

Lived Experience of Spouses of Persons with Motor Neuron Disease: Preliminary Findings through Interpretative Phenomenological Analysis

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Abstract

Introduction: Motor neuron disease (MND) is a progressive neuromuscular disorder that can have significant and debilitating impact on the affected patient and families. Spouses are the primary carers for persons with MND in India, and the life of the person with MND and their spouse is never the same after the diagnosis. **Aim:** The objective was to explore the lived experience of spouses of persons diagnosed with MND. **Methods:** A qualitative exploratory study with three-point interviews was conducted with spouse caregivers of two persons diagnosed with MND who were receiving treatment from a national tertiary referral care center for neurological disorders. All the patients were diagnosed as definite MND according to the modified El Escorial criteria. With the spouses, in-depth interviews were conducted at their home, lasting on an average of 1 hour using a semi-structured interview guide (prompts). Interpretative phenomenological analysis was used to derive themes from the interviews. **Results:** The major themes emerged from the analysis were meaning of MND which contained the subthemes of *delay in diagnosis and deterioration, psychological response across illness trajectory*, relationship with the subthemes of *changing roles in being acarer, marital relationship, to be seen as doing "right," and communication*; adaptation with the subthemes of *coping strategies and support system* and life without the loved one. **Conclusion:** The changes in the lives of spouses and in strategies for caring the partner with deterioration of symptoms in the illness trajectory are explained in this study. The palliative approach in the management of MND has to take into account, the experiences and needs of carers since care happens at home.

Keywords: IPA, lived experiences, motor neuron disease, palliative care, spouse caregivers

INTRODUCTION

Motor neuron disease (MND), a fatal neurodegenerative condition affects the essential voluntary muscle activities, such as upper and lower limb activities, speaking, breathing, swallowing, and general movement of the body.^[1] The prevalence of MND varies from 1 to 7/100000 in developed countries and in India, it was observed to be 4/100,000 population.^[2] It usually affects males in their fifth or sixth decade. However, females being affected with MND, and also earlier age of onset is not very rare. The condition is incurable, though not untreatable; these treatments do not arrest progression or reverse weakness. The median time from symptom onset to death is found to be 23–48 months in various studies, whereas 10-year survival rates are there for 8%–16%.^[3,4] Occasionally, survival following diagnosis is <6 months.^[5] In a study conducted in India, it was

found that the median survival duration of persons with MND was 114.8 ± 25.9 months.^[6] As there are limited treatment options for MND at present, the management of MND targets symptom relief, and palliative approach to care is gaining wider acceptance in the disease management.^[7-9]

The cause for this fatal condition mostly remains unknown, and hence, the complete cure is difficult. As the focus of the

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intervention is palliation, the specialist palliative care team can be involved in different epochs of illness such as during the times of change in symptoms, crisis, or decision-making, for example, at diagnosis, when discussing gastrostomy or ventilatory support, when there are cognitive changes and end of life.^[7-12] The complex needs of this group can be addressed through a multidisciplinary team, including interprofessionals (medical and allied health professionals), informal family caregivers, and voluntary support groups.^[13]

People with MND are mostly cared for at home, and family carers are central in providing care throughout illness trajectory, including the early period of dying.^[14] In further stages of illness, a person with MND depends on caregiver for the basic activities of daily living and even for communicating with others. Family caregivers, especially the spouses, remain responsible for the care and are profoundly affected by the illness.

There are studies which have tried to understand the experiences of family caregivers. In most of those studies, spouses form the majority.^[13,15-20] The studies which have specifically explored experiences of spouses^[18,19] were quantitative, and they focused explicitly on caregiver's felt burden, needs, and resilience. There were a few studies among the spouses which looked into the positive aspects of caregiving^[19] and positive ways of coping.^[18]

In-depth understanding of the experiences of the spouses and the spouse's meaning-making process were looked by the previous studies^[20,21] using qualitative methodologies. However, such an attempt in an Indian scenario has not occurred. As the facilities and support available for palliative care in India are inadequate at best, and health insurance to cover the cost of care is limited, health expenses are mostly met by the family carers.^[22] Many a time, the person with MND and their family members spend their time, energy, and money in search of "cure" for the illness which leads to distress spending and delays initiation of effective ways of caring the person. Hence, the current study aimed at understanding the lived experiences of spouses of persons with MND in India. The meaning they make out of their experience is portrayed using interpretative phenomenological analysis. This article presents the preliminary findings of the study.

METHODS

Design

The in-depth understanding of the experiences can be gathered through qualitative inquiry. The current study attempts to explore the experiences of spouses caring for a person with

MND in India through an interpretative phenomenological analysis (IPA) and is based on the theoretical framework of "Social constructionism."^[23,20] Phenomenological component of the study focused on how the respondents perceive the experience of being a spouse of a person with MND. The hermeneutic component enabled the researcher to decode that meaning and making sense of the participants' meaning making. An idiographic element of the design enabled the researcher to do a purposive sampling and in-depth analysis of single cases and examining individual perspectives of the study participants, in their unique contexts.

Ethics

The study received ethical clearance from the Institute Ethics Board of National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru.

Participants

Two participants were recruited for the pilot study from July 2017 to January 2018. They were the spouses of persons with MND who were receiving treatment from national tertiary referral center for neurological disorders in South India. Inclusion criteria were that they should be able to speak English/Malayalam/Tamil/Kannada, and they should have given consent for audio recording of the interviews and home visits by the researcher. Written informed consent was collected in person by the first author after ensuring the anonymity of the participants. Demographic details of the participants and the brief illness profile of their spouses are given in Tables 1 and 2.

Data collection

The first author took permission for a home visit from the patient and the spouse after briefly describing the purpose of the study during their initial consultation at the hospital.^[24] Subsequently, the researcher visited the participants in their homes and conducted three interviews each, with two participants, over a period of 5 months. The spouse caregivers were administered the depression, anxiety, and stress scale,^[25] to refer them for appropriate services if required. Interviews lasted for an average of 1 hour and were conducted with the help of a semi-structured interview guide (prompts). The interviews were participant led, thus ensuring rigor. These interviews were audio recorded and transcribed. One interview was in English, whereas the other one was in Tamil. Interview in Tamil was transcribed in English and back translated by a Tamil speaking person, to ensure the conformability of data. The researcher used to send the location of the house to the research guide soon after reaching the home for data collection, as a safety precaution.

Table 1: Brief illness details of the patient's whose spouses are recruited for the study

Participants and spouses	Age	Education	Occupation	Duration of illness	Mode of onset
Patient 1	42	10 th standard	Contractor (stopped working after 3 years of onset of illness)	5 years (patient passed away in September 2017)	Limb onset ALS
Patient 2	40	BE	Manager (working)	5 years	Limb onset ALS

ALS: Amyotrophic lateral sclerosis

Table 2: Socioeconomic profile of the participants

Participants and spouses	Age	Education	Occupation	Currently working
Participant 1	36	8 th standard	Home maker	No
Participant 2	33	BE	Montessori teacher	Yes

Analysis

Interviews were subjected to interpretative phenomenological analysis after the transcription. Transcripts were read and reread multiple times to identify the themes. Later, the emergent themes were clustered into tables, as superordinate and subordinate themes. Themes in the tables were substantiated with the verbatim. Later, the connection between the themes was sought and arranged accordingly. At this point, certain themes which do not fit into the broader themes were removed. This entire process of analysis for three-point interviews of single participant was completed before moving on to the next participant.

As the participants had some difference in the illness trajectory, a separate table of final themes was formed for both the participants; and later, they were compared and contrasted. Reflexive diary helped the researcher in the process of analysis. Peer debriefing about the themes was done as a part of ensuring the rigor. The analysis was initially done by the first author, and it was audited by the corresponding author. Whenever, there were differences in the interpretations and the themes, discussions were made, and finally, an agreement about the themes was reached.

RESULTS

The present study is an attempt to explore the lived experience of spouses caring for persons with MND using IPA. The following themes emerged from the exploration.

Meaning of motor neuron disease

Participants discussed what the illness meant to them, how it was known, and the psychological response to the condition.

Delay in diagnosis and deterioration

Both the participants had difficulty to recognize their partner's symptoms. They reported that there was a delay from the part of health-care professionals in diagnosing the illness; by then, the deterioration in symptoms had already occurred.

Participant 1 (P1) said, *"He used to tell. But we couldn't believe it. He used to drink (alcohol)... (low voice)... may be because of that."*

There is a general tendency to attribute the weakness and tremors to alcohol consumption among the general public. Being less aware of a condition such as MND could not think about anything else than alcohol use for her spouse's difficulties.

Participant 2 (P2) said, *"Anyways, he was going to the office and coming back. We didn't notice much difference. Only in*

September when we went for trip, we came to know. Twotimes he fell down."

As long as our socio-occupational functioning is adequate, even with minor difficulties, we tend to move ahead in our lives. Similarly, P2 also did not notice her husband's symptoms, as he was regular to the office.

Treating doctors had a lack of clarity regarding the diagnosis. P1 said *"We were showing him to local doctors. Nobody told this"*. P2 also had similar experience in initial consultations. She said, *"Doctor's first thought it is spondylitis, and he was on treatment for 8-9 months."*

Not only in the first interview but also in the subsequent interviews also participants reported about the progression of illness and the difficulties faced by their partners due to the symptom deterioration. Even after the death of the spouse, in the last interview, P1 was talking about their views regarding MND, concerns regarding hereditary inheritance of MND.

Psychological response across illness trajectory

Participants and their perception about their spouses' reaction to the illness were narrated by them.

From participant's narration of their partner's psychological response, it was identified that the persons diagnosed with MND go through *denial*, *Mum effect*, and *distress* during the initial phase and later on *fear*, *anger*, and *shame*.

The participants during the initial stages of diagnosis were more in *denial*, *fear*, *distress*, and slowly moving toward *"adaptation"*, but later on when the symptom advances, feeling more *distress*, *helplessness*, *low threshold to frustration*, and *hoping for a magical cure* were seen.

P1 said *"When NIMHANS doctors told there is no medicine for this, we couldn't digest. It was so difficult."* P2 also said *"I didn't believe at first that there is no treatment and all."*

From the periods of denial and distress, the stage of adaptation is visible when P2 reported *"1 day I told him, doctor told 10 years later you would have great difficulty. It is 10 years later know, why we are suffering now for that. If we just think and worry, there is no end to the worries."*

Relationship

Marital bonding between the couple, change in the relationship and communication between the couple were described by the participants.

There were two different opinions about the marital relationship. P1 reported that there is a change in the marital relationship; intimacy in the relationship is no longer the same. She said, *"No, those things changed. Everything changed. He doesn't see me as his wife. Nothing like that, just living. How to tell that."*

Whereas, P2 denied of any change in the relationship, though there were indicators to infer the same. She said, *"If I get*

irritation or frustration, immediately I will tell him. That is there that bond is there. That has not broken till now a little also."

With the deterioration of symptoms, the role of the participants changed. They had to take up *financial roles, and there was a change from spouse to parent*. Participants narrated that they no more have time for themselves; caregiving became their primary focus and major responsibility. As a result of the multiplicity of these roles, there will be physical exhaustion, which leads to further emotional distress and frustration.

Participants have a need to be validated for doing "right thing." They want to be acknowledged and seen as doing "right thing" by the in laws, relatives, and friends.

Participants mentioned about the *communication between the couple, treating team, and communication with the extended family members and friends*. Partners are communicating, but their concerns about the illness and the plans if the symptoms further worsen, were not discussed. It is clear when P2 reports "Actually what will happen know, we will express, but not that much, I told you know about business, about job." Participants did not forget to mention what kind of communication they expect from the treating team.

Adaptation

A major theme that emerged was that of adaptation. Spouses of persons with MND may never accept the situation completely. After going through different stages of psychological responses, they adapt and readjust their life to the new normal. It is a process of frequent challenges. The coping strategies which they generally use, and the support system which facilitate this process of adaptation is depicted here.

Coping strategies

Spouses cope through *denial, emotional venting, avoidance, humor, and religious coping* across the illness trajectory.

Here, P2 tries to reemphasize her denial in these words. "Sleep? For whom? For Me eh? (Surprised tone) I am sleeping very nicely, very nicely. I am not thinking."

P1 vented out her distress when she narrated, "We couldn't tolerate seeing him in that pain. It was so difficult, that pain."

"This suffering is given to us by God and we have to go through it. Nobody else should be called to share this." These words show P1's way of using religious coping to overcome the difficulties.

Support system

Both the participants had adequate primary, secondary, and tertiary support. Despite the age of the children, they played an active role in caregiving.

P1 said, "my mother in law will come and stay for few days. She will do some bit of household chores. Earlier she used to do things for him as well. But now a days, she is not able to understand his speech."

Support from children is seen when P2 says "I cooked everything and kept. I told my elder one, you have to give it to daddy. Because we have to mix and give. Both my children were enthusiastically helping."

The support from the palliative care agency, how it helped her to deal with the end stage of the patient in a better way was described by P1.

Life without the loved one

P1's husband passed away after the first interview. In subsequent interviews, P1 talked about her experience of death of her loved one and her life after that. She was *unprepared to face death, felt vacuum after death, and she strived to find where went wrong*. Later, she attempted to adapt to the absence of the partner by trying to get engaged in normal family routine.

P1's efforts to find out if she was wrong somewhere when she said, "At the village, many tell if we had taken earlier something could have been done. I keep on thinking whether if we did something differently, he could have been saved."

Death of a spouse means a loss, of more than a "spouse." Her loss which implies loss of security, social status, her routine; which is visible in her words "I am a little scared. Now slowly getting better. If he was there, nothing to worry. Even if he was just here, sitting here, it was fine (secure)."

DISCUSSION

In the current study, "illness" forms a central theme. Its identification, diagnosis, deterioration, death, and anxiety regarding hereditary nature were derived as themes across illness trajectory. The prominence of illness over other aspects of life is visible in this theme. It is interesting to note that though the participants are preoccupied with illness, they are never prepared to face death. The shift from cure to care also does not occur for the participants and their partners. As a result, the affected individual and spouse are totally unprepared for the inevitable death. Participant in the current study tried to avoid seeing death of her loved one. Physical exhaustion and other impact of the illness on the spouse are seen in the current study in similar lines with other studies.^[10,20,21] A recent meta-summary of qualitative studies among bereaved caregivers highlighted the emotional impact of the bereavement as the most frequently identified theme for bereaved carers.^[26,27]

Another major theme from the current analysis, "caregiving responsibilities overshadow their life" has been discussed in earlier studies as well.^[10,28] The change in the relationship between the couple, a major finding of the current study is described in earlier studies.^[10,20] Caregivers experience a significant change from role functions associated with being a spouse, to that of being "only" a caregiver.

It has been observed in the current study that there is a difficulty for the spouse to talk about intimacy issues. There is a hesitation to discuss the same, and they tend to portray the marital relationship as same and "never changed." This

could be due to the sociocultural barriers inherent in the Indian society, where sexual intimacy and discussions on sex are seen as taboo. Often, participants came across as hesitant to explore this dimension of relationship, to the extent that it was seen as unacceptable to talk about sexual intimacy when the person is so ill.

The coping strategies of the spouse found in the current analysis are in similar lines with earlier studies,^[19,29] where the spouse is inhibiting or avoiding the emotional responses and focusing on the immediate and practical needs. The spouses in the current study, similar to the participants in other studies^[20] tried to avoid expressing grief and to portray themselves as strong individuals. One of the participants had sought help from palliative care organization, and she reported being able to handle the deterioration of her husband's symptoms in a better manner. The visit by the home care team of the palliative care agency and the suggestions given by the team to enhance caring improved the confidence level of the participant. Hence, support from palliative care organization has been mentioned by her as a primary source of support.^[20]

Under the theme "life without the loved one," the participant is trying to normalize her routine as far as possible, and she is trying to find new meaning to life.^[21] Indian society thrives on the institution of marriage as a social norm. There is a complex relationship involving marital status, gender roles, and economic independence in India. When the bereaved spouse is a wife, the loss is not just that of the marital partner, but also of her social identity as a married woman. The spouse, in this case, is a symbol of social identity and social security, and the loss is of "more than a spouse" makes it challenging for her to adapt to the situation.

The small sample size of the current study is a major limitation. The lack of proximity of the patient's residence for the home visit and language was the major hurdles for recruiting more respondents. The difference in the illness trajectory of the spouses of participants would have made some difference in the themes derived from their interviews. The struggle to make consensus among the themes in a slightly different illness trajectory is another challenge for the current study.

The study has several implications in the Indian context, in the emerging field of neuropalliative care. The felt needs of the spouse caregivers in different stages of illness, such as the need for physical assistance, support for handling deterioration of symptoms, respite, financial aid, a need for validation, and emotional support can guide the development of interventions for this group. Many of these felt needs of the spouses can be addressed through palliative care interventions. Even if the person diagnosed with MND and their families are not referred to formal palliative care services, interventions with a palliative approach initiated from diagnosis can be integrated into routine clinical practice. The current study gives a framework to develop guidelines for such interventions in the field of neurodegenerative conditions.

CONCLUSION

Disease and adaptation are an ongoing process. Once the diagnosis is made, it defines the family's life henceforth. Due to the spiraling of losses, as in this study, when the participant adjusts to one stage of deterioration of her loved one's health status, suddenly, another loss happens. The very nature of the illness requires the spouse to constantly change the ways of caring, the future plans, and dreams according to it. In Indian culture, family is an integral part. The sacrifices made for the family, especially the spouse is much expected as "taken for granted" and usually not counted. The interventions planned for the spouses of persons with a debilitating condition, MND, have to be contextualized to suit this particular scenario.

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Conflicts of interest

There are no conflicts of interest.

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