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*
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 pres- sure 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

### 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 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 independent (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.
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, Interview 1)

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.](image-url)
| Sl No | Expert                | Item                                                                 | Response (1-5) | Suggestions                                                                 |
|-------|-----------------------|----------------------------------------------------------------------|----------------|-----------------------------------------------------------------------------|
| 1     | Neurologist 1         | The contents are adequate                                              | 5              | Psycosocial factors                                                          |
|       |                       | The contents represent and address all psycosocial needs of MND caregivers | 5              |                                                                             |
|       |                       | Guidelines clearly spell out things that would aid clinical practice   | 5              |                                                                             |
|       |                       | The contents are comprehensive                                          | 5              |                                                                             |
|       |                       | Any other inputs                                                       | 5              | 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 psycosocial 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 psycosocial 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     | PSW1                  | The contents are adequate                                              | 4              | Include tips to address caregiver burden, self-assessment of anxiety and depressive symptoms |
|       |                       | The contents represent and address all psycosocial needs of MND caregivers | 5              |                                                                             |
|       |                       | Guidelines clearly spell out things that would aid clinical practice   | 5              |                                                                             |
|       |                       | The contents are comprehensive                                          | 5              |                                                                             |
|       |                       | Any other inputs                                                       | 5              | 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              |                                                                             |
|       |                       | The contents represent and address all psycosocial needs of MND caregivers | 5              |                                                                             |
|       |                       | Guidelines clearly spell out things that would aid clinical practice   | 5              |                                                                             |
|       |                       | The contents are comprehensive                                          | 5              |                                                                             |
|       |                       | Any other inputs                                                       | 5              | Chapter 4- marital relationship, adaptation need to be emphasized.          |
|       |                       |                                                                       |                | 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 psycosocial needs of MND caregivers | 5              |                                                                             |
|       |                       | Guidelines clearly spell out things that would aid clinical practice   | 5              |                                                                             |
|       |                       | The contents are comprehensive                                          | 5              | 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.

### Module 1: Guidelines to equip the spouses of persons with motor neuron disease for care

| Sl No | Title                      | Objectives                                                                                   | Content                                                                                     |
|-------|----------------------------|---------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| 1     | Understanding MND          | Assess patient and family knowledge about illness.                                           | Facts about MND, classification, clinical signs and symptoms, management of MND              |
|       |                             | Clarifying the myths and misconceptions, educating about facts on the course and prognosis and management strategies |                                                                                            |
|       |                             | Long term management                                                                        |                                                                                            |
| 2     | Communication              | How to improve illness communication to the person with MND and family                     | 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, between the couple and significant others. | Tips to enhance communication within the family. Clear communication about advance care planning. |
|       |                             | Clear communication about the advance care plan                                             |                                                                                            |
| 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. | Nonpharmacological management of symptoms like muscle spasms, speech difficulties, swallowing difficulties, sialorrhea, uncontrollable laughing or crying, breathing difficulties, mental health issues. |
|       |                             | Discussion about the non-pharmacological management strategies                             |                                                                                            |
| 4     | Marital relationship       | Changes in marital relationship among the persons with MND and spouses                      | Steps to enhance marital relationship, realignment to be made in couple relationship, how to adapt to the changes posed by symptoms of the illness. |
|       |                             | Strategies to enhance the quality of marital relationship of persons with MND-spouse dyad.  |                                                                                            |
| 5     | Palliative care            | MND and Palliative Care                                                                     | Educating family on palliative care, issues unique to palliative care in MND in Indian context. |
|       |                             | Educating family on Palliative Care                                                         | Steps to ensure better care for persons with MND.                                          |
| 6     | Everyday life made easier  | Challenges in everyday life due to symptom deterioration                                      | Information on some assistive tools which can benefit persons.                               |
|       |                             | Assistive devices to make the life of MND patients easier.                                   |                                                                                            |

### Module 2: Guidelines to ensure well-being of the spouse caregivers

| Sl No | Title                      | Objectives                                                                                   | Content                                                                                     |
|-------|----------------------------|---------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| 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.                                | 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 |
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 (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).

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 socioeconomic 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 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

**Table 3. (continued)**

| Sl No | Title | Objectives | Content |
|-------|-------|------------|---------|
| 4     | Supporting carers’ during neuropalliative care | Challenges for the Caregivers offering palliative care | Possible ways of addressing caregivers’ challenges- ways to handle uncertainty, emotional coping strategies, bereavement support. |
|       |       | Support for the caregivers for effective neuropalliative care | |
| 5     | Where to find help | How to get recent updates on MND and various care strategies? | 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. |
|       |       | Where to find help for practical aspects of care? | |
|       |       | How to get support? | |

Abbreviation: MND-motor neuron disease.
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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