

Original Article

Constraints of the Palliative Care Patients during Pandemic — A Cross-sectional Study

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Background : The challenge faced by Palliative care patients is vast even in the absence of a pandemic. COVID-19 is anticipated to surpass the capacity of the Healthcare system including Palliative care services.

Aim : To address the challenges faced by the palliative care patients during COVID-19 pandemic.

Setting and Design : This cross-sectional study was conducted in a Cancer institute.

Materials and Methods : This study was conducted among patients receiving Palliative care services in a Cancer Institute between September and October 2020 using semi-structure questionnaire.

Statistical Analysis Used : Independent and dependent variables were expressed as percentages. Analysis was done using IBM SPSS Version 20.0.

Results : The quantitative analysis revealed that 66% of the Palliative care patients were unable to access the health care facility, 41% had delay in diagnosis and 83% of them were unable to apply insurance schemes.

Conclusion : Accessibility of Healthcare facility, delay in diagnosis, and application of insurance schemes are the most common challenges faced by palliative care patients which led to the postponement of treatment, privatization of the health sector and increased hospital stay. Government should necessarily recognize the integration of Palliative care with various health schemes and digital Healthcare may support Palliative care to patients living in remote areas.

[J Indian Med Assoc 2023; 121(6): 29-32]

Key words : Constraints, Palliative care patients, COVID-19, Pandemic.

Palliative care which is also known as supportive care is defined according to the World Health Organization (WHO) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, Physical, Psychosocial and Spiritual”¹. Since the proportion of elderly increases in India, the burden of non-communicable diseases increases leading to the drastic increase in need of Palliative Care Services.

A survey done at Villupuram district in Tamil Nadu stated that the prevalence of people in need of Palliative care is around 4.5/1000 population^{2,3}. The highest proportion of adults in need of palliative care at the

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Received on : 23/03/2022

Accepted on : 27/06/2022

Editor's Comment :

- Palliative care patients finding difficult to access centre facilities, diagnosis and application of insurance schemes.
- Digitalization of health care system by the government will improve the accessibility for the palliative care patients, increasing more centres.

end of life is from low- and middle-income countries. As per the World Health Organization- Global Health estimates, around 54.6 million deaths occurred globally and among those deaths, 66% were due to Non-communicable diseases. The trend in India is as such similar.

The coverage of Palliative care services is very sparse in our country. According to the recent estimate, only <2% of people have access to any type of Palliative care^{4,5}. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice during the COVID-19 Pandemic mentioned that the hospice and palliative services have an essential role in the response to COVID-19 by responding rapidly and flexibly; ensuring protocols for symptom management are available and training non-specialists in their use; being involved in triage; considering shifting resources into the community; considering redeploying volunteers to provide psychosocial and bereavement care; facilitating trust and adopting measures to deal with

stress; using technology to communicate with patients and carers; and adopting standardized data collection systems to inform operational changes and improve care⁶.

A study done in 2020 stated many challenges to provide high-quality advance care planning during COVID-19. Professionals and Healthcare providers need to ensure advance care planning is well-founded for individuals and genuinely tailored to their values and priorities and attuned to their ethnic, cultural, and religious context. Policymakers for health and social care need to consider carefully how high-quality ACP can be resourced and normalized as a part of standard Healthcare ahead of future pandemic waves⁷.

A review article on "Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach" concluded that the challenges are promoting early interventions that extend to all patients, in all settings, and to integrate Palliative care program with public health⁸.

Hence, little is known about the challenges faced by Palliative care patients even in the absence of a pandemic. COVID-19 pandemic is anticipated to surpass the capacity of the healthcare system including Palliative care services. Therefore this study aimed to address the challenges and the solutions for the Palliative care services among patients during COVID-19.

MATERIALS AND METHODS

After obtaining clearance from Institutional Human Ethical Committee we have conducted a mixed-methods study among patients (>18 years of age) receiving palliative care services in a Cancer Institute at Cuddalore for a duration of 2 months. The subjects were recruited based on the inclusion and exclusion criteria and informed written consent was obtained. The study was conducted using a pre-tested, semi-structured interview schedule. The sample size was calculated as 92 patients based on the prevalence.

Inclusion Criteria :

- Patients (>18 years of age) who are receiving Palliative care services in Cancer Institutes were included in the study.

Exclusion Criteria :

- Patients with cognitive impairment who are in the absence of care-givers.
- Moribund persons who were unable to answer.

Data Analysis :

The data was entered in EpiCollect⁵ and analysis was done using IBM SPSS software Version 20.0. All

the independent variables such as age, gender, monthly family income, morbidity profile, place of diagnosis, and treatment were expressed in frequency and percentage. The dependent variables such as constraints related to diagnosis and treatment, insurance schemes were also expressed in frequency and percentage.

RESULTS

The study results showed 59% of the people were above 60 years of age and 76% of them were females. Most of them were Hindu and married with a monthly family income of Rs.5000. There were 97.8% of people with cancer among the subjects requiring palliative care. Their place of diagnosis and treatment was the Private sector with a duration of illness of more than 6 months as per the characteristics given in Table 1.

Constraints of palliative care patients were divided into sections like constraints of palliative care patients, constraints in diagnosis and treatment, and insurance schemes. The constraints of palliative care patients were:

- Difficulty in travel (66%),
- Difficulty in crossing the check-post at the borders of the state while assessing for treatment (87%),

Table 1 — Socio-demographic details and morbidity profile of study participant (n= 92)

Socio-demographic Data		Frequency	Percentage
Age	< 60 years	37	40.22
	> 60 years	55	59.78
Gender	Male	22	23.91
	Female	70	76.09
Religion	Hindu	86	93.48
	Muslim	5	5.43
	Christian	1	1.09
Marital Status	Single	1	1.09
	Married	86	93.48
	Widowed	2	2.17
	Divorced	1	1.09
	Separated	2	2.17
Monthly family income	< 5000	87	94.57
	5000 – 10000	3	3.26
	10000 – 30000	2	2.17
	> 30000	0	0
Disease condition	Cancer	90	97.83
	Trauma/injuries	2	2.17
Place of diagnosis	Government	37	40.22
	Private	55	59.78
Duration of illness	< 6 months	24	26.09
	> 6 months	68	73.91
Place of treatment	Government hospital/ Medical colleges	30	32.61
	Private hospital/ Medical colleges	60	65.22
	Home-based treatment	2	2.17

- Difficulty to avail food during the travel (86%),
- Emotional constraints and social issues during accompanying the person during pandemic were 89% and 91 % respectively as stated in Fig 1.

Constraints in diagnosis and treatment were segregated into 5 divisions like:

- Difficulty in undergoing initial screening (65%),
- Delay in treatment initiation (53%),
- Delay in initial investigations (45%),
- Delay in diagnosis and change in the treatment plan was 41% and 14% respectively as per Fig 2.

- Constraints in insurance schemes were expressed as 97% of patients had a delay in the application of insurance scheme for treatment, change in treatment plan due to non-availability of schemes (83%), and change in financial expenses (94) respectively as given in Fig 3.

DISCUSSION

Based on the objective of the study which is to address the challenges and the solution exploration on the challenges faced by the Palliative care patients during the Pandemic, our study showed 97.8% of people with cancer among the subjects were requiring Palliative care. Their place of diagnosis and treatment was the Private sector with the duration of illness of more than 6 months.

Our study showed the constraints of palliative care patients were difficulty in travel, difficulty in crossing the check-post at the borders of the state while assessing for treatment, difficulty to avail food during the travel, emotional constraints and social issues during accompanying the person during the Pandemic. A study stating similar features regarding the Palliative care services during COVID-19 pandemic is as follows: “An exploratory study done on Palliative care interventions from a social work perspective and the

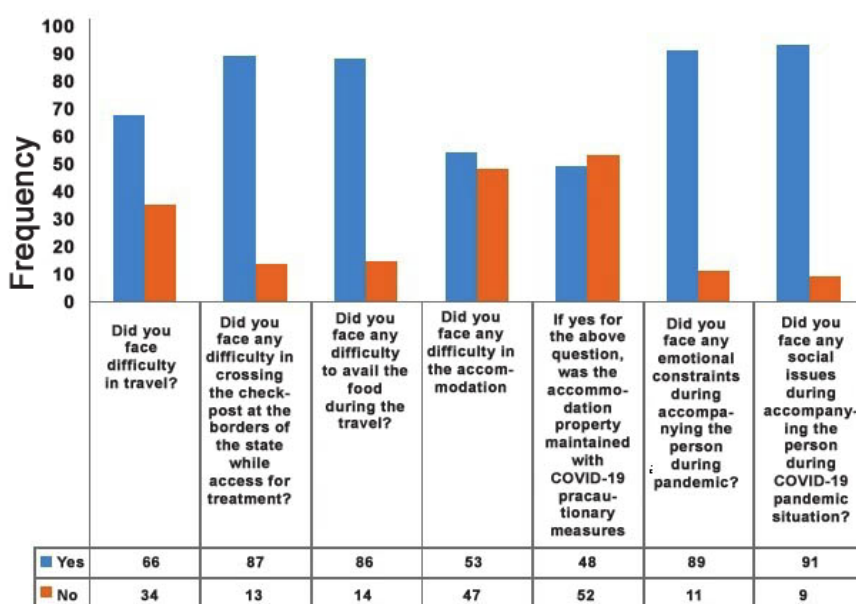


Fig 1 — Constraints of palliative care patients (n=92)

challenges faced by patients and care-givers during COVID-19” showed that in COVID pandemic, patients and caregivers are left more vulnerable at this time. It highlights on the physical and emotional distress due to the lack of care, access to treatment and interruption in treatment.

In our study, we captured the constraints in diagnosis and treatment and segregated them into 5 divisions like difficulty in undergoing initial screening, delay in treatment initiation, delay in initial investigations, delay in diagnosis and change in the treatment plan. We also captured the constraints in insurance schemes and among them the majority of patients had a delay in the application of insurance scheme for treatment, change in treatment plan due

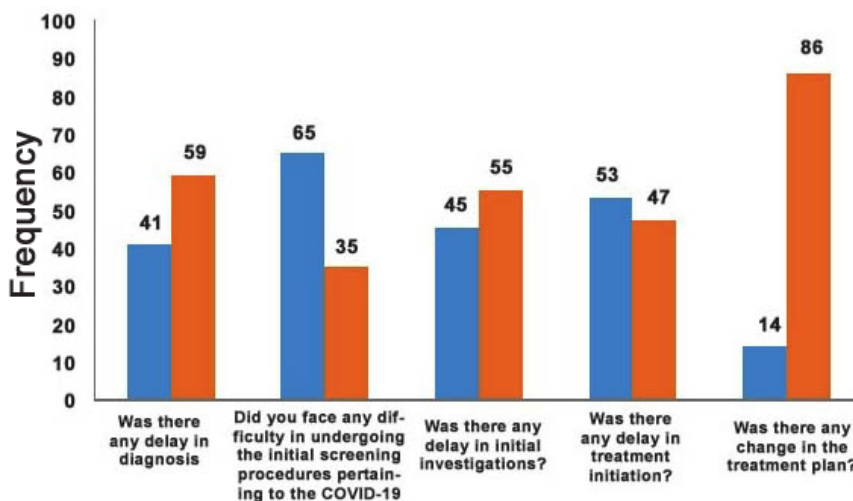


Fig 2 — Constraints in diagnosis and treatment (n=92)

to non-availability of scheme, and change in financial expenses. "A study on Palliative care challenges and strategies for the management amid COVID-19 Pandemic in India: Perspectives of Palliative care nurses, cancer patients, and care-givers" showed the similar results that the COVID-19 pandemic is increasing day by day that makes the patients still live with a fear of getting infected and compromised family life. The lockdown has brought a lot of challenges to the patient and family members to cope with the difficult situations. Adequate resource allocation can make a significant change in patient care which would ensure safe and effective practice for the nurses. Financial challenges and insurance schemes were the more important component among them.

Hence, our study findings mainly highlighted that there are many constraints like difficulty in the accessibility of health care facilities, delay in diagnosis, and application of insurance schemes due to COVID-19 which made the Palliative care patients postpone their treatment and prefer the private sectors and to increase their stay in hospitals.

CONCLUSION

- Accessibility of health care facility, delay in diagnosis and application of insurance schemes are the most common challenges faced by Palliative care patients during COVID-19 pandemic.
- This led to the postponement of treatment, privatization of the health sector and increased hospital stay.

Recommendations :

- Government should necessarily recognize the integration of Palliative care with various health schemes.
- Digital health care may support Palliative care for patients living in remote areas.
- With increasing needs, more Palliative care center initiatives can be done at the community level to increase awareness.

Authors' Contribution :

- All authors read and approved the final article. MM participated in the design of the study, analyzed data, interpreted results and drafted the initial article. KR revised the article. KV analyzed the data. BPS revised again the article for the intellectual content in it.

ACKNOWLEDGMENT

This is to acknowledge the services rendered by The Medical Superintendent of the Cancer Institute for permission to conduct the study and the Doctors and

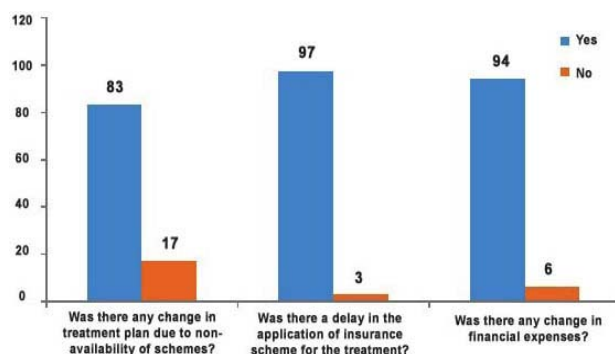


Fig 3 — Constraints in insurance schemes (n=92)

Staff Nurse for their extreme support in the data collection process. Also, I would like to acknowledge my Dean for allowing me to conduct the study at Cancer Institute and HOD for his support.

Funding : NIL

Conflict of interest : NIL

REFERENCES

- 1 World Health Organization- Definition of Palliative Care. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
- 2 Elayaperumal S, Venugopal V, Dongre AR — Identifying People in Need of Palliative Care Services in Rural Tamil Nadu: A Survey. *Indian J Palliat Care* 2018; **24(4)**: 393-6.
- 3 Khosla D, Patel FD, Sharma SC — Palliative Care in India: Current Progress and Future Needs. *Indian J Palliat Care* 2012; **18(3)**: 149-54.
- 4 Daya AP, Sarkar S, Kar SS — Estimation of palliative care need in the urban community of Puducherry. *Indian J Palliat Care* 2017; **23(1)**: 81-7.
- 5 The current status of palliative care in India | Cancer Control. Available from: <http://www.cancercontrol.info/cc2015/the-current-status-of-palliative-care-in-india/>
- 6 Etkind SN, Lovell N, Higginson IJ, Sleeman KE — The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. *J Pain & Sympt Man* 2020; **60(1)**: 31-40
- 7 Bradshaw A, Dunleavy L, Walshe C, Preston N, Cripps R, Hocaoglu MB, *et al* — Understanding and addressing challenges for Advance Care Planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services. *medRxiv*. 2020 Oct 30;2020.10.28.20200725.
- 8 Gómez-Batiste X, Martínez-Muñoz M, Blay C, Espinosa J, Contel JC, Ledesma A — Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. *Curr Opin Support Palliat Care* 2012; **6(3)**: 371-8.
- 9 Pai RR, Nayak MG, Sangeetha N — Palliative Care Challenges and Strategies for the Management Amid COVID-19 Pandemic in India: Perspectives of Palliative Care Nurses, Cancer Patients, and Caregivers. *Indian J Palliat Care* 2020; **26(Suppl 1)**: S121-5.
- 10 Dhavale P, Koparkar A, Fernandes P — Palliative care interventions from a social work perspective and the challenges faced by patients and caregivers during COVID-19. *Indian J Palliat Care* 2020; **26(5)**: 58.