providing care .. with carer's own denial of the diagnosis	
Understanding your relative's illness	.. understanding the different stages of the illness including which stage the patient is currently at .. understanding the speed of progression of the illness .. knowing the restrictions of the disease	Advice and information: • initial general information about MND (usually from MNDA) Directly delivered input • an early (pro-active) contact by healthcare professional for discussion following shock of the diagnosis • consultations with a person who understands MND to answer questions: specialist nurses, GPs, Community Matrons • a separate explanation to the carer about the disease they are dealing with to sensitise them to the changes • carer/consultant consultation to ask questions *without* patient present
Knowing what to expect in the future ..	.. fears/worries about managing next stage of deterioration .. ambivalence of wanting to know about the future .. talking about the dying process .. preferred place of care discussions .. treatment decisions • Do Not Resuscitate (DNR) – with patient and carer and their situation as a couple • patient's decision on DNR/or not • refusing treatment • respect from hospital about DNR signed by the patient .. dealing with the unpredictability of prognosis .. understanding the proximity of death	Advice and information: • symptoms to expect as patient deteriorates • illness trajectory (some relied on discussion of patient symptoms in clinics as a clue to progression) • realistic prognosis including preparing for a short prognosis • signs of dying • services providing support like hospice at home • Directly delivered input – pro-actively • revisiting what to expect over the course of the illness, not just a one off. • Advance care planning discussions to put support in place when needed: • DNR and Advance refusal of treatment discussions as part of care from GP • From OT service on equipment likely to be needed • visits from the Carers' Centre to discuss 'what the future holds' Openness by HCPs to talk when family ask • Honesty about what death involves • That time of death is close so family can prepare and be present

	.. issues arising after the death • moving the body after death • funeral arrangements	

Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study. Ewing, Croke, Rowland, Grande.

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Noted in the paper, p5,6
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	All researchers have PhDs, noted on p1
3.	Occupation	What was their occupation at the time of the study?	Noted on p1
4.	Gender	Was the researcher male or female?	Female. Not noted in the paper
5.	Experience and training	What experience or training did the researcher have?	Evident in author credentials on p1
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	SC the study researcher established relationships with participants through telephone contacts to set up data collection. Not included in the paper.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Full introduction given to participants at the start of interviews/focus groups/workshops.

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	As above
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Content analysis - p6
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Included in Methods section – p5 and Table 1 p15
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Included in Methods section - p5
12.	Sample size	How many participants were in the study?	Included in Methods section – p5
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	We include how many people were invited and how many took part. We do not have information on reasons for not

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
			participating because we did not have access to the NHS database of eligible participants
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Included in Methods section – p5,6
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	In one home interview with a carer, the patient with MND they were caring for was present.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Reported in the paper – p16,17
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The topic guide for focus groups/interviews comprised three broad question areas. These broad areas are included in the paper – p5. The topic guide was informed by PPI work, it was not pilot tested. In qualitative studies 'all is data' and it is usual practice to refine questions asked/areas explored.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording: as detailed in the paper – p6
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, as detailed in the paper – p6
21.	Duration	What was the duration of the interviews or focus group?	Detailed in the paper – p5,6
22.	Data saturation	Was data saturation discussed?	No as this is only really pertinent to grounded theory which was not used in this study. Recurrent themes emerged throughout and there were no 'disconfirming cases'.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Transcripts were not returned to participants. Feedback of Stage 1 findings took place during Stage 2 workshops sessions, as detailed in the paper – p6.
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Included in the paper – p6
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Not in the paper

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes on experience of caregiving were derived from the data, as included in the paper – p6. For identification of domains of support needs the existing framework of CSNAT support domains was used which is usual practice with the directed content analysis approach used – p6.
27.	Software	What software, if applicable, was used to manage the data?	Atlas/ti – p6
28.	Participant checking	Did participants provide feedback on the findings?	Feedback on the findings formed part of the Stage 2 workshop discussion sessions and these were included as data. This is reported in the paper – p6.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Yes, included in the paper – pp 7-11
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	pp 7-11

No	Item	Guide questions/description	Are the COREQ items addressed/in what way?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	pp 8-10 plus tables 4 and 5