

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study
AUTHORS	Ewing, Gail; Croke, Sarah; Rowland, Christine; Grande, Gunn

VERSION 1 – REVIEW

REVIEWER	Prof Mary O'Brien School of Nursing, Midwifery and Allied Health Professions Faculty of Health, Social Care and Medicine Edge Hill University Ormskirk Lancashire UK
REVIEW RETURNED	15-May-2020

GENERAL COMMENTS	<p>Overall comment:</p> <p>This paper presents the findings from the first two phases of a 3-phase study designed to explore the suitability, acceptability and feasibility of using the Carers' Support Needs Assessment Tool (CSNAT) intervention with carers of people with MND. For me, herein lies a problem with the manuscript - it is only reporting on 2/3 of the study and without data on the feasibility of using the CSNAT in everyday practice there is no way of knowing how useful a tool it is in the context of already busy clinical settings where the focus is on the person with MND. Whilst I welcome raising awareness of the needs of carers of people with MND I don't get a sense of the paper adding much to what is already known about the needs of this specific group of carers.</p> <p>Consistency is needed when referring to carers/caregivers to ensure it is clear that it is family carers that are being referred to.</p> <p>Introduction:</p> <p>Para 1- final sentence is rather convoluted and would benefit from being phrased more clearly. There is brief reference to interventions for carers and the authors are correct that specific interventions for carers of people with MND are not only lacking but those used have limited effects. There is, however, no reference to the Carers' Alert Thermometer (CAT) which has been used to identify the needs of carers of people with MND (https://doi.org/10.12968/bjnn.2019.15.3.114). Furthermore, other recent publications addressing the needs of carers of people with MND are not cited either (see references at the end of the review). No research question is provided but two objectives are included; 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; to make any adaptations to the</p>
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	<p>existing CSNAT specifically to support family carers of people with MND.</p> <p>Methods: Reference to 'practitioners'- who were they? what was their involvement? I appreciate this aspect is intended as a separate paper but the text seems to suggest both carers and practitioners contributed to phase 1 & 2 so I would expect to see how they contributed in this paper.</p> <p>A positive aspect to the design is the inclusion of both current and bereaved carers which allows caring across the full disease trajectory to be included. The sample size is small but this can be a difficult group to engage in research because of the time commitment required for their caring duties which is known to average 11-15 hours a day. The choice of focus groups for the main data collection could be justified. Some participants were interviewed individually rather than in a focus group- a comment on whether there was any difference in the findings between the two approaches would be helpful, given the lack of discussion with others for those interviewed separately.</p> <p>Research ethics: More information about how research ethics and governance principles were adhered to during the study is needed e.g. support for participants, confidentiality, data protection etc.</p> <p>Findings: The findings are presented under three main headings which map onto the objectives presented earlier.</p> <p>Verbatim quotations are presented to support the findings. The identifiers used are very impersonal and don't give any sense of the participant's context and whether they were a current or bereaved carer. Previous research has indicated that the length of time caregiving can impact on the caregiving experience. It would be helpful to know whether the carers quoted have had some years of experience or are carers of people more recently diagnosed. This type of analysis may provide new insight into caregiving.</p> <p>The first part of the findings reports on the experience of caring for a family member with MND and generally re-iterates what has been reported elsewhere. The second part of the findings focuses on carers' support needs (both met and unmet) and supportive input required to meet those needs as they relate to the existing CSNAT 'direct' and 'enabling' domains. An additional domain, on managing relationships, was found to be needed. The CSNAT could therefore provide a practical means of identifying and helping to address areas of support arising from caring for a family member with MND.</p> <p>The claim, in both the abstract and the implications for practice that 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' is not substantiated by the data presented. Without data from its use in clinical practice there is no way of knowing how appropriate or relevant it is in that setting.</p> <p>P8 line 18 additional 'that' at start of the line.</p> <p>P13 line 18 'studies' should be 'study'</p> <p>A number of recent publications focusing on carers of people with MND were not cited e.g.</p> <p>Holkham & Soundy The experience of informal caregivers of patients with motor neurone disease: A thematic synthesis Palliative and Supportive Care (2018), 16, 487–496.</p>
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	<p>Gluyas et al Factors to consider for motor neurone disease carer intervention research: A narrative literature review <i>Palliative and Supportive Care</i> (2017), 15, 600–608.</p> <p>Harris et al Supporting wellbeing in motor neurone disease for patients, carers, social networks, and health professionals: A scoping review and synthesis <i>Palliative and Supportive Care</i> (2018), 16, 228–237.</p> <p>Lerum et al Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: a qualitative study <i>BMC Palliative Care</i> (2016) 15:22</p>
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REVIEWER	Letitia Burrige Griffith University, Australia
REVIEW RETURNED	09-Jun-2020

GENERAL COMMENTS	<p>It was a pleasure to read this manuscript. I have only minor comments to make:</p> <p>Several abbreviations were used without explanation; the authors may wish to consider including the full term at the first mention: PPI, MNDA (p.7) PLS, PMA (Tables 2 and 3, pp.16-17) DN (Table 4, p.18) OTs, HCPs (Table 5, p.22) PEG/RIG (Table 5, p.23) DNR (Table 5, p.25)</p> <p>In the Findings section, it would be helpful to number the section 1 and 3 headings as for the section 2 heading, for consistency: (1) The context of caregiving in MND (p.7) (3) An additional domain of support needs in MND (p.10)</p> <p>There seems to be a typo in first line of paragraph under the 'Enabling' domains heading (p.9): "...to enable them to carer for the person..." It would make more sense if this read: "...to enable them to care for the person..."</p> <p>On p.18, it would make sense to delete "provided" from the explanatory sentence under the Table 4 title, given that the column 2 heading identifies supportive input (received or needed) – if some kinds of support were needed rather than received, this implies they weren't provided.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer comments	Authors' response
Reviewer #1	
General remarks	
This paper presents the findings from the first two phases of a 3-phase study designed to explore the suitability, acceptability and feasibility of using the Carers' Support Needs Assessment Tool (CSNAT) intervention with carers	As the CSNAT was developed in the context of palliative home care where the sample of carers was predominately carers of people with

<p>of people with MND. For me, herein lies a problem with the manuscript - it is only reporting on 2/3 of the study and without data on the feasibility of using the CSNAT in everyday practice there is no way of knowing how useful a tool it is in the context of already busy clinical settings where the focus is on the person with MND.</p>	<p>cancer, we felt it was important first of all to evidence that the support needs (and required supportive input) of MND carers mapped well to the existing CSNAT domains as well as to an additional domain on 'relationships'. Therefore, in this paper we provided carer data from stages 1 and 2 which identify that carers themselves found the adapted CSNAT acceptable and relevant to their caring situation in the context of MND. This essential step, of ascertaining suitability and acceptability of the CSNAT from the carers' own perspective, is vital before any feasibility testing in practice. Unless carers feel it captures their support needs, there is no basis for feasibility testing.</p> <p>These findings are presented in this first paper with a further paper (noted as in progress in the manuscript) will present the feasibility data.</p>
<p>Whilst I welcome raising awareness of the needs of carers of people with MND I don't get a sense of the paper adding much to what is already known about the needs of this specific group of carers.</p>	<p>We agree that there is a considerable literature on MND, including carers' needs which quite often are presented thematically. However, we would suggest that the findings presented in the paper provide added dimensions to previous studies. The analysis presented not only provides a detailed account of the types of support needs carers have, but also new information on the types of supportive input which was helpful in their circumstances, and the study is wholly based on carers' own accounts of their support needs.</p> <p>We would hope therefore that the findings presented have the potential to be a useful resource to assist healthcare professionals in tailoring support provision to carers in the context of MND.</p>

Consistency is needed when referring to carers/caregivers to ensure it is clear that it is family carers that are being referred to.	We have added a clarification in the text of the manuscript to address this point.
Introduction	
Para 1- final sentence is rather convoluted and would benefit from being phrased more clearly.	This sentence has been revised.
There is brief reference to interventions for carers and the authors are correct that specific interventions for carers of people with MND are not only lacking but those used have limited effects. There is, however, no reference to the Carers' Alert Thermometer (CAT) which has been used to identify the needs of carers of people with MND (https://doi.org/10.12968/bjnn.2019.15.3.114).	<p>We have corrected the omission of reference to the use of CAT in MND in the introduction and provided a short summary of this work.</p> <p>Having reviewed again the CAT literature we feel that while the CAT provides a valuable contribution, it still leaves room within the literature and field of carer support for MND patients, for further interventions for carers of people with MND; specifically, one such as the CSNAT-MND which provides a full assessment.</p> <p>The new additions to our manuscript are based on our understanding of the CAT as described. We welcome further debate if we have misunderstood or misrepresented the CAT development and research to date.</p>
Furthermore, other recent publications addressing the needs of carers of people with MND are not cited either (see references at the end of the review).	We have reviewed the papers mentioned by the reviewer and have included additional citations in the paper.
No research question is provided but two objectives are included; 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; to make any adaptations to the existing CSNAT specifically to support family carers of people with MND	The two objectives make clear what the study sets out to achieve.
Methods:	
Reference to 'practitioners'- who were they? what was their involvement? I appreciate this aspect is intended as a separate paper but the text seems to suggest both carers	The focus of this paper is on the experiences of caregiving and the suitability and acceptability of the CSNAT domains to identify the

<p>and practitioners contributed to phase 1 & 2 so I would expect to see how they contributed in this paper.</p>	<p>support needs of carers of people with MND. Data on these areas were collected only from carers. Practitioners did take part in separate Stage 2 workshops about implementing the adapted CSNAT in their routine practice and so provided data on the implementation process. These workshops form part of the second paper on implementation in practice.</p> <p>This has been clarified in the manuscript.</p>
<p>A positive aspect to the design is the inclusion of both current and bereaved carers which allows caring across the full disease trajectory to be included.</p>	<p>No response required</p>
<p>The sample size is small but this can be a difficult group to engage in research because of the time commitment required for their caring duties which is known to average 11-15 hours a day.</p>	<p>No response required</p>
<p>The choice of focus groups for the main data collection could be justified.</p>	<p>This has been added to the methods section.</p>
<p>Some participants were interviewed individually rather than in a focus group- a comment on whether there was any difference in the findings between the two approaches would be helpful, given the lack of discussion with others for those interviewed separately.</p>	<p>This has been addressed in the paper.</p>
<p>Research ethics:</p>	
<p>More information about how research ethics and governance principles were adhered to during the study is needed e.g. support for participants, confidentiality, data protection etc.</p>	<p>The research team employed a Distress Protocol which was reviewed and taken to each FG/interview. This provided clear guidance on different levels of distress and how these should be managed and also included details of contacts for support at each of the data collection sites. Additionally, the MND Study FG checklist provided to team members ensured that</p> <ul style="list-style-type: none"> • Participants were telephoned the day before the FG/interview to check they still wished to attend • Support contacts were called to ensure they were on duty and available on the day of the FG/interview

	<ul style="list-style-type: none"> • Participants were welcomed as they arrived at the venue and offered refreshments • Participants had already read the study information sheet and were given the opportunity to ask questions before signing a consent form • Participants were given a contact card if they wished to get in touch with the research team • One of the facilitators was identified to help any carer who became upset including offering to leave the room with them and returning only if the carer wished to do so • The introduction to the session by main facilitator recognised the sensitivity of the discussion and assured participants that they could take a break, leave the session and withdraw at any time if they so wished. The confidential nature of the discussion was reiterated. • At the end of the discussion session, the facilitators checked on whether any participants upset and that they had contact details for further support if needed. There was a period of after the 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. <p>The manuscript has been updated to reflect this support.</p>
Findings:	
<p>The findings are presented under three main headings which map onto the objectives presented earlier. Verbatim quotations are presented to support the findings. The identifiers used are very impersonal and don't give any sense of the participant's context and whether they were a current or bereaved carer. Previous research has indicated that the length of time caregiving can impact on the caregiving experience. It would be helpful to know whether the carers quoted have had some years of experience or</p>	<p>We have added a sentence to clarify that the identifiers used do indicate whether the respondents were bereaved or current carers, which was the main distinction in carer context in this sample. To improve</p>

<p>are carers of people more recently diagnosed. This type of analysis may provide new insight into caregiving.</p>	<p>clarity we have moved these indicator letters to the start of each code.</p> <p>The majority of participants had been caring for 1-4 years. Only four carers (1 current, three bereaved) were caring for less than one year (4-11 months). Given the qualitative nature of the study and sample size from which it is difficult to draw any inferences, we have summarised the caregiving information in Tables 2 and 3 rather than provide further detail for each carer quote.</p>
<p>The first part of the findings reports on the experience of caring for a family member with MND and generally reiterates what has been reported elsewhere. The second part of the findings focuses on carers' support needs (both met and unmet) and supportive input required to meet those needs as they relate to the existing CSNAT 'direct' and 'enabling' domains. An additional domain, on managing relationships, was found to be needed. The CSNAT could therefore provide a practical means of identifying and helping to address areas of support arising from caring for a family member with MND.</p>	<p>No response required</p>
<p>The claim, in both the abstract and the implications for practice that 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' is not substantiated by the data presented. Without data from its use in clinical practice there is no way of knowing how appropriate or relevant it is in that setting.</p>	<p>The wording of the abstract and implications for practice has been revised.</p>
<p>P8 line 18 additional 'that' at start of the line.</p>	<p>Corrected on the manuscript</p>
<p>P13 line 18 'studies' should be 'study'</p>	<p>Corrected on the manuscript</p>
<p>A number of recent publications focusing on carers of people with MND were not cited e.g. Holkham & Soundy The experience of informal caregivers of patients with motor neurone disease: A thematic synthesis Palliative and Supportive Care (2018), 16, 487–496. Gluyas et al Factors to consider for motor neurone disease carer intervention research: A narrative literature review Palliative and Supportive Care (2017), 15, 600–608. Harris et al Supporting wellbeing in motor neurone disease for patients, carers, social networks, and health professionals: A scoping review and synthesis Palliative and Supportive Care (2018), 16, 228–237. Lerum et al Family caregivers' accounts of caring for a family member with motor neurone disease in Norway: a qualitative study BMC Palliative Care (2016) 15:22</p>	<p>See response above</p>

Reviewer #2	
It was a pleasure to read this manuscript. I have only minor comments to make:	Thank you for this positive comment
Several abbreviations were used without explanation; the authors may wish to consider including the full term at the first mention: PPI, MNDA (p.7) PLS, PMA (Tables 2 and 3, pp.16-17) DN (Table 4, p.18) OTs, HCPs (Table 5, p.22) PEG/RIG (Table 5, p.23) DNR (Table 5, p.25)	These abbreviations have now been updated in manuscript
In the Findings section, it would be helpful to number the section 1 and 3 headings as for the section 2 heading, for consistency: (1) The context of caregiving in MND (p.7) (3) An additional domain of support needs in MND (p.10)	This has been corrected.
There seems to be a typo in first line of paragraph under the 'Enabling' domains heading (p.9): "...to enable them to carer for the person..." It would make more sense if this read: "...to enable them to care for the person..."	This has been corrected.
On p.18, it would make sense to delete "provided" from the explanatory sentence under the Table 4 title, given that the column 2 heading identifies supportive input (received or needed) – if some kinds of support were needed rather than received, this implies they weren't provided.	This has been corrected.

VERSION 2 – REVIEW

REVIEWER	Mary O'Brien Edge Hill University UK
REVIEW RETURNED	21-Aug-2020
GENERAL COMMENTS	Thank you for responding to my feedback. I am happy with the responses. I enjoyed reading about the work you have undertaken.