

Palliative Care Needs and Care Giver Burden in Neurodegenerative Diseases: A Cross Sectional Study

Zacharias Lithin, Priya T. Thomas, Manjusha Warriar G, Adhin Bhaskar¹, Saraswathi Nashi², Seena Vengalil², Kiran Polavarapu², Preethish Kumar², Ravi Yadav², Suvarna Alladi², Nalini Atchayaram², Pramod K. Pal²

Department of Psychiatric Social Work and ²Neurology, NIMHANS, Bengaluru, Karnataka, ¹Department of Statistics, NIRT, Chennai, Tamil Nadu, India

Abstract

Background and Aims: Palliative care is an important area of intervention in neurodegenerative diseases. The aim of this study is to understand the relationship between Palliative Care Needs and Caregiver Burden among persons diagnosed with neurodegenerative diseases. **Methods:** A cross-sectional study design was adopted to explore the research problem. A prospective sample of 120 participants (60 Patient Caregiver dyads) of Motor Neurone Disease (MND) and Parkinson's disease (PD) were recruited for the study based on inclusion and exclusion criteria from a quaternary referral care centre for neurology in south India. Patients seeking care were recruited for the study consecutively. Palliative care outcome scale and Zarit Burden Interview scale were administered to understand the relationship. **Results:** It was found that Palliative care outcomes score was positively correlated with caregiver burden ($r = 0.597$), showing that there is a bi-directional relationship between palliative care needs and caregiver burden. **Conclusion:** Irrespective of the differences in illness characteristics, the study found that palliative care needs are high among chronic neurological conditions which requires a noncategorical psychosocial approach in ensuring care.

Keywords: Caregiver burden, neurodegenerative, palliative care needs

INTRODUCTION

Palliative Care (PC) aims at holistic care for persons suffering from life-threatening illnesses and their families.^[1] The concerns of patients and families affected by neurologic illnesses include goals of care, caregiver support, spiritual wellbeing, complex symptom management, and working with emotions.^[2] As the neurodegenerative disease progresses, many patients choose palliation as an important goal of care. It is quite known that everyone facing life-threatening disease will require some degree of care in addition to treatment for their condition. Hence the relevance of palliative care and the need to bring evidence for palliative care is felt.

Palliative care in neurology is of paramount importance which requires increased collaboration between the fields of neurology and palliative care.^[3] A consensus statement on neuro palliative care by the European Association of Palliative Care Taskforce highlighted the need for early integration of palliative care to routine neurological care and the need for capacity building.^[4] Selective death of certain group of neurons results in neurodegenerative diseases such as Parkinson's disease, Huntington's disease, and Amyotrophic lateral sclerosis.^[5] The current study focused on the two neurodegenerative groups. In Parkinson's disease, it is reported that caregiver burnout increases as the disability progresses.^[6] People with Parkinson's disease and caregivers experienced a high illness burden and reported the need for additional support.^[7] Whereas the significant challenges faced in the management of motor neuron disease are the diagnosis experience, assisted ventilation, cognitive changes and end-of-life decision making.^[8] Irrespective of the

illness, it is important to adopt palliative approach in managing such conditions. The challenges in providing palliative care in some aspects of the disease progression are genetics, cognitive change, respiratory dysfunction, end of life issues, advance care planning etc.^[9]

Irrespective of better understanding of disease process, it is reported that care of the neurological patients involves many challenges as they have multiple difficulties such as issues in cognition, communication, behavioural and altered sensorium, physical ailments.^[10] Caregivers of neurology patients also have similar rates of distress and burnout as caregivers of patients with cancer.^[2] Therefore, neuro palliative care is gaining acceptance in the management of persons with neurological conditions who have been assessed as having a limited life expectancy. There is a need to understand the needs of patients suffering from life-threatening neurological

Address for correspondence: Mr. Zacharias Lithin, Department of Psychiatric Social Work, M V Govindswamy Centre, National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru - 560 029, Karnataka, India. E-mail: lithinzacharias@gmail.com

Submitted: 04-Jun-2019 **Revised:** 23-Jul-2019

Accepted: 20-Aug-2019 **Published:** 10-Jun-2020

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

DOI: 10.4103/aian.AIAN_304_19

disorders and their families since the concept of palliative care is long understood as part of cancer care. This study aimed to look into the relationship of palliative care needs and caregiver burden among neurodegenerative diseases in the Indian context.

METHODS

Study design

A cross-sectional descriptive study was performed among 60 patients caregiver dyads with the diagnosis of Motor neuron disease and Parkinson's disease receiving treatment from a national quaternary referral care centre for neurological disorders in Southern India. Participants were recruited from the IP and OP services. Diagnosis of Motor Neuron Disease by El Escorial Criteria and Parkinson's disease by United Kingdom Parkinson's disease brain bank criteria were used as inclusion criteria. Patients seeking care who fulfilled the inclusion, exclusion criteria were recruited for the study consecutively. Ethical clearance for the study was received from the Institute Review Board. Participants were explained about the purpose and nature of the study. Informed Consent Form was given and filled up by the respondents to indicate their willingness to participate in the research. If the consent form was signed, the interview proceeded at a time convenient to both parties, using the structured interview schedule and lasting about 40 to 60 minutes. Interviews were held over a period of 5 months from October 2016 to February 2017.

Measures

Demographics

The following information was collected: age, gender, education, religion, occupation, domicile, marital status, primary caregiver details and duration of illness.

Instruments

The palliative care outcome scale

Palliative care outcome (POS) Scale^[11] was used to understand patient reported outcome (patient version) and carer reported outcome (carer version) in Palliative care needs. POS has 10 items which assess the following dimensions: physical, emotional, psychological, spiritual and provision of information and support. In this study palliative care outcome scale was used to calculate an overall profile score of palliative care needs. Each item is scored from 0 (minimum attention) to 4 (maximum attention). The overall profile score can range from 0 to 40. Individual POS item scores of zero or one require less clinical attention than items that score three or four.

The Zarit Burden Interview (ZBI)

The Zarit Burden Interview,^[12] a popular caregiver self-report measure used in aging research, originated as a 29-item questionnaire. The revised version contains 22 items. Each question is scored on a 5-point Likert scale ranging from never to nearly always present. Total scores range from 0 (low burden) to 88 (high burden). The items are worded subjectively, focusing on the affective response of the caregiver.

Analysis

Variables were summarized using mean and standard deviation for quantitative variables and frequency distribution was used to summarise the qualitative variables. The normality was tested using Shapiro Wilk test. Spearman's correlation coefficient was computed to study the relationship between palliative care outcome and caregiver burden among persons with neurodegenerative diseases. Independent sample *t* test was used to compare the quantitative variable between MND and PD groups as well as male and female categories.

RESULTS

The study sample consisted of 120 participants which included person diagnosed with both MND and PD and their caregivers. The socio demographic profile of the study sample is shown in

Table 1: Socio Demographic Profile of the patients

Variable		Patient	
		Motor Neuron Disease (MND) n (%)	Parkinson's Disease PD n (%)
Gender	Male	23 (76.7)	18 (60.0)
	Female	7 (23.3)	12 (40.0)
Age	40-50 years	7 (23.3)	3 (10.0)
	51-60 years	10 (33.3)	10 (33.3)
	61 & above	13 (43.3)	17 (56.7)
Education	Illiterate	6 (20.0)	3 (10.0)
	Literate	24 (80.0)	27 (90.0)
Occupation	Unemployed	6 (20.0)	11 (36.7)
	Employed	24 (80.0)	19 (63.3)
Religion	Hindu	23 (76.7)	26 (86.7)
	Muslim	4 (13.3)	3 (10.0)
	Christian	3 (10.0)	1 (3.3)
Domicile	Rural	17 (56.7)	18 (60.0)
	Urban	13 (43.3)	12 (40.0)
Marital Status	Married	26 (86.7)	28 (93.3)
	Unmarried	4 (13.3)	2 (6.7)
Primary caregiver	Spouse	23 (76.7)	20 (66.7)
	Other family members	7 (23.3)	10 (33.3)
Duration of illness	8-11 years	12 (40.0)	3 (10.0)
	4-7 years	5 (16.7)	4 (13.3)
	Below 3 years	13 (43.3)	23 (76.7)

Table 2: Socio Demographic Profile of the caregivers

Variable		MND n (%)	PD n (%)
Gender	Male	7 (23.3)	7 (23.3)
	Female	23 (76.7)	23 (76.7)
Age	20-40 years	7 (23.3)	7 (23.3)
	41-60 years	19 (63.3)	13 (43.3)
	61-80 years	4 (13.3)	10 (33.3)
Education	Illiterate	8 (26.7)	8 (26.7)
	Literate	22 (73.3)	22 (73.3)
Occupation	Unemployed	3 (10.0)	3 (10.0)
	Employed	27 (90.0)	27 (90.0)

Tables 1 and 2. In the profile of patients, 76.7% of them were male and 23.3% of them were female in MND group, whereas the PD group consisted of 60% male patients. Majority of the patients ($n = 23$, 76.7%) had a duration of below three years of illness in MND, and in PD it was 43.3% ($n = 13$).

40% of the patients diagnosed with MND were Clinically Definite ALS and 36.7% of them were Clinically Probable ALS. Patients were assessed on United Kingdom Parkinson's Disease Brain bank criteria when patients were on medication (26.53 ± 14.40) and off medication (38.03 ± 14.74).

The Table 3 shows the mean score of palliative care outcome scale and caregiver burden. The palliative care outcome score that assessed the physical, psychological, spiritual, social and information needs was found to be similar in both disease groups among both patients and caregivers. Caregiver's burden was found to be more in MND group (37.43 ± 18.75) as compared to PD group (29.56 ± 16.85), though it was not statistically significant ($t = 1.709$, $P = 0.093$).

The Table 4 depicts the relationship between the study variables. The correlation matrix showed that Palliative care outcome patient version had a high positive correlation with Palliative care outcome carer version ($r = 0.802$; $P < 0.001$), which was significant. This shows that the patients and caregivers tended to see the needs in similar way. Palliative care outcomes score was also positively correlated with caregiver burden ($r = 0.597$, $P < 0.001$), showing that higher palliative care needs, higher the caregiver burden.

Table 5 shows the result of independent sample t test performed to compare palliative care outcome, and caregiver burden between male and female patients. The palliative care outcome of patients ($t = -2.416$, $P = 0.019$) as well as caregivers ($t = -2.353$, $P = 0.022$) were significantly different between male and female patients. The palliative care need was found to be more in female patients as compared to male patients, whereas caregiver burden was similar in both male and female patients.

DISCUSSION

The present study was an attempt to understand the palliative care needs among the persons with MND and PD and its relationship with caregiver burden. The mean score for palliative care outcome in MND for patient version was 21.66 ± 6.74 , and in carer version, it was 20.86 ± 6.24 and where as in PD for patient version 21.56 ± 6.13 , and in carer version, it was 21.00 ± 6.16 which indicated that no discrepancy was felt between patient and carer felt needs. A study done assessing the palliative care needs in views of patients, informal carers and healthcare professionals revealed that all participants were able to identify the same needs in the areas of social and psychological support, financial concerns, and the need for choice and information.^[13] This is important for care management since the carer's recognition of patients' needs would facilitate better care for the patient.

Table 3: Palliative care outcome (POS)& Caregiver burden

Variable	Diagnosis	n	Mean±SD	t statistic	P
POS -Patient	MND	30	21.66±6.74	0.06	0.952
	PD	30	21.56±6.13		
POS-Carer	MND	30	20.86±6.24	-0.083	0.934
	PD	30	21.00±6.16		
Caregiver burden	MND	30	37.43±18.75	1.709	0.093
	PD	30	29.56±16.85		

Table 4: Relationship between Palliative Care Outcome and Caregiver Burden

		POS Patient	POS Carer	Caregiver burden
POS Patient	R	1.000	0.802**	0.597**
	P		<0.001	<0.001
POS Carer	R		1.000	0.505**
	P			<0.001

**Correlation is significant at 0.05 level.

Table 5: Mean difference on Palliative care outcome, and Caregiver burden with respect to the Gender of the patient

Variable	Gender of patient	n	Mean±SD	t statistic	P
POS-Patient	Male	41	20.46±6.79	-2.416	0.019
	Female	19	24.10±4.66		
POS-Carer	Male	41	19.70±6.36	-2.353	0.022
	Female	19	23.57±4.83		
Caregiver burden	Male	41	33.68±19.05	0.114	0.91
	Female	19	33.10±16.40		

Taking care of a patient with neurodegenerative disorder is an extremely demanding task, resulting in significant caregiver burden. The Zarit burden inventory was used to ascertain the distress experienced by caregivers of persons diagnosed with neurodegenerative disease. The scale classifies the extent of burden as little to severe. The present study showed that 36.7% of the caregivers reported mild to moderate burden in taking care of the patient's needs in MND where as in PD it was 43.3%. Moderate and severe burden was reported by the remaining 33.3% in MND and 20% in PD. The need to go beyond disease diagnosis was felt when examining caregiver experiences in a study.^[14] It is evident that the role of caregiver becomes progressively more important with disease progression, until caring for the patient becomes the caregiver's main or almost only activity. Caregivers of persons with neurodegenerative disorders are vulnerable to detrimental factors related to caregiving because of the progressive drawn-out course and multiple disabilities. The findings are significant and align with previous studies that have assessed the caregiver burden in neurodegenerative disorders. Previous studies among caregivers of Parkinson's disease have

reported significant correlations between caregiver burden and sense of coherence in caregivers, functionality of the patient, depressive symptoms in caregiver and patient, patient subjective health and time since diagnosis.^[15] With regards to the economic burden it is reported that patients with PD have twice the direct medical costs compared to those without PD as the disability and therapy-related complications increases in the later stages of progression of illness.^[16] Caregiver burden in amyotrophic lateral sclerosis (also known as MND) was associated with behavioral and other changes in the patients.^[17] Hence, higher caregiver burden reported among patients with MND and PD has therapeutic implications and has to be taken into consideration in developing management plans for these diseases. There were no studies found out that looked into the relationship between palliative outcome, and caregiver burden especially in India. Few studies have attempted to explore either one aspect of the study variable. More studies have focused on economic burden and cost associated with various neurological disorders.

Females have reported higher score in palliative care outcome which indicated that they have more physical symptoms, psychological, emotional and spiritual, and information and support needs compared to men. No studies were found to support this finding but male-female patient differences in the association between end-of-life discussions and receipt of intensive care near death^[18] have been explored. It reiterates the further need to explore gender difference on the palliative care needs, and gender sensitive care.

Limitations

The present study, similar to other studies reported among other rare disease groups, had a small sample size. This might have influenced the results. The concept of palliative care is less understood and not well defined in neurodegenerative disorders hence the present study may be limited in using appropriate indicators for understanding palliative care needs. The present study does not explore the gap between identified needs and existing services. Among the respondents of the study the focus on the curative treatment was evident. In the absence of clearly speltout palliative care approach in the neurodegenerative disorders, lack of understanding and acceptance of palliative approach may have contributed to the results. Palliative care needs in neurodegenerative disorders are constantly changing and increases with progression of the disease. The research question of the present study can be better answered by longitudinal study that takes into account the changes across time.

Implications of the study

The findings of the study have several implications for Neuro palliative care. While the limitations of the study necessitate that the results be interpreted cautiously, it offers a good indication of intervention strategies that will help the patients diagnosed with neurodegenerative disorders to cope better with the disease. While the results are to be expected, the present study has provided the data substantiating the necessity on a

palliative 'lens' while managing neurodegenerative disorders in India. Palliative care, by definition, encompasses care in different dimensions of life, i.e., physical, psychological, social, spiritual and emotional. As a field that is rapidly growing in knowledge base and practice strategies, psychosocial approach in neuro palliative care is an important area of practice. The use of a non-categorical approach in dealing with chronic diseases, with its emphasis on psychosocial outcomes ensures that the psychosocial issues are considered as part of the normative care, and not taken into account only when dysfunction is suspected. It also helps to identify specific times when support is necessary for the family.

In spite of the advances and research in medical technology, neurodegenerative disorders remain a group of diseases with limited chances of recovery. The illness and its disability are not transient or time limited, but relentless in its progression, with periodic crisis. The challenge for the individual patient and family is to live and cope with the consequences of the illness. Professionals who are trained in understanding and developing effective interventions related to human behavior, emotions, life cycle stages and tasks need to be deployed to provide effective management of the illness. When there is an imbalance in the life cycle in the form of the manifestations of the disease, what happens to the affected individual and the family? This understanding and appropriate interventions form the focus of the role of psychosocial professionals in neuro palliative care.

CONCLUSION

There is a need for training in addressing the psychosocial care in end of life and working with individuals with chronic and terminal disorders and their families. Incorporation of such topics in the graduation and post-graduation curriculum can be implemented to sensitize the young clinicians to gain exposure to such issues and thus contribute to the quality of life of the patients and families.

Acknowledgments

This research was part of the MPhil in Psychiatric Social Work, in NIMHANS.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Ragesh G, Zacharias L, Thomas PT. Palliative care social work in India: Current status and future directions. *Indian J Palliat Care* 2017;23:93-9.
2. Boersma I, Miyasaki J, Kutner J, Kluger B. Palliative care and neurology: time for a paradigm shift. *Neurology* 2014;83:561-7.
3. Kluger BM, Persenaire MJ, Holden SK, Palmer LT, Redwine HM, Berk J, *et al.* Implementation issues relevant to outpatient neurology palliative care. *Ann Palliat Med* 2017;7:339-48.
4. Oliver DJ, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzl S, *et al.* A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurol* 2016;23:30-8.

5. Komine O, Yamanaka K. Neuroinflammation in motor neuron disease. *Nagoya J Med Sci* 2015;77:537-49.
6. Boersma I, Jones J, Coughlan C, Carter J, Bekelman D, Miyasaki J, *et al.* Palliative care and Parkinson's disease: Caregiver perspectives. *J Palliat Med* 2017;20:930-8.
7. Bhimani R. Understanding the burden on caregivers of people with Parkinson's: A scoping review of the literature. *Rehabil Res Pract* 2014;2014:718527.
8. Aoun SM, Chochinov HM, Kristjanson LJ. Dignity therapy for people with motor neuron disease and their family caregivers: A feasibility study. *J Palliat Med* 2015;18:31-7.
9. Oliver DJ. Palliative care for patients with motor neurone disease: Current challenges. *Degener Neurol Neuromuscul Dis* 2016;6:65-72.
10. Bhatnagar S, Prabhakar H. Palliative care beyond oncology! *Indian J Palliat Care* 2012;18:85-6.
11. Palliative care outcome scale (POS). Available from: <https://pos-pal.org/maix/>. [Last accessed on 2016 Aug 10].
12. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist* 1980;20:649-55.
13. McIlfatrick S. Assessing palliative care needs: Views of patients, informal carers and healthcare professionals. *J Adv Nurs* 2007;57:77-86.
14. Roland KP, Chappell NL. Caregiver experiences across three neurodegenerative diseases: Alzheimer's, Parkinson's, and Parkinson's with dementia. *J Aging Health* 2019;31:256-79.
15. Caap-Ahlgren M, Dehlin O. Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. *Aging Clin Exp Res* 2002;14:371-7.
16. Chen JJ. Parkinson's disease: Health-related quality of life, economic cost, and implications of early treatment. *Am J Manag Care* 2010;16:S87-93.
17. 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.
18. Sharma RK, Prigerson HG, Penedo FJ, Maciejewski PK. Male-female patient differences in the association between end-of-life discussions and receipt of intensive care near death. *Cancer* 2015;121:2814-20.