

Original Article

# Neuropalliative Care Needs Checklist for Motor Neuron Disease and Parkinson's Disease: A Biopsychosocial Approach

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## ABSTRACT

**Objectives:** Neurodegenerative disorders necessitate comprehensive palliative care due to their progressive and irreversible nature. Limited studies have explored the comprehensive assessment needs of this population. This present study is designed to develop a checklist for evaluating the palliative care needs of individuals with motor neuron disease (MND) and Parkinson's disease (PD).

**Materials and Methods:** The checklist was created through an extensive literature review and discussions with stakeholders in neuropalliative. Feedback from six field experts led to the finalisation of the checklist, which comprised 53 items addressing the unique biopsychosocial needs of MND and PD. Sixty patient-caregiver dyads receiving treatment in a tertiary referral care centre for neurology in south India completed the checklist.

**Results:** People with MND had more identified needs with speech, swallowing, and communication, while people with PD reported needs in managing tremors, reduced movements, and subjective feelings of stiffness. People denying the severity of the illness was found to be a major psychosocial issue. The checklist addresses the dearth of specific tools for assessing palliative care needs in neurodegenerative disorders, particularly MND and PD. By incorporating disease-specific and generic items, the checklist offers a broad assessment of patients' multidimensional needs.

**Conclusion:** This study contributes to the area of neuropalliative care by developing the neuropalliative care needs checklist (NPCNC) as a valuable tool for assessing the needs of individuals with neurodegenerative diseases. Future research should focus on refining and validating the NPCNC with larger and more diverse groups, applicability in different contexts, and investigating its sensitivity to changes over time.

**Keywords:** Checklist, Motor neuron disease, Neurodegenerative disorders, Palliative care needs, Parkinson's disease

## INTRODUCTION

Neurodegenerative disorders constitute a collection of progressive and irreversible conditions of the nervous system that eventually lead to dysfunction and death. As this group of diseases has a debilitating course and is fatal, the management needs to include a palliative care approach.<sup>[1]</sup> Palliative care is a comprehensive approach offered to individuals grappling with illnesses that impose limitations on life, along with their families.<sup>[2]</sup> Providing care for individuals afflicted by neurological disorders is intricate and demanding for patients, their caregivers, and the healthcare professionals engaged in their treatment.<sup>[3]</sup> Since the care demands are multifaceted and complex, it is

crucial that patients with life-limiting conditions have access to specialised services. The European Academy of Neurology and the European Association for Palliative Care stressed that, depending on the underlying illness, neuropalliative care must be implemented in the early stages of disease progression.<sup>[4]</sup> The need for neuropalliative care has been well recognised in motor neuron disease (MND) and Parkinson's disease (PD).<sup>[5-9]</sup>

In cases of progressive neurological conditions, access to specialised palliative care services is often limited.<sup>[10]</sup> The importance of adopting a biopsychosocial approach in neuropalliative care in routine practice has been discussed in previous studies.<sup>[2,11]</sup> The existing literature also

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indicates that there is limited understanding of the palliative care requirements for individuals with neurodegenerative conditions.<sup>[12]</sup> The specific tools for MND or PD do not evaluate the palliative care needs; hence, for assessing the palliative care aspects in these conditions, other general tools are used. One challenge that exists in instituting optimum neuropalliative care is the limited understanding of when the transition to palliative care should take place in neurodegenerative disorders. There is a need for a targeted, easy-to-administer tool to identify specific areas that require immediate palliative care support.

The available tools used to assess the palliative care aspects of people with neurodegenerative disorders include the Cambridge Palliative Audit Schedule (CAMPAS-R),<sup>[13]</sup> Edmonton Symptom Assessment System (ESAS),<sup>[14]</sup> Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC),<sup>[15]</sup> Functional Assessment of Chronic Illness Therapy-Palliative subscale (FACIT-Pal),<sup>[16]</sup> Palliative Care Outcome Scale (POS),<sup>[17]</sup> Palliative Performance Scale (PPS),<sup>[18]</sup>

The illness-specific tools to assess Motor Neuron Disease (MND) include the Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFERS),<sup>[19]</sup> Amyotrophic Lateral Sclerosis Severity Scale (ALS-SS),<sup>[20]</sup> ALS Specific Quality of Life-Revised (ALSSQOL-R),<sup>[21]</sup> Edinburgh Cognitive and Behavioural ALS Screen (ECAS),<sup>[22]</sup> Emotional Lability Questionnaire,<sup>[23]</sup> Motor Neuron Disease Dyspnea Rating Scale,<sup>[24]</sup> MND-specific Quality of Life instrument (ALSAQ-40).<sup>[25]</sup>

For Parkinson's Disease (PD), the specific assessment tools are Hoehn and Yahr Scale (HY),<sup>[26]</sup> MDS-Unified Parkinson's Disease Rating Scale (MDS-UPDRS),<sup>[27]</sup> Non-Motor Symptoms Questionnaire (NMSQ),<sup>[28]</sup> Parkinson's Disease Questionnaire (PDQ-39),<sup>[29]</sup> Parkinson's Fatigue Scale (PFS-16),<sup>[30]</sup> Parkinson's Disease Sleep Scale (PDSS).<sup>[31]</sup>

Given the multidimensional nature of neurodegenerative disorders and the need for holistic care, a blend of disease-specific as well as generic scales is at present being used to understand the varied needs. The current paper describes the development of a checklist to recognise the palliative care needs of people with neurodegenerative disease, with special reference to MND and PD within a biopsychosocial framework.<sup>[11]</sup>

## MATERIALS AND METHODS

### Checklist development

Checklists are used as a tool in clinical settings to enhance the standard of patient care and to minimise medical error, especially during taxing conditions when retention, vigilance, and cognitive functions are affected.<sup>[32]</sup> The process of developing the checklist<sup>[33]</sup> to identify the palliative care needs in MND and PD, neuropalliative care needs checklist (NPCNC), is given below.

### Step 1: Development of a draft checklist

A thorough review literature was undertaken to formulate a comprehensive topic guide for organising Key Informant Interviews (KIIs) and focus group discussions (FGDs), along with the creation of a corresponding checklist. Various databases (including MEDLINE through PubMed, Psych INFO, Google Scholar, PILOTS, Cochrane Database of Systematic Reviews, and grey literature) were examined to gather insights into palliative care needs in neurodegenerative conditions. The study search was limited to publications written in English, with a focus on recent studies.

After conducting the literature review, the opinions of field experts were sought to identify the areas to be explored. Based on their input, an interview guide was developed to elicit detailed and comprehensive responses. Individuals with experience in palliative care were selected for face-to-face, in-depth interviews. In addition, patients capable of expressing their palliative care needs were recruited for in-depth interviews as well. To acquire an understanding of caregivers' viewpoints on palliative care requirements, three separate group discussions were organised, each involving a total of eight participants.

The data acquired from the KIIs and FGDs underwent a process of thematic analysis.<sup>[34]</sup> Initially, the interview transcripts were thoroughly read to become acquainted with the data. Following this, initial codes were assigned and differentiated using different colour codes. Potential themes were then identified by conducting a card-sorting exercise based on these codes. The recognised themes underwent a review process, leading to the creation of a thematic map that visually depicted the interconnections among these various themes. A draft checklist of items was generated from the emerging themes.

### Step 2: Review rounds

The formulated checklist was printed and distributed among a panel of experts. They were directed to assess each item on the checklist using a 4-point ordinal scale: 4 (Highly relevant), 3 (Considerably relevant), 2 (Moderately relevant), and 1 (Not relevant at all). In addition, the experts provided feedback regarding the clarity of the items, potential redundancies, and suggestions for improving the phrasing. Furthermore, an open card sorting technique was implemented to extract the categories for the created items. To determine the acceptability of the items, the researcher utilised the average congruency percentage (ACP) formula.<sup>[35]</sup> It was deemed that an ACP of 90% or above was regarded as an acceptable standard.<sup>[36]</sup> Utilising the input received from subjective feedback and item evaluations, the definitive edition of the checklist items was crafted.

### Step 3: Design of the final checklist and pilot testing

After reviewing the feedback, the researcher incorporated the suggestions and reworked the items that were ambiguously

formulated. The researcher obtained statistical consultation for following a Dichotomous scales response pattern. The pilot test was conducted with 30 patients to evaluate the effectiveness and suitability of the palliative care needs checklist in evaluating patients' perceived needs across various domains. The objective was to determine if the checklist was a valuable tool for identifying the specific assistance required by patients in different areas of palliative care.

#### Step 4: Final review round

The final checklist was reviewed by the same experts who did the initial review of the checklist.

#### Step 5: Item weighting

The internal consistency of the items was measured, which denoted for the overall reliability. The results indicated a good level of internal consistency for this checklist.

#### Participants and setting

The finalised checklist was administered among 60 patient-caregiver dyads with the diagnosis of MND and PD. These participants were undergoing treatment at a nationally recognised referral care centre specialising in neurological disorders located in Southern India. Participants were recruited from the in-patient and out-patient services, diagnosed with MND by El Escorial Criteria and PD by United Kingdom PD brain bank criteria. The researcher administered the checklist to elicit the physical, psychological, and social needs of the participants after building rapport with them for a few sessions. It took almost 20–35 min for participants to complete a 53-item checklist. A post-administration debriefing was conducted to explore participants' experiences and impressions of the checklist.

#### Ethics statement

This study obtained ethical approval from the Institute Review Board. Participants were given a detailed overview of the study's purpose and nature, and their participation was contingent on obtaining written consent from each individual before their engagement in the study.

## RESULTS

### Step 1: Development of a draft checklist

A preliminary checklist consisting of 50 items was developed using a scientific methodology to capture perspectives on palliative care needs in neurodegenerative conditions. This process involved the collaboration of three authors.

### Step 2: Review rounds by experts

The developed checklist was given to a team of six experts, including two neurologists, two clinical psychologists, and two psychiatric social workers. These experts were chosen due to their expertise in the field of neuropalliative care, with a minimum of 2 years' experience. Throughout the

review iterations, the experts offered feedback, proposing the inclusion of five items, the removal of two items, and the revision of three items. Ultimately, the final checklist contained 53 items. The open card sorting method was utilised to identify two domains: Physical and psychosocial.

### Step 3: Design of the final checklist and pilot testing

The final 53-item checklist was administered to two groups of patients: 15 individuals with MND and 15 individuals with PD. The patients' feedback on the palliative care needs checklist was highly satisfactory, indicating that it was well-received and easily understood. Patients expressed that the checklist was a valuable tool for expressing their perceived needs across various domains of palliative care. This positive feedback suggests that the checklist effectively captured and assessed the specific assistance required by patients in different areas of palliative care.

### Step 4: Final review round

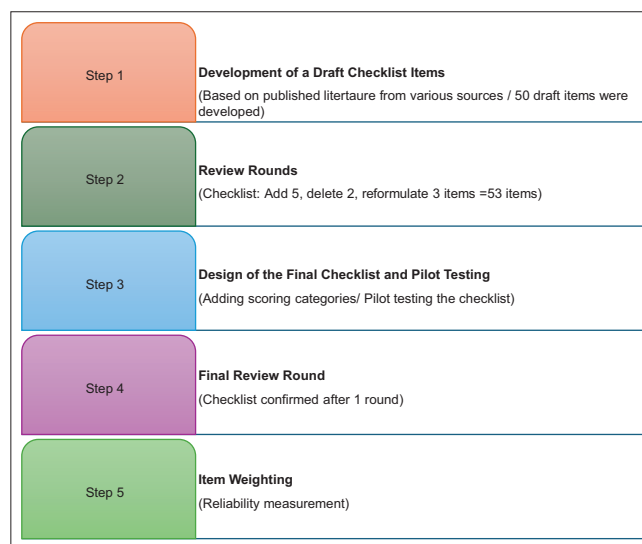
All six experts concurred with the adjustments made in phrasing and content, as outlined in Step 3.

### Step 5: Item weighting

Cronbach's alpha was utilised to evaluate the internal consistency of the items on the checklist, yielding a value of 0.80. This value suggests a good level of internal consistency for the checklist. Figure 1 explains the five steps<sup>[33]</sup> used to develop the checklist.

#### Sociodemographic profile

The sociodemographic characteristics of the study's participants revealed that within the MND group, 76.7% were male, and 23.3% were female. In the PD group, 60% of the patients were male. Additional sociodemographic profiles and further details can be found in a separate publication.<sup>[9]</sup>



**Figure 1:** The five steps<sup>[33]</sup> used to develop neuropalliative care needs checklist NPCNC.

**Table 1:** Neuropalliative care needs checklist.

Items	Yes	No
<b>Physical needs (illness-specific-MND)</b>		
1. I experience trouble while sleeping	34 (56.7)	26 (43.3)
2. I find it difficult to control my excessive drooling	40 (66.7)	20 (33.3)
3. At times, I require medicines to cope with my musculoskeletal pain	28 (46.7)	32 (53.3)
4. I feel weakness and wasting of the muscles and my body parts	53 (88.3)	7 (11.7)
5. I suffer from muscle cramps	54 (90)	6 (10)
6. The moment I start to speak, the speech goes slurred or unclear to others	58 (96.7)	2 (3.3)
7. I lost weight a lot because I was not able to have food	30 (50)	30 (50)
8. I feel weakness in my grip	33 (55)	27 (45)
9. I experience neck weakness	13 (21.7)	47 (78.3)
10. I am not able to communicate properly	55 (91.7)	5 (8.3)
11. I am not able to swallow or chew anything	57 (95)	3 (5)
12. I am often choking with whatever I eat or even with saliva	42 (70)	18 (30)
13. I feel shortness of breath and other respiratory issues	38 (63.3)	22 (36.7)
<b>Physical needs (illness specific-PD)</b>		
14. I find it difficult to control tremors	58 (96.7)	2 (3.3)
15. I experience slowing of movements	57 (95)	3 (5)
16. I feel loss of desire and dissatisfaction with my sexual life	49 (81.7)	11 (18.3)
17. I experience a jerking movement in my arm or leg while I rest	53 (88.3)	7 (11.7)
18. I experience stiffness and tension in the muscles	55 (91.7)	5 (8.3)
19. I have lost my sensory experiences, such as smell, taste, touch, sight, and hearing.	50 (83.3)	10 (16.7)
20. I have difficulty in blinking of eyes	38 (63.3)	22 (36.7)
21. I often feel excessive sweating	42 (70)	18 (30)
<b>Physical needs (generic –MND and PD)</b>		
22. I often experience a deep fatigue	55 (91.7)	5 (8.3)
23. I find difficulty with passing bowel motions	59 (98.3)	1 (1.7)
24. I am often at the risk of fall as I have weakness in my balance and posture	48 (80)	12 (20)
25. I feel difficulty with activities of daily living due to the stiffness of my muscles	45 (75)	15 (25)
26. I am not able to perform a normal walk to even a short distance	34 (56.7)	26 (43.3)
27. I experience problems with urination	58 (96.7)	2 (3.3)
28. I feel like my thinking and mental abilities are not as sharp as they used to be	28 (46.7)	32 (53.3)
29. I experience dizziness and fainting at times	53 (88.3)	7 (11.7)
30. I have constipation issues	43 (71.7)	17 (28.3)
31. I have back pain issues	15 (25)	45 (75)
<b>Psychosocial needs (Generic–MND and PD)</b>		
32. I feel sad all day	7 (11.7)	53 (88.3)
33. I often feel angry	44 (73.3)	16 (26.7)
34. I am afraid of having this illness	19 (31.7)	41 (68.3)
35. I get irritated when I think about why it happened to me	46 (76.7)	14 (23.3)
36. The fear of being dead always disturbs me	24 (40)	36 (60)
37. It is better to die rather than being alive in this situation	47 (78.3)	13 (21.7)
38. I have difficulty in thinking or speaking and poor awareness of what is going on	54 (90)	6 (10)
39. I have some unrealistic expectations about my health condition	30 (50)	30 (50)
40. I do not find any meaning in living further	53 (88.3)	7 (11.7)
41. I am not sure how the future of mine will be	42 (70)	18 (30)
42. I am afraid that I may reach a completely locked-in state	55 (91.7)	5 (8.3)
43. I feel guilty that my spouse/children are tied to home	44 (73.3)	16 (26.7)
44. I encounter so many interpersonal relationship issues	50 (83.3)	10 (16.7)
45. I find that people are not receptive to talk about my illness	54 (90)	6 (10)
46. I have not received any support from others	7 (11.7)	53 (88.3)
47. I feel that other people do not understand my condition	52 (86.7)	8 (13.3)
48. I do not have people to share my own experience	45 (75)	15 (25)
49. People deny the severity of my condition	56 (93.3)	4 (6.7)
50. I receive very little care from others	29 (48.3)	31 (51.7)

(Contd...)

**Table 1:** (Continued).

Items	Yes	No
51. I am unable to express my feelings about the disease to others	52 (86.7)	8 (13.3)
52. I feel that I am isolated due to illness	39 (65)	21 (35)
53. Unresolved conflict leading to compromise in my care	43 (71.7)	17 (28.3)

MND: Motor neuron disease, PD: Parkinson's disease

The developed checklist for identifying palliative care needs in neurodegenerative disorders encompassed both disease-specific and generic items within the physical domain. Similarly, the psychosocial domain consisted of generic items applicable to both conditions. This palliative care needs checklist was utilised to evaluate patients' perceived help required across each domain. A score of zero indicated the absence of a perceived need for assistance or minimal distress in those specific areas. Conversely, a score of ten indicated a high level of assistance needed or increased distress in those areas. Table 1 displays the final NPCNC used to evaluate the physical and psychosocial needs of 60 individuals with specific neurological conditions.

## DISCUSSION

The dearth of tools to categorise the palliative care needs among neurodegenerative diseases resulted in the development of neuropalliative care checklist for neurodegenerative disorders with a special focus on the physical and psychological illness-specific needs identification. Collaborating with individuals, families, and communities is crucial for delivering holistic palliative care services that enhance the quality of life. To provide any services, it is important to assess their needs, and for that, one needs a scientific instrument. The existing scale on palliative care evaluates the gradual deterioration in mobility, activity engagement, self-care capabilities, oral intake, and levels of consciousness, as well as the presence of depressive symptoms and the burden on caregivers. These instruments are employed for particular target populations within specific contexts. Therefore, there was a recognised need to create a checklist tailored to discern the palliative care requirements of individuals, with a distinct emphasis on two neurodegenerative conditions, namely, MND and PD, within the framework of Indian culture.

Research has demonstrated that neurological disorders are predominantly incurable, characterised by a restricted life expectancy<sup>[37]</sup>, and linked with pain, depression, and other symptomatic manifestations.<sup>[38]</sup> The symptoms that require relief as a person nears the end of life in these disorders need to be evaluated from a biopsychosocial framework with equal emphasis given to physical as well as psychosocial and other domains such as spiritual and cultural. Essentially, this care has to be multidisciplinary and involves different disciplines that contribute to the well-being of the affected individual and their families.

From the diagnosis of neurodegenerative conditions, patients and families are informed about the incurable nature and possible progressive deterioration. Existing literature underscores the recommendation for early referral to palliative care services, even from the point of diagnosis.<sup>[39]</sup> Nevertheless, considering the constrained availability of palliative care services in resource-limited low- and middle-income nations, it becomes imperative to establish certain explicit indicators that can facilitate the referral process for these essential services.<sup>[40]</sup> This necessitates the development of instruments that give clear indications about transition points to palliative care.

Unlike other medical conditions that may require palliative care interventions, except for MND, most neurodegenerative conditions have a prolonged course. Cognitive impairment, behavioural issues, and communication difficulties are commonly observed in progressive neurodegenerative conditions.<sup>[39]</sup> This highlights the need for palliative care assessment tools specifically designed for these neurological conditions. Since neurodegenerative conditions encompass a wide range of symptoms and illness courses, a generic indicator for palliative care services may not be applicable. Disease-specific rating scales and palliative outcome scales, supplemented by the checklist, are necessary to identify the specific areas that require support.

These implications highlight the significance of individualised and extensive palliative treatment for people with neurodegenerative illnesses. Developing and implementing appropriate assessment tools, such as the neuropalliative care checklist, can significantly elevate the quality of care provided to patients and their families grappling with these complex illnesses.

## Strength and limitations

This pioneering study represents the initial effort to develop a checklist catering to the unique palliative care needs of individuals with neurodegenerative diseases, specifically focusing on MND and PD. It has a solid foundation for future studies as it has limited generalizability due to the study's specific setting and small sample size. The checklist emphasises the essential aspects of palliative care through the biopsychosocial model. By considering additional domains such as spirituality, economics, culture, ethics, and legality, the checklist can be further strengthened. Further field testing and validation studies involving larger and more diverse samples are required to establish the psychometric properties

of the checklist. Finally, the lack of a longitudinal component hinders understanding the checklist's sensitivity to change over time and its ability to track evolving palliative care needs.

## CONCLUSION

The development of the neuropalliative care checklist for neurodegenerative conditions is a valuable contribution to the field of neuropalliative care. Existing assessment tools for palliative care in neurodegenerative disorders have limitations, and the NPCNC addresses the need for a comprehensive checklist that captures the multidimensional nature of these conditions. By focusing on both disease-specific and generic needs, the NPCNC provides a more holistic assessment of palliative care needs in MND and PD. With further testing and refinement, the NPCNC has the potential to enhance the provision of holistic and patient-centered care for individuals with these neurodegenerative disorders.

## Ethical approval

The study was part of the MPhil degree in Psychiatric Social Work. Ethical approval (No. NIMH/DO/IEC (Beh. Sc. Div)/ 2016) was received from the Institute Review Board of National Institute of Mental Health & Neuro Sciences (NIMHANS) in October 2016.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

## Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript, and no images were manipulated using AI.

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