


# Development of Guidelines for Spouses Engaged in Home-Based Care of Persons With Motor Neuron Disease From Indian Context

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## Abstract

**Background:** The caregivers of persons with motor neuron disease (MND) have several needs that are usually not voiced on any platform. **Aim:** To explore the lived experience of spouses of persons with MND, identify their needs and develop guidelines for better home-based care. **Method:** An exploratory study with 3-point in-depth interviews among 13 participants was conducted. Participants were the spouses of persons with MND under treatment at a national quaternary referral center. The interpretative phenomenological analysis identified participants' needs. These needs, with literature review synthesis, guided the drafting of guidelines, which was validated by experts. **Results:** The needs were emotional, social, care systems, and skills. The guidelines developed contained 2 sections (1) Information for the spouses: *understanding MND, communication, symptom management, marital relationship, palliative care, and everyday life made easier.* (2) Well-being of the spouse caregivers: *well-being of the spouse caregivers, self-care, mental health, supporting carers in palliative care, where to find help.* **Conclusion:** The guidelines can be developed as a manual for the caregivers and for training healthcare professionals working with neurodegenerative conditions.

## Keywords

guidelines, home-based care, interpretative phenomenological analysis, motor neuron disease, spouse caregivers

## Introduction

Motor neuron disease (MND), a chronic debilitating disease, with its progressive course and eventual locked-in state, has high support needs, as the illness progresses. Often, family members provide support in carrying out daily activities. The role of caregivers in MND from the diagnosis through different stages of the illness is widely represented in the literature across the globe. The positive and detrimental effects of caregiving on the caregivers (1–3), especially during the initial stages of symptom identification and diagnosis, the communication in the healthcare context (4,5), coping strategies employed and crisis management and decision-making at crucial stages of the illness (6) are well-documented. The literature states anxiety and psychological distress, depression, and burden felt by the caregivers (7–11). The needs felt by the family changes with the illness deterioration, and this affects the family's coping and adjustment (12). The beneficial effects from support groups, appropriate

information and training, and respite care are also well established (4,13).

In the context of informal caregiving, spouses form the majority among the caregivers. There exists published literature that exclusively looks at spouses' experiences of living with persons with MND (14), their psychological distress (15), marital satisfaction (16,17), sexuality (3) and their experiences during bereavement phase (13). It was found that these various experiences which spouse caregivers go through can

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be supported through dignity therapy interventions (18), intensive case management (19), and support programs based on acceptance and commitment therapy framework (20).

There are disease-specific treatment and care guidelines for patients with MND. Limited studies have reported need-based guidelines that can inform and support caregivers through the disease progression. Although there are sections on psychosocial aspects in the NICE guidelines for MND (21), it is not specific to spouse caregivers. For the efficacy of any intervention, the prevailing sociocultural and economic resources of the target of intervention need to be considered. Identifying the needs of the specific target group and formulating guidelines can be a crucial first step in planning interventions for the group. Thus, the current paper attempts to develop guidelines for spouse caregivers in a resource-limited context through identifying the needs of spouse caregivers of persons with MND. The guidelines aim to equip them with strategies to ensure appropriate care for their ill partner while ensuring their own well-being.

## Participants and Methods

### Participants

We had 3-point interviews across 5 months with 13 spouse caregivers of persons with MND, residing in Bangalore, who were receiving treatment at national quaternary referral care center for neurological disorders in South India. The sample size was determined by idiographic mode of inquiry as per interpretative phenomenological analysis (22) and hence with the meaning saturation by 10th participant, the recruitment was extended to 3 more. The ethical clearance was obtained from the Institute ethics board (No.NIMH/DO/IEC (BEH.sc.DIV)/ 2016, dated April 21, 2017). Patients with MND and their spouses were explained in detail about the study, and written informed consent was taken for the participation and researcher's home visit. The interviews were conducted at participant's house. Participants had their partners with MND in different stages of illness.

### Instruments

There was a separate interview guide for each of the 3-point in-depth interviews, which was developed by the research team through intensive literature review. These interview guides were validated by experts from the field of neurology, palliative medicine, psychology, and social work. The researcher used a life grid which allowed to get the diagrammatic chronology of participants' life. The rows in the diagram had years in participant's life and columns representing different areas in their life. Another major tool used in this study was the home visit and the observations made by the researcher. Observations were recorded in the reflective diary maintained by the researcher.

### Analysis

The in-depth interviews were audio-recorded and transcribed. The transcripts were subjected to interpretative phenomenological analysis (22–24). The analysis started with getting familiarized with the data, making exploratory codes, and then developing emergent themes from it. After this, table of themes were developed across 3-point interviews for one participant. Later, the research team moved to the analysis of transcription of the next participant. In the next step, analysis was done across the participants to identify the pattern of themes. Steps to ensure the rigor in qualitative research such as peer debriefing, supervisor's audit, and triangulation from home visit observations and reflective diary were done. From the themes derived, the needs of the participants were identified. The needs along with the literature review synthesis, guided in drafting the guidelines for spouses engaged in home-based care.

## Results

### Demographic Characteristics

Among the participants, there were 8 females and 5 males. Five of the participants lost their partners after the first interview. The further demographic details of the participants and brief clinical details of their partners are given in Table 1.

### Lived Experience of Spouses of Persons With MND

The essence of the phenomena of the lived experience of the spouses was understood as a "voyage," characterized by changes that are distinctive for caregiving in chronic illness. The major themes derived from the analysis were *Care as an all-consuming process, nearing the end of life, life after the loss, and scaffolding for care*. The theme scaffolding for care explored the needs of the participants.

### Scaffolding for Care

Throughout the sharing and interpretation of the lived experience of spouse caregivers, the research team was sensitive to the myriad of difficulties expressed and could cull out the needs in caregiving. Together, these themes could help in developing the scaffolds for care to the person with MND and also to support the journey as a caregiver. Some of these needs were explicitly articulated by the participants, whereas others were implicit in the journey shared by them, that described the experiences and difficulties faced as caregivers. In many instances, the felt needs were intricately linked to the context of caregiving, influenced by social norms, socioeconomic status, availability, and accessibility to health and social care systems. Needs identified can be classified as *emotional, social, system-related, and skills*.

Emotional caregiving was identified to be more strenuous than physical caregiving. *Emotional support, need for*

**Table 1.** Sociodemographic Profile of the Participants and Illness Status of Persons With MND.

Sl. No	Gender	Age	Religion	Education	Occupation	No: of years of marriage	No: of members in family	Status of pwMND during initial interview	Status of pwMND after 5 months
1	Female	33	Hindu	B Tech	Play school teacher	11	4 (couple and 2 school going children)	Working, needs some support in ADL	Working, needs more assistance
2	Female	36	Hindu	Primary	Homemaker	20	4 (couple and 2 adolescent children)	Wheelchair bound, Fully dependent	Passed away
3	Male	55	Christian	Graduate	Freelancer	26	3 (couple and a son who is working)	Partially dependent	More support needed (wheelchair bound)
4	Female	37	Christian	Graduate	Tuitions	12	5 (couple and 2 school going girls, a baby girl)	Fully dependent (wheelchair bound)	Passed away
5	Male	63	Muslim	Secondary	Not working	39	5 (couple and 2 college going girls, a working son)	Fully dependent (Bed-bound)	Fully dependent, (Bed-bound)
6	Female	48	Hindu	Primary	Caretaker in day care	30	3 (couple and a working daughter)	Partially dependent	Passed away
7	Male	68	Muslim	Secondary	Ret. Police constable	38	3 (couple and a working daughter)	Fully dependent (Bed-bound)	Fully dependent (Bed-bound)
8	Male	64	Hindu	PhD	Ret. Professor	32	4 (couple and in-laws)	Independent (Bulbar symptoms)	Passed away
9	Female	52	Hindu	Primary	Home maker	36	10 (couple, relatives)	Partially dependent	Passed away
10	Female	52	Hindu	Primary	Homemaker	39	5(couple, son and family)	Working, Needs some support	Stopped Working. Needs more support
11	Female	45	Hindu	Primary	Fruit vendor	32	5 (couple and 3 children)	Fully dependent	Fully dependent
12	Female	55	Hindu	Illiterate	Homemaker	39	7 (couple, son and his family, 2 unmarried sons)	Independent. Working (Bulbar symptoms)	Independent. Working (Bulbar symptoms)
13	Male	47	Hindu	Secondary	Bus conductor	23	4 (couple and 2 children)	Working, Some support needed	Working, Some support needed

Abbreviations: ADL-activities of daily living; MND-motor neuron disease; pwMND-persons with MND; PhD- Doctor of Philosophy.

*validation, and bereavement support* was identified as major perceived needs for continuing the role as caregivers. The journey of a spouse across the illness trajectory, from symptom onset to death and post death, is extremely challenging. They experience these emotional needs throughout their journey. The following excerpts from the interviews highlight the emotional changes that the spouse caregivers have reported.

Sometimes I feel like crying a lot. But I will not cry (216-262)  
I have so many things in heart(.) I want to blast one second and I want to cry (268-269, P1. Female, Interview 2).

I get angry for minor things. I do not cry, get angrier, and scolds even on minor issues (37-39, P5. Male, Interview 2).

I used to think that... whether all these causes mental pressure for me. It is affecting me psychologically (256-257, P7. Male, Interview 2)

Many of the spouses wished to have a *better social life* and they constantly try to live a near-normal life. They wish for *normalisation of their routine*. They also wish for better mainstreaming opportunities for their partner. Spouse caregivers shared the changes in their routine due to the caregiving and their felt

need to be part of a routine, as shown in the following excerpts.

Nowadays, I am feeling bad about him. This thing I did not tell you ... in our apartment our age only, ladies are mingling like this. And gents are also, every week they are playing cricket or shuttle. There were almost all of them. All gather there and will be playing. But he is not going. I am feeling bad... if he is able to go and he is able to play know, he will also be like them only. He will also play, and he will also enjoy, and he will be of fresh mind. Because of this only he is not going... (665-673, P1. Female, Interview 3).

We go to church and come. We went to a movie. Last Sunday we went. We parked inside the entrance (129-130, P3. Male, Interview 2).

As the occupational functioning of most of the persons with MND as well as the spouse is impaired with the progression of illness; and the financial constraints incurred due to catastrophic health expenses, many of them are pushed toward financial debt. Hence, they keep looking for *financial assistance* to get support to continue their life with caregiving responsibilities. Participants shared their financial constraints that make them struggle to provide care as depicted in the following excerpts.

Support is not there. That is why we are like this. We would have been better if there is some support know. Do not even have 1 rupee support from anyone. That is why even if it is difficult, somehow managing to open this stall and being here. My son still studying. This girl started going as home maid recently. She will bring some 4000 per month. That is sufficient only for paying house rent (56-61, P11. Female, Interview 1).

Is there someone who will help? Person or organization, who are willing to help children who lost their father? (275-276, P2. Female, Interview 2).

The spouse caregivers felt that *sensitive healthcare interaction* is crucial in optimum care. Several dimensions of healthcare interaction and communication needs were highlighted, as shown in the following excerpts:

Very patiently he was talking to us. That is what we want from doctors... (905-906, P1. Female, Interview1)

Doctor did not tell anything, doctor talks in Kannada (local language) also. When they speak in English, I will not understand (. (106-107) they said we are doing whatever possible ma'am, can't give any guarantee (111-112) I was upset hearing that ma'am. Even now I am upset of it (116. P 10. Female, Interview 1).

what they said(.) there is some problem in brain, a clotting(.) blood clotting. That will be cleared and asked to continue

some medication and it will be cleared (17-19, P7. Interview1).

Participants expect healthcare professionals to spend adequate time with them and set the stage before revealing the diagnosis. They prefer the process of communicating the bad news in a gentle, but realistic way while instilling some amount of hope.

Repeated hospital visits were increasingly difficult as disease progressed. Often, when crisis arises, such as respiratory distress or other emergencies, spouses find it difficult to get their local hospital to help. They also felt a *need to have a contact person*, who they can rely on to get suggestions and help during emergencies.

we tried in many hospitals. This hospital was at least willing to admit. First, they were also not willing to admit. We got through recommendation of MLA (236-238, P2. Female, Interview 2).

It is always good to be registered in a hospital. If anything happens otherwise, it is very difficult to sort out things (89-92, P4. Female, Interview 1).

As the disease progressed, more and more acute events such as choking occurred. The caregivers were helpless in handling crisis due to medical emergencies. Guidance *for handling emergencies* was significantly felt at times. The caregivers expressed their helplessness in responding to the emergencies and the emotions of the affected partner in their sharing, as depicted in the following excerpts.

now breathing is difficult. It will be there for the entire day.... (605-606) cannot see him facing trouble in breathing..... (611) last night 10 pm similar thing happened (615, P2. Female, Interview 1).

Another major concern for the participants is *managing the emotional issues* of their partners, such as anger. They are not able to understand anger as a means for communication of distress. Often, they treat anger as a psychological issue that needs professional intervention.

she need only suggestions to control anger. Anger is only problem which we cannot control (349-350, P8. Interview 1) Compared to her earlier self, ya, now, after getting this problem, getting too much angry, throwing things and all (234-235, P8. Male, Interview 1).

She due to her anger (she)denies(refuses to have) having food (46-47, P7. Male, Interview 2).

## Guidelines for Spouse Caregivers of Persons With MND

From the needs identified and the synthesis of literature on the same, guidelines for the spouses engaged in home-based care of the persons with MND were developed. The guidelines are based on the therapeutic framework of cognitive behavioral and supportive psychotherapy. Both the modules integrate and synergize psychotherapeutic and educational interventions. It has a holistic and competence-based approach, stressing health, collaboration, coping, and empowerment of the spouse caregivers.

The guidelines included specific issues and the ways to handle them with case excerpts and the synthesis of a review of existing guidelines. The guidelines contained 2 sections-

1. Guidelines to equip the spouses of persons with MND for care

This part of the guidelines focused mainly on practical skills and knowledge to provide better care for person with MND in the home context. It included information about the illness, transition in different stages of illness, the care needs at each stage of the illness, immediate care, crisis intervention,

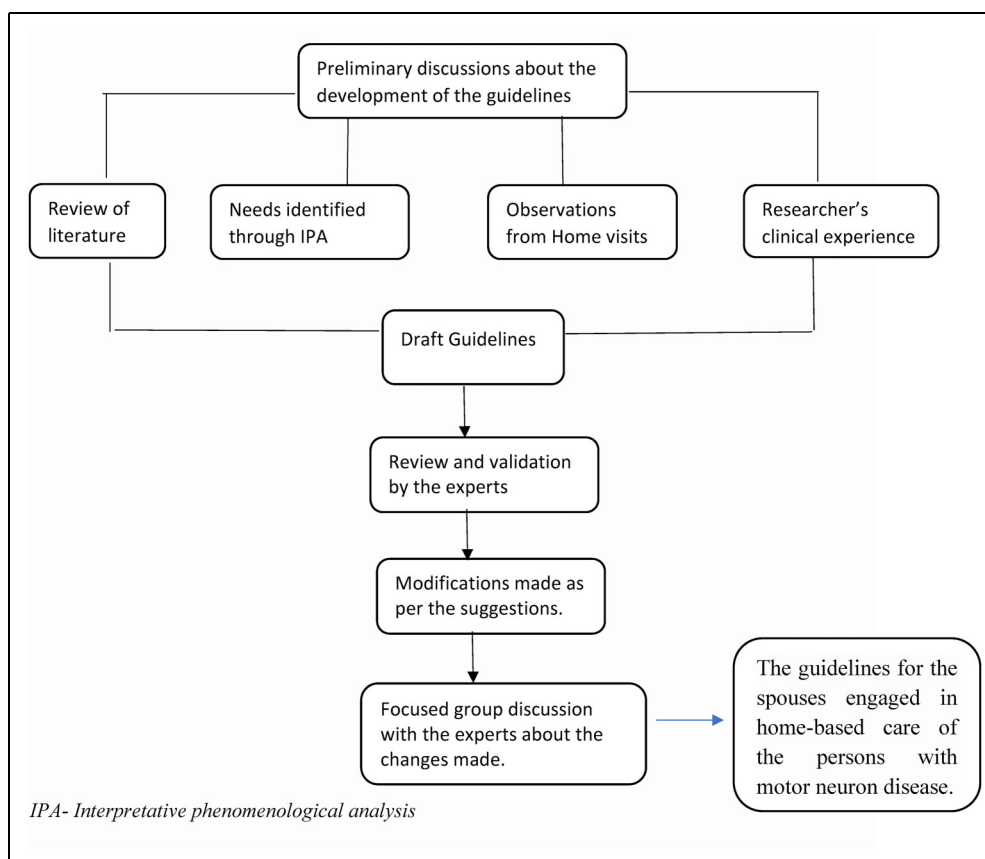
environment modification, and assistive devices and networking.

2. Guidelines to ensure the well-being of the spouse caregivers

In this part, caregiver's well-being is focused. This includes self-care, mental health, supportive counseling, initiating discussion about advance care planning, and guidance to find help.

Each module of the guideline was enriched by researcher's observations made during home visit. The specific strategies used in caring for the person with MND, ensured that the resources are customized according to the difficulties of persons with MND. This approach aided the transfer of this information in the form of practical symptom management strategies. The contents of the guidelines were also strengthened by research team's clinical experience of working with persons with MND and their families. The guidelines are aimed to ensure better care for the person with MND as well as the quality of life of the caregivers. The process of development of the guidelines is depicted in Figure 1.

The draft was validated by the experts from neurology, palliative medicine, psychiatric social work and nursing. The experts validated the guidelines in 4 domains on a Likert scale of 1 to 5, 1 being strongly disagree and 5 being strongly agree. There was space provided to mention



**Figure 1.** Process of development of the guidelines for the spouses engaged in home-based care of the persons with motor neuron disease.

**Table 2.** Suggestions Given by the Experts Who Validated the Guideline.

Sl No	Expert	Item	Response (1-5) 1 = strongly disagree 5 = strongly agree	Suggestions
1	Neurologist 1	The contents are adequate	5	Psychosocial factors
		The contents represent and address all psychosocial needs of MND caregivers	5	
		Guidelines clearly spell out things that would aid clinical practice	5	
		The contents are comprehensive	5	
		Any other inputs	Some spelling and grammatic errors in the guidelines to be corrected.	
2	Neurologist 2	The contents are adequate	5	
		The contents represent and address all psychosocial needs of MND caregivers	5	
		Guidelines clearly spell out things that would aid clinical practice	5	
		The contents are comprehensive	5	
		Any other inputs	Nil	
3	Palliative physician	The contents are adequate	5	Include addressing uncertainty
		The contents represent and address all psychosocial needs of MND caregivers	5	
		Guidelines clearly spell out things that would aid clinical practice	5	
		The contents are comprehensive	5	
		Any other inputs	Nil	
4	PSW 1	The contents are adequate	4	Include tips to address caregiver burden, self-assessment of anxiety and depressive symptoms
		The contents represent and address all psychosocial needs of MND caregivers	5	
		Guidelines clearly spell out things that would aid clinical practice	5	
		The contents are comprehensive	5	
		Any other inputs	Emotional health and stress management can be combined. Add mental health as a separate domain in both the modules	
5	PSW2	The contents are adequate	5	Chapter 4- marital relationship, adaptation need to be emphasized.
		The contents represent and address all psychosocial needs of MND caregivers	5	
		Guidelines clearly spell out things that would aid clinical practice	5	
		The contents are comprehensive	5	
		Any other inputs	Rephrase some of the sentences like “will be benefited” to “might be benefited”	
6	Nurse	The contents are adequate	5	
		The contents represent and address all psychosocial needs of MND caregivers	5	
		Guidelines clearly spell out things that would aid clinical practice	5	
		The contents are comprehensive	5	
		Any other inputs	May have to orient people at early stages of the disease that these contents may be useful in future.	

Abbreviations: MND-motor neuron disease; PSW-psychiatric social workers.

**Table 3.** Content of the Guidelines for the Spouses Engaged in Home-Based Care of the Persons With Motor Neuron Disease.

<b>Module 1: Guidelines to equip the spouses of persons with motor neuron disease for care</b>			
Sl No	Title	Objectives	Content
1	Understanding MND	Assess patient and family knowledge about illness. Clarifying the myths and misconceptions, educating about facts on the course and prognosis and management strategies Long term management	Facts about MND, classification, clinical signs and symptoms, management of MND
2	Communication	How to improve illness communication to the person with MND and family Tips to enhance communication within the family, between the couple and significant others. Clear communication about the advance care plan	Different guidelines to be followed by healthcare professionals in communicating to person with MND and family about illness, course, and prognosis. Tips to enhance communication within the family. Clear communication about advance care planning.
3	Symptom Management	The common symptoms at different stages of illness—muscle problems, speech difficulties, swallowing difficulties, excess saliva, uncontrollable laughing or crying, breathing difficulties, mental health issues. Discussion about the non-pharmacological management strategies	Nonpharmacological management of symptoms like muscle spasms, speech difficulties, swallowing difficulties, sialorrhea, uncontrollable laughing or crying, breathing difficulties, mental health issues.
4	Marital relationship	Changes in marital relationship among the persons with MND and spouses Strategies to enhance the quality of marital relationship of persons with MND-spouse dyad.	Steps to enhance marital relationship, realignment to be made in couple relationship, how to adapt to the changes posed by symptoms of the illness.
5	Palliative care	MND and Palliatives Care Educating family on Palliative Care Issues unique to palliative care in MND in Indian Context Steps to ensure better care for persons with MND.	Educating family on palliative care, issues unique to palliative care in MND in Indian context. Steps to ensure better care for persons with MND.
6	Everyday life made easier	Challenges in everyday life due to symptom deterioration Assistive devices to make the life of MND patients easier.	Information on some assistive tools which can benefit persons.
<b>Module 2: Guidelines to ensure well-being of the spouse caregivers</b>			
1	Well-being of spouse caregivers	What is Well-being? Why is the spouses'/caregiver's well-being important?	Explanation about well-being, the need of focusing on well-being. Physical and emotional well-being.
2	Self-care	Why self-care? How to improve self-care	Explanation about self-care. Steps to improve self-care, identifying personal barriers to self-care.
3	Mental health	Signs of being stressed out, burn-out and Strategies to deal. Identifying mental health issues and self-management strategies Orientation on help-seeking	Physiological and psychological signs associated with stress, burn out and psychosocial strategies for addressing those. Early warning signs and self-identification of mental health issues like depression and anxiety and behavioral management strategies to

(continued)

**Table 3.** (continued)**Module I: Guidelines to equip the spouses of persons with motor neuron disease for care**

Sl No	Title	Objectives	Content
4	Supporting carers' during neuropalliative care	Challenges for the Caregivers offering palliative care Support for the caregivers for effective neuropalliative care	address those. Detailed orientation on advantages of help seeking and when to seek help. Possible ways of addressing caregivers' challenges- ways to handle uncertainty, emotional coping strategies, bereavement support.
5	Where to find help	How to get recent updates on MND and various care strategies? Where to find help for practical aspects of care? How to get support?	Details about Governmental and non-governmental agencies providing care and support to persons with MND and their families. Details on social networking sites, palliative care agencies, home care teams that work for persons with MND and their families.

Abbreviation: MND-motor neuron disease.

any other comments in each of these domains and other areas which were not covered in the validation schedule. Table 2 describes the suggestion given by the experts while validating the guidelines. The draft was modified according to the suggestions of the experts and final guidelines were prepared. This was presented to the experts in a focused group discussion and approved by them. The details of the guidelines are given in Table 3.

## Discussion and Conclusion

The current study aimed at exploring the lived experience of spouses of persons with MND and developing guidelines to facilitate better home-based care for persons with MND. Spouses needed specific support as they go forward in their journey of caregiving. Some of these were explicitly told by the spouses during the interviews, whereas some are interpreted from the narrations of the participants. The needs identified were classified as emotional, social, system-related, and skills. More than the physical demands of caregiving, the need for validation and bereavement support are found as major emotional needs. Hence, the guidelines may require adequate validation (25) and demonstrate support in these areas (26). The mixed emotions of anger, grief, guilt, and a sense of relief of the spouse after the death of the partner can be managed with appropriate bereavement support (4,7). They also get benefited from specific therapeutic interventions (13,18,20,27,28). Supportive palliative care interventions from the beginning of treatment ensure the emotional support for the spouse caregivers (29,30).

Increased caregiving needs with the progression of illness affects the social life of the person with MND. Financial

needs are easily articulated by many participants as most of the participants in the present study were from lower socio-economic background (31). The participants expressed the need to mainstream the person with MND, having a better social life and making their life to near normal (32,33). Need for respite are not much verbalized but latent in participants' narrations (4,13). Timely provision of adequate information from reliable sources is a need mentioned by most of the participants. They have expectations of being provided realistic information and sensitive communication of the news of diagnosis to them (4–6,13) and they wish that the healthcare professionals be trained on the same (29). The participants require guidance in terminal stage regarding advance care (7,26) and they feel supported in having a person to contact, a case manager in case of emergencies or for emotional support (13,19). The caregivers feel benefited with improving their skills to handle anger issues of their partners (13). Spouses need better way to deal with their anxiety and distress and to cope with the loss of their partner, their future, and their dreams. They need to enhance their adaptive coping skills (3,5). Spouses feel confident as caregivers if adequate training in handling emergencies and providing care has been given to them (4,34). They need information on appropriate supportive devices, where to get the equipment to assist care (13).

For multiple needs identified among the spouses of persons with MND, there are established preventive, promotive, and curative psychosocial interventions. Interventions based on cognitive behavioral therapy (27), mindfulness (28), dignity therapy (13), group therapy (35), and acceptance and commitment therapy (20) are some of the empirically proven interventions. They will be benefited by



having a case management approach with multidisciplinary care focus (19). There are existing guidelines for management of MND, where family carers are also included (21).

The current study results need to be discussed in view of certain limitations. Participants of the current study are represented only from Urban Bangalore. Hence, the guidelines framed, which were strengthened by home visit observations, may not be generalizable to the rural context. Again, the needs identified were not segregated based on gender. The in-depth interviews with a focus on specific gender and its analysis might have enriched the understanding of the needs. The guidelines have not covered psychological interventions in detail. This can be seen as one of the limitations. But the researchers believe that the guidelines on mental health aspects, suggestions for physical and environmental modifications and enhancing the circle of support, marital relationship, and well-being interventions can improve the psychological and emotional well-being of persons with MND and their spouses.

## Practice Implications

There is limited literature, specifically for spouses on their needs and possible interventions from a resource-limited setting. The legal provisions for care in a country play a major role in determining the validity and larger acceptance of the advance care plan (36) which was mentioned as an important need by the caregivers. The palliative care policies, the socioeconomic resources, and facilities of the country determine how the needs can be met to optimize the care. In this context, this paper becomes relevant and an addition to the existing body of literature from the context of a low- and middle-income country.

The guidelines described in the study can act as an aid to the practitioners working in the field of neuropalliative care. This can also be developed as a manual and disseminated among the caregivers to improve the quality of life of the caregivers and their spouses. There is a scope for developing further psychosocial interventions for the group of spouse caregivers to address their needs.

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## References

1. Ray RA, Street AF. Who's there and who cares: age as an indicator of social support networks for caregivers among people living with motor neurone disease. *Health Soc Care Community*. 2006;13:542-52.
2. Irfan B, Irfan O, Ansari A, Qidwai W, Nanji K. Impact of caregiving on various aspects of the lives of caregivers. *Cureus*. 2017;9:e1213.
3. Weisser FB, Bristowe K, Jackson D. Experiences of burden, needs, rewards and resilience in family caregivers of people living with motor neurone disease/amyotrophic lateral sclerosis: a secondary thematic analysis of qualitative interviews. *Palliat Med*. 2015;29:737-45.
4. O'Brien MR, Whitehead B, Jack BA, Mitchell JD. From symptom onset to a diagnosis of amyotrophic lateral sclerosis/motor neuron disease (ALS/MND): experiences of people with ALS/MND and family carers—a qualitative study. *Amyotroph Lateral Scler*. 2011;97-104.
5. Galvin M, Gaffney R, Corr B, Mays I, Hardiman O. From first symptoms to diagnosis of amyotrophic lateral sclerosis: perspectives of an Irish informal caregiver cohort—A thematic analysis. *BMJ Open*. 2017;7:e014985.
6. Cipolletta S, Amicucci L. The family experience of living with a person with amyotrophic lateral sclerosis: a qualitative study. *Int J Psychol*. 2015;50:288-94.
7. Whitehead B, O'Brien MR, Jack BA, Mitchell D. Experiences of dying, death and bereavement in motor neurone disease: a qualitative study. *Palliat Med*. 2012;26:368-78.
8. Chiò A, Vignola A, Mastro E, Giudici AD, Iazzolino B, Calvo A, et al. Neurobehavioral symptoms in ALS are negatively related to caregivers' burden and quality of life. *Eur J Neurol*. 2010;17:1298-303.
9. Lillo P, Mioshi E, Hodges JR. Caregiver burden in amyotrophic lateral sclerosis is more dependent on patients' behavioral changes than physical disability: a comparative study. *BMC Neurol*. 2012;12:156.
10. Cui B, Cui LY, Liu MS, Li XG, Ma JF, Fang J, et al. Behavioral symptoms in motor neuron disease and their negative impact on caregiver burden. *Chin Med J (Engl)*. 2015;128:2295-300.
11. Burke T, Elamin M, Galvin M, Hardiman O, Pender N. Caregiver burden in amyotrophic lateral sclerosis: a cross-sectional investigation of predictors. *J Neurol*. 2015;262:1526-32.
12. Williams MT, Donnelly JP, Holmlund T, Battaglia M. ALS: family caregiver needs and quality of life. *Amyotroph Lateral Scler*. 2009;9:279-86.
13. Aoun SM, Chochinov HM, Kristjanson L J. Dignity therapy for people with motor neuron disease and their family caregivers: a feasibility study. *J Palliat Med*. 2015;18:31-7.
14. Oyebo JA NR, Smith H, Morrison K. The personal experience of partners of individuals with motor neuron disease.

- Amyotroph Lateral Scler Frontotemporal Degener. 2013;8421:39-43.
15. Goldstein LH, Atkins L, Landau S, Brown R, Leigh P N. Predictors of psychological distress in carers of people with amyotrophic lateral sclerosis: a longitudinal study. *Psychol Med.* 2006;36:865-75.
  16. Watermeyer TJ, Brown RG, Sidle KC, Oliver D J, Allen C, Karlsson J, et al. Impact of disease, cognitive and behavioural factors on caregiver outcome in amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Frontotemporal Degener.* 2015;16:316-23.
  17. Christensen A, Atkins DC, Baucom B, Yi J. Marital status and satisfaction five years following a randomized clinical trial comparing traditional versus integrative behavioral couple therapy. *J Consult Clin Psychol.* 2010 Apr;78:225-35.
  18. Bentley B, O'Connor M, Breen LJ, Kane R. Feasibility, acceptability and potential effectiveness of dignity therapy for family carers of people with motor neurone disease [published correction appears in *BMC Palliat care.* 2016; 15:19]. *BMC Palliat Care.* 2014;13:12.
  19. Bakker M, Creemers H, Schipper K, Beelen A, Nollet F, Abma T. Need and value of case management in multidisciplinary ALS care: a qualitative study on the perspectives of patients, spousal caregivers and professionals. *Amyotroph Lateral Scler Frontotemporal Degener.* 2015;16:180-6.
  20. de Wit J, Vervoort SCJM, van Eerden E, van den Berg LH, Visser-Meily JMA, Beelen A, et al. User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: a qualitative study. *BMC Psychol.* 2019;15:35.
  21. National Clinical Guideline Centre. Motor neurone disease: assessment and management Clinical guideline Methods, evidence and recommendations - Draft for Consultation. (September). Retrieved from <https://www.nice.org.uk/guidance/gid-cgwave0680/resources/motor-neurone-disease-full-guideline2>. 2015.
  22. Smith JA. Evaluating the contribution of interpretative phenomenological analysis. *Health Psychol Rev.* 2011;5:9-27.
  23. Larkin M. Life after caring: the post-caring experiences of former carers. *Br J Soc Work.* 2009;39:1026-42.
  24. Pietkiewicz I, Smith JA. A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychol J.* 2015;20: 7-14.
  25. Boerner K, Mock SE. Impact of patient suffering on caregiver well-being: the case of amyotrophic lateral sclerosis patients and their caregivers. *Psychol Health Med.* 2012;17:457-66.
  26. Ray RA, Brown J, Street AF. Dying with motor neurone disease, what can we learn from family caregivers? *Health Expect.* 2014;17:466-76.
  27. van Groenestijn AC, Schröder CD, Visser-Meily JM, Reenen ET, Veldink J H, van den Berg LH. Cognitive behavioural therapy and quality of life in psychologically distressed patients with amyotrophic lateral sclerosis and their caregivers: results of a prematurely stopped randomized controlled trial. *Amyotroph Lateral Scler Frontotemporal Degener.* 2015;16:309-15.
  28. Pagnini F, Phillips D, Bosma CM, Reece A, Langer E. Mindfulness as a protective factor for the burden of caregivers of amyotrophic lateral sclerosis patients. *J Clin Psychol.* 2016;72:101-11.
  29. Oliver DJ. Palliative care for patients with motor neurone disease: current challenges. *Degener Neurol Neuromuscul Dis.* 2016;6:65-72.
  30. Warriar MG, Thomas PT, Sadasivan A, Balasubramaniam B, Vengalil S, Nashi S, et al. Family Caregivers' experiences with dying and bereavement of individuals with motor neuron disease in India. *J Soc Work End Life Palliat Care.* 2019;15:111-25.
  31. Courts NF, Newton AN, McNeal LJ. Husbands and wives living with multiple sclerosis. *J Neurosci Nurs.* 2005;37:20-7.
  32. Kitko LA, Hupcey JE. The work of spousal caregiving of older adults with end-stage heart failure. *J Gerontol Nurs.* 2013;39:40-7.
  33. Lindqvist G, Albin B, Heikkilä K, Hjelm K. Conceptions of daily life in women living with a man suffering from chronic obstructive pulmonary disease. *Prim Health Care Res Dev.* 2013;14:40-51.
  34. Ang K, Umaphathi T, Tong J, Ng J, Tseng LJ, Woo IM. Healthcare needs of patients with amyotrophic lateral sclerosis (ALS) in Singapore: a patient-centred qualitative study from multiple perspectives. *J Palliat Care.* 2015;31:150-7.
  35. Almeida LMS, Falcao IV, Carvalho TL. Evaluation of overloading on caregivers of people with amyotrophic lateral sclerosis (ALS). *Cad Bras Ter Ocup Sao Carlos.* 2017;25:585-93.
  36. Gursahani R, Simha S, Mani RK. Legislation for end-of-life care in India: reflections on 5 years of the end-of-life care in India taskforce journey. *Indian J Palliat Care.* 2020 Sep;26:269-70.