

# A Nationwide Survey on the Practice of End-of-life Care Issues in Critical Care Units in India

Indu Kapoor<sup>1</sup>, Hemanshu Prabhakar<sup>2</sup>, Charu Mahajan<sup>3</sup>, Kapil Gangadhar Zirpe<sup>4</sup>, Swagata Tripathy<sup>5</sup>, Jaya Wanchoo<sup>6</sup>, Gaurav Kakkar<sup>7</sup>, Harsh Sapra<sup>8</sup>, Nidhi Gupta<sup>9</sup>, Vasudha Singh<sup>10</sup>, Arvind Chaturvedi<sup>11</sup>

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## ABSTRACT

**Background:** End-of-life (EOL) care is the care of terminally ill patients who are nearing their end. It includes important components like palliative care, supportive care, hospice care, patient's right to choose, and choice of medical intervention, including continuation of routine medical interventions. The aim of this survey was to assess the practices of EOL care in various critical care units in India.

**Methods:** The participants included clinicians involved in EOL care of patients with advanced diseases in different hospital across India. We sent blast emails and posted links on social media for inviting participants to take the survey. Study data were collected and managed by using Google Forms. The collected information was automatically entered into a spread sheet and stored in a secure database.

**Results:** In total, 91 clinicians took the survey. The years of experience, practice area, and setting had significant effect on the palliative care, terminal strategy, and prognostication in terminally ill patients ( $p < 0.05$ ). Statistical analysis was done using software STATA. Descriptive statistics were performed, and results were presented as number (percentage).

**Conclusion:** The years of work experience, the practice area, and the practice setting have a strong impact on EOL care management of terminally ill patients. There are a lot of gaps in providing EOL care for these patients. Many reforms are needed in the Indian health care system to make EOL care better.

**Keywords:** Critical care unit, End-of-life care, India, Terminally ill patient.

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## HIGHLIGHTS

- End-of-life (EOL) care is defined as the care of patients who are nearing death.
- The goal of EOL care is to control pain and other symptoms to make the patient comfortable.
- Years of experience, practice area, and setup affect the EOL care and approach to prognostication.
- Reforms are needed in the Indian healthcare system to make EOL care efficient.

## INTRODUCTION

End-of-life (EOL) care is defined as the care of terminally ill patients who are nearing death and have stopped treatment to cure their disease. Patients who are nearing their death need care in important areas such as mental, emotional and physical needs, spiritual needs, and maintenance of functionality as long as possible.<sup>1</sup> The goal of EOL care is to control pain, anxiety, and other symptoms so the patient can be comfortable. End-of-life care may include many important decisions like palliative care, supportive and hospice care, patient's right to choose the manner and location of further treatment, and choice of medical treatment, including continuation of routine medical interventions.<sup>1,2</sup> There are a few signs that might point toward approaching death, which include increased drowsiness, sleepiness, unresponsiveness, disorientation to time, place, restlessness, identity of loved ones, visual hallucinations, reduced socialization and withdrawal, loss of bladder or bowel control, and decreased urine output or dark colored urine.<sup>3</sup> The excellent care toward EOL focuses mainly on the palliation of the symptoms and quality-of-life instead of disease treatment.<sup>4</sup> Prognostication plays

<sup>1-3,11</sup>Department of Neuroanaesthesiology and Critical Care, All India Institute of Medical Sciences, New Delhi, India

<sup>4</sup>Department of Neurotrauma Unit, Grant Medical Foundation, Pune, Maharashtra, India

<sup>5</sup>Department of Anesthesia and Intensive Care, All India Institute of Medical Sciences, Bhubaneswar, Odisha, India

<sup>6,8,10</sup>Department of Neuroanaesthesia and Neurocritical Care, Medanta The Medicity, Gurgaon, Haryana, India

<sup>7</sup>Department of Neuroanaesthesia and Neurocritical Care, Amrita Hospital, Faridabad, India

<sup>9</sup>Department of Neuroanaesthesia, Indraprastha Apollo Hospital, New Delhi, India

**Corresponding Author:** Indu Kapoor, Department of Neuroanaesthesiology and Critical Care, All India Institute of Medical Sciences, New Delhi, India, Phone: +91 9013439134, e-mail: dr.indu.me@gmail.com

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important role in deciding the treatment plan in these patients. Unfortunately, the healthcare providers inaccurately predict the

time of death and often overestimate the survival time.<sup>5,6</sup> According to a multi-centric cohort study involving hospitalized patients with advanced cancer, palliative care providers can predict time to death only in 41% of patients, and the survival rate was overestimated in 85% of patients.<sup>7</sup> The recognition of impending death is important for healthcare providers to notify the close family members who may want to personally provide care and companionship to the patient. It is important that at final hours, care should be provided to patients as well as to the patient's relatives. Educating family members about some expected symptoms and signs in the final hours or days is important. For patients dying in the hospital, it is important to enquire about the family's desire for autopsy.

The aim of our survey was to assess the practices of EOL care issues in intensive care units (ICUs) across various hospitals setting in India. The primary outcome of the survey was to assess the quality of palliative care of the terminally ill patients in the ICUs in India. The secondary outcome of the study was to determine: (i) treatment strategies in the patient management, (ii) challenges faced during care of patients, and (iii) approaches to prognostication in terminally ill patients.

## MATERIALS AND METHODS

This cross-sectional online survey was approved by the Institute's Ethics Committee (IEC) (IEC-696/02.09.2022). The Society of Neurocritical Care [SNCC (S/RS/DW(SW)/314/2018)] endorsed this activity and approved the final document. A steering committee consisting of 10 intensivists involved in the management of patients requiring EOL care was formed. A questionnaire was prepared which was then circulated among the committee members. The questionnaire comprised of pertinent questions related to EOL care. After discussion and two rounds of circulation, the questionnaire was finalized. The participants of this survey included clinicians involved in EOL care of patients with advanced diseases in different hospital settings across India. Participants were considered as collaborators. We allowed more than one submission from any hospital, provided the survey was taken by different clinicians. We sent blast emails and posted links on social media for inviting participants to take the survey. We also shared links through personal contacts. Study data were collected and managed by using Google Forms. Google Forms is a survey administration software included as part of the free, web-based Google Docs Editors suite offered by Google. The application allowed users to create and edit surveys online with online collaboration with other users in real time. The collected information was automatically entered into a spreadsheet. Data were collected and stored as a spreadsheet in a secure database.

Statistical analysis was done using the software STATA. Descriptive statistics were performed, and results were presented as numbers (percentage).

## RESULT

A total of 91 clinicians took the survey. The questionnaire used in the survey is appended (Appendix 1), and responses are shown in Table 1. About 50 (54.95%) clinicians had <15 years of experience, and 41 (45.05%) clinicians had >15 years of practice. About 75 (82.42%) clinicians worked in an urban setting, whereas 16 (17.58%) had practice in either suburban or rural area. About 16 (17.58%) clinicians were from government centers, 53 (58.24%) from private teaching centers, and 22 (24.18%) worked at private nonteaching institutes.

The effect of years of experience, the practice area, and the practice setting on various treatment strategies and approach to prognostication are shown in Tables 2 to 4.

## DISCUSSION

In this survey, we noted the years of experience, the practice area, and the practice setting of the clinicians and their effect on various treatment strategies and approaches to prognostication in terminally ill patients.

### Effect of Years of Experience

The relationship between a clinician's years of experience and EOL care outcome is not well-defined. Ours is the first of its kind of study, where the effect of a clinician's years of experience has been noted on EOL care management in terminally ill patients in India. We found that clinicians with long years of experience tend to discuss care/management plans with relatives (92% versus 74%;  $p = 0.026$ ), regularly assessed their patients (97% versus 72%;  $p = 0.002$ ), addressed the symptoms (95% versus 72%;  $p = 0.008$ ), and provided the bereavement support (68% versus 48%;  $p = 0.031$ ). The spiritual support to take care of the symptoms (43% versus 24%;  $p = 0.04$ ) and involvement of social care workers in handling grief among terminally ill patients and their relatives were more often done by clinicians with long years of experience (51% versus 24%;  $p = 0.009$ ).

Earlier studies done mostly in acute emergency settings have shown the increasing correlation of the clinician seniority with improved clinical outcomes.<sup>8,9</sup> According to a retrospective cohort study where authors aimed to examine the influence of emergency physician's seniority (junior group (less than 5 years of experience), intermediate group (6–10 years of experience) and senior group (more than 10 years of experience) on decisions regarding patient dispositions in the emergency department, concluded that the senior physicians had the excellent quality of care with lowest mortality rate with fewer patient coming back to the emergency department (ED) within 72-hour after discharge.<sup>8</sup> In another retrospective study by Li et al., the authors observed that although senior emergency physicians (>10 years' experience) take more time to order prescriptions and use less diagnostic investigations, but are associated with a lower mortality rate in ED.<sup>9</sup> Harvey et al. observed that the patient waiting time, time seen to disposition, and total ED length of stay was reduced when ED was staffed by senior physicians.<sup>10</sup>

Our survey also arrived to the similar finding that the clinicians with longer years of experience provided better EOL care and support to terminally ill patients than that of clinicians with less years of experience (Table 2).

### Effect of Practice Area

Rural–urban disparities exist in provision of healthcare services, but there is limited research on how working in different practice areas can impact clinician's adherence to clinical services in terms of care and support to the patient. The role of geographic access to inpatient EOL care facilities is little known. In our survey, we noted the impact of clinicians working in urban/sub-urban and rural areas on EOL care and support in terminally ill patients. We observed that clinicians working in urban setup frequently provided the palliative sedation ( $p = 0.028$ ), often recognized that the patient is terminally ill ( $p = 0.029$ ), and imposed more restrictions on the number of relatives or loved ones of the patients who can meet them ( $p = 0.021$ ).

**Table 1:** Baseline responses from different hospitals across India

	Yes	No	Sometimes
Recognition of symptoms	61 [67.03]	–	30 [32.97]
Communication to patient	35 [38.46]	15 [16.48]	41 [45.05]
Communication to relatives	87 [95.6]	–	4 [4.4]
Provide spiritual care	24 [26.37]	14 [15.38]	53 [58.24]
Medicine in anticipation of symptoms	74 [81.32]	1 [1.1]	16 [17.58]
Review clinical intervention	78 [85.7]	1 [1.1]	12 [13.19]
Review hydration	83 [91.21]	1 [1.1]	7 [7.69]
Review nutrition	83 [91.21]	1 [1.1]	7 [7.69]
Discuss care plan with patient	43 [47.25]	7 [7.69]	41 [45.05]
Discuss care plan with relatives	75 [82.42]	–	16 [17.58]
Regular assessment	76 [83.52]	1 [1.1]	14 [15.38]
Palliative sedation	34 [37.36]	2 [2.2]	55 [60.44]
Terminology awareness	89 [97.8]	2 [2.2]	–
Consider withholding	34 [37.36]	15 [16.48]	42 [46.15]
Continue invasive intervention	5 [5.49]	54 [59.34]	32 [35.16]
Continue costly medicines	5 [5.49]	64 [70.33]	22 [24.18]
Address symptoms	75 [82.42]	2 [2.2]	14 [15.38]
Bereavement support	52 [57.14]	10 [10.99]	29 [31.87]
Dedicated team in ICU	11 [12.09]	80 [87.91]	–
Social workers involvement	33 [36.26]	58 [63.74]	–
Ask patient their last wish	36 [39.56]	55 [60.44]	–
Ask patient their will	29 [31.87]	62 [68.13]	–
Restriction on number of relatives	39 [42.86]	52 [57.14]	–
Allow children to meet	46 [50.55]	45 [49.45]	–
Use term dying	22 [24.18]	39 [42.86]	30 [32.97]
Allow relative to speak before intubation	81 [89.01]	10 [10.99]	–
Discuss will of patient with relatives	34 [37.36]	36 [39.56]	21 [23.08]
Pain as distressing symptom	70 [76.92]	21 [23.08]	–
Fear as distressing symptom	41 [45.05]	50 [54.95]	–
Breathlessness as distressing symptom	52 [57.14]	39 [42.86]	–
Delirium as distressing symptom	43 [47.25]	48 [52.75]	–
Agitation as distressing symptom	34 [37.36]	57 [62.64]	–
Pharmacological support for distressing symptom	–	91 [100]	–
Psychological support for distressing symptom	70 [76.92]	21 [23.08]	–
Spiritual support for distressing symptom	30 [32.97]	61 [67.03]	–

According to national population-based observational study by Chukwusa et al., geographic access is one of the important determinants of place of death and that the rural and urban areas affect the size of the effect. The death in the EOL hospice care inpatient facilities is less among rural dwellers compared to their urban counterparts.<sup>11</sup> Baernholdt et al. compared quality of hospice care between rural and urban patients and their families. The authors used three *interventions*: explanation of plan of care, information about patient's condition, and emotional support. They included three *outcomes* which included: overall satisfaction, satisfaction with pain management, and satisfaction with other symptom management. Rural participants reported higher overall satisfaction with pain/symptom management. Regardless of geographic location, satisfaction was higher when patients were informed and emotionally supported. There was no significant difference between patient and their family satisfaction.<sup>12</sup>

Awareness among people about palliative care in terminally ill patients also differs in urban and rural areas. Joseph et al. in their

comparative study observed that 15.7% participants in urban and only 4.2% in rural areas had some knowledge of palliative care in terminally ill patients.<sup>12</sup> About 86.8% participants in urban and 77.8% in rural areas felt that palliative care helps in improving quality of life. About 78.9% urban participants felt that the terminal condition of the illness needs to be told to the patient first followed by their family members.<sup>13</sup> Our survey also revealed that irrespective of the practice area, the care plan discussion is mostly conducted with the relatives (84% in urban, 75% in suburban/rural) than with patient himself (Table 3).

### Effect of Practice Setting

The concept of EOL care is relatively new in India, but the requirement of such care is beyond imagination. There are 108 entities in India that currently provide EOL care facilities to improve the quality of life and palliative treatment services.<sup>14</sup> Non-government organizations (NGOs), government hospitals, private hospitals, and hospice centers are primary care providers. According to our survey, clinicians

**Table 2:** Years of work experience and its effect on various baseline responses

	<15 years: 50 [54.95%]			>15 years: 41 [45.05%]			<i>p</i> -value
	Yes	No	Sometimes	Yes	No	Sometimes	
Recognition of symptoms	36 [72]	0	14 [28]	25 [60.98]	0	16 [39.02]	0.266
Communication to patient	15 [30]	11 [22]	24 [48]	20 [48.78]	4 [9.76]	17 [41.46]	0.115
Communication to relatives	46 [92]	0	4 [8]	41 [100]	0	0	0.124
Provide spiritual care	12 [24]	11 [22]	27 [54]	12 [29.27]	3 [7.32]	26 [63.41]	0.163
Medicine in anticipation of symptoms	38 [76]	1 [2]	11 [22]	36 [87.8]	0	5 [12.2]	0.275
Review clinical intervention	42 [84]	1 [2]	7 [14]	36 [87.8]	0	5 [12.2]	1.000
Review hydration	44 [88]	1 [2]	5 [10]	39 [95.12]	0	2 [4.88]	0.559
Review nutrition	45 [90]	1 [2]	4 [8]	38 [92.68]	0	3 [7.32]	1.000
Discuss care plan with patient	22 [44]	5 [10]	23 [46]	21 [51.22]	2 [4.88]	18 [43.90]	0.621
Discuss care plan with relatives	37 [74]	0	13 [26]	38 [92.68]	0	3 [7.32]	0.026
Regular assessment	36 [72]	1 [2]	13 [26]	40 [97.56]	0	1 [2.4]	0.002
Palliative sedation	16 [32]	1 [2]	33 [66]	18 [43.9]	1 [2.44]	22 [53.66]	0.493
Terminology awareness	49 [98]	1 [2]	0	40 [97.56]	1 [2.44]	0	1.000
Consider withholding	17 [34]	6 [12]	27 [54]	17 [41.46]	9 [21.95]	15 [36.59]	0.205
Continue invasive intervention	2 [4]	34 [68]	14 [28]	3 [7.32]	20 [48.78]	18 [43.9]	0.172
Continue costly medicines	2 [4]	40 [80]	8 [16]	3 [7.32]	24 [58.54]	14 [34.15]	0.076
Address symptoms	36 [72]	2 [4]	12 [24]	39 [95.12]	0	2 [4.88]	0.008
Bereavement support	24 [48]	9 [18]	17 [34]	28 [68.29]	1 [2.44]	12 [29.27]	0.031
Dedicated team in ICU	5 [10]	45 [90]	0	6 [14.63]	35 [85.37]	0	0.535
Social workers involvement	12 [24]	38 [76]	0	21 [51.2]	20 [48.78]	0	0.009
Ask patient their last wish	18 [36]	32 [64]	0	18 [43.9]	23 [56.1]	0	0.520
Ask patient their will	16 [32]	34 [68]	0	13 [31.71]	28 [68.29]	0	1.000
Restriction on number of relatives	26 [52]	24 [48]	0	13 [31.71]	28 [68.29]	0	0.052
Allow children to meet	22 [44]	28 [56]	0	24 [58.54]	17 [41.46]	0	0.168
Use term dying	11 [22]	20 [40]	19 [38]	11 [26.83]	19 [46.34]	11 [26.83]	0.527
Allow relative to speak before intubation	42 [84]	8 [16]	0	39 [95.12]	2 [4.88]	0	0.107
Discuss will of patient with relatives	17 [34]	22 [44]	11 [22]	17 [41.46]	14 [34.15]	10 [24.39]	0.624
Pain as distressing symptom	39 [78]	11 [22]	0	31 [75.61]	10 [24.39]	0	0.788
Fear as distressing symptom	19 [38]	31 [62]	0	22 [53.66]	19 [46.34]	0	0.135
Breathlessness as distressing symptom	25 [50]	25 [50]	0	27 [65.85]	14 [34.15]	0	0.128
Delirium as distressing symptom	22 [44]	28 [56]	0	21 [51.22]	20 [48.78]	0	0.492
Agitation as distressing symptom	19 [38]	31 [62]	0	15 [36.59]	26 [63.41]	0	0.890
Pharmacological support for distressing symptom	50 [100]	0	0	41 [100]	0	0	–
Psychological support for distressing symptom	37 [74]	13 [26]	0	33 [80.49]	8 [19.51]	0	0.465
Spiritual support for distressing symptom	12 [24]	38 [76]	0	18 [43.9]	23 [56.10]	0	0.04

working in private nonteaching setting discuss maximally about the care plan with relatives of the patient (95.45%), followed by private teaching centers (86.79%), and government institutes (50%) ( $p = 0.001$ ). We also observed that private nonteaching institutes often consider withholding or withdrawal of care in terminally ill patients (50%) followed by private teaching centers (41.51%) and government centers (6.25%) ( $p = 0.036$ ).

The Surviving Sepsis Guidelines 2008 recommend that realistic goals of management and limitation of life support be discussed

with the relatives of terminally ill patient.<sup>15</sup> According to an Indian report prospectively collected as a part of the international Simplified Acute Physiology Score (SAPS3) study data, an average end-of-life decision (EOLD) rate recorded in four Mumbai hospitals was 34%.<sup>16</sup> It preceded to 41–50% of ICU deaths in a cancer referral center and two private hospitals that admit both free and paying patients. In the government hospital that serves to non-paying patients, 23% deaths occurred in the ICU with 19% EOLD rate only. As per a study conducted from a “closed” ICU, out of

**Table 3:** Practice area and its effect on baseline responses

	Urban: 75 [82.42%]			Sub/Rural:16 [17.58%]			p-value
	Yes	No	Sometimes	Yes	No	Sometimes	
Recognition of symptoms	54 [72]	0	21 [28]	7 [43.75]	0	9 [56.25]	0.029
Communication to patient	31 [41.33]	11 [14.67]	33 [44]	4 [25]	4 [25]	8 [50]	0.351
Communication to relatives	71 [94.67]	0	4 [5.33]	16 [100]	0	0	1.000
Provide spiritual care	21 [28]	9 [12]	45 [60]	3 [18.75]	5 [31.25]	8 [50]	0.208
Medicine in anticipation of symptoms	61 [81.33]	1 [1.33]	13 [17.33]	13 [81.25]	0	3 [18.75]	1.000
Review clinical intervention	64 [85.33]	1 [1.33]	10 [13.33]	14 [87.5]	0	2 [12.5]	1.000
Review hydration	69 [92]	1 [1.33]	5 [6.67]	14 [87.5]	0	2 [12.5]	0.673
Review nutrition	70 [93.33]	1 [1.33]	4 [5.33]	13 [81.25]	0	3 [18.75]	0.261
Discuss care plan with patient	38 [50.67]	5 [6.67]	32 [42.67]	5 [31.25]	2 [12.5]	9 [56.25]	0.266
Discuss care plan with relatives	63 [84]	0	12 [16]	12 [75]	0	4 [25]	0.470
Regular assessment	63 [84]	1 [1.33]	11 [14.67]	13 [81.25]	0	3 [18.75]	0.760
Palliative sedation	30 [40]	0	45 [60]	4 [25]	2 [12.5]	10 [62.5]	0.028
Terminology awareness	74 [98.67]	1 [1.33]	0	15 [93.75]	1 [6.25]	0	0.322
Consider withholding	26 [34.67]	13 [17.33]	36 [48]	8 [50]	2 [12.5]	6 [37.5]	0.618
Continue invasive intervention	5 [6.67]	42 [56]	28 [37.33]	0	12 [75]	4 [25]	0.456
Continue costly medicines	4 [5.33]	51 [68]	20 [26.67]	1 [6.25]	13 [81.25]	2 [12.5]	0.477
Address symptoms	61 [81.33]	2 [2.67]	12 [16]	14 [87.5]	0	2 [12.5]	1.000
Bereavement support	44 [58.67]	7 [9.33]	24 [32]	8 [50]	3 [18.75]	5 [31.25]	0.558
Dedicated team in ICU	8 [10.67]	67 [89.33]	0	3 [18.75]	13 [81.25]	0	0.401
Social workers involvement	29 [38.67]	46 [61.33]	0	4 [25]	12 [75]	0	0.396
Ask patient their last wish	31 [41.33]	44 [58.67]	0	5 [31.25]	11 [68.75]	0	0.577
Ask patient their will	23 [30.67]	52 [69.33]	0	6 [37.5]	10 [62.5]	0	0.594
Restriction on number of relatives	28 [37.33]	47 [62.67]	0	11 [68.75]	5 [31.25]	0	0.021
Allow children to meet	39 [52]	36 [48]	0	7 [43.75]	9 [56.25]	0	0.549
Use term dying	19 [25.33]	30 [40]	26 [34.67]	3 [18.75]	9 [56.25]	4 [25]	0.567
Allow relative to speak before intubation	68 [90.67]	7 [9.33]	0	13 [81.25]	3 [18.75]	0	0.372
Discuss Will of patient with relatives	29 [38.67]	30 [40]	16 [21.33]	5 [31.25]	6 [37.5]	5 [31.5]	0.678
Pain as distressing symptom	58 [77.33]	17 [22.67]	0	12 [75]	4 [25]	0	1.000
Fear as distressing symptom	35 [46.67]	40 [53.33]	0	6 [37.5]	10 [62.5]	0	0.506
Breathlessness as distressing symptom	43 [57.33]	32 [42.67]	0	9 [56.25]	7 [43.75]	0	0.937
Delirium as distressing symptom	38 [50.67]	37 [49.33]	0	5 [31.25]	11 [68.75]	0	0.158
Agitation as distressing symptom	27 [36]	48 [64]	0	7 [43.75]	9 [56.25]	0	0.561
Pharmacological support for distressing symptom	75 [100]	0	0	16 [100]	0	0	-
Psychological support for distressing symptom	60 [80]	15 [20]	0	10 [62.5]	6 [37.5]	0	0.131
Spiritual support for distressing symptom	27 [36]	48 [64]	0	3 [18.75]	13 [81.25]	0	0.247

88 deaths among 830 admissions, 49% were preceded by EOLD. Of them, 58% had withholding of treatment, 35% had do-not-resuscitate (DNR) orders, and 7% had a withdrawal decision.<sup>17</sup> For a clinician, it is a critical stage when to start discussion on EOL care with patient or relatives. Indian Societies of Critical Care medicine (ISCCM) consensus Ethical Position Statement has issued a bedside checklist for initiating EOL discussion.<sup>18</sup> Our survey also identified that the care plan discussion with the relatives is significantly higher in private nonteaching centers compared with government or private teaching centers. However, there is

no percentage difference in care plan discussion with the patient among different practice settings.

Clinicians are the strong pillars who can handle the crisis the patient is going through during the final stage of life. The years of work experience, the practice area, and the practice setting have a strong impact on EOL care management of terminally ill patients. Still, there are lots of gaps in providing EOL care for these patients. End-of-life care should be made a mandatory part of treatment plan for any terminally ill patient. Many reforms are needed in Indian healthcare system to make both families and patients satisfied with EOL care.



**Table 4:** Effect of practice setting on baseline responses

	Government: 16 [17.58%]			Private Teaching: 53 [58.24%]			Private Non-Teaching: 22 [24.18%]			p-value
	Yes	No	Sometimes	Yes	No	Sometimes	Yes	No	Sometimes	
Recognition of symptoms	14 [87.5]	0	2 [12.5]	33 [62.26]	0	20 [37.74]	14 [63.64]	0	8 [36.36]	0.166
Communication to patient	5 [31.25]	1 [6.25]	10 [62.50]	22 [41.51]	10 [18.87]	21 [39.62]	8 [36.36]	4 [18.18]	10 [45.45]	0.600
Communication to relatives	16 [100]	0	0	50 [94.34]	0	3 [5.66]	21 [95.45]	0	1 [4.55]	1.000
Provide spiritual care	1 [6.25]	3 [18.75]	12 [75]	14 [26.42]	8 [15.09]	31 [58.49]	9 [40.91]	3 [13.64]	10 [45.45]	0.191
Medicine in anticipation of symptoms	12 [75]	0	4 [25]	43 [81.13]	1 [1.89]	9 [16.98]	19 [86.36]	0	3 [13.64]	0.792
Review clinical intervention	12 [75]	0	4 [25]	45 [84.9]	1 [1.89]	7 [13.21]	21 [95.45]	0	1 [4.55]	0.348
Review hydration	15 [93.75]	0	1 [6.25]	48 [90.57]	1 [1.89]	4 [7.55]	20 [90.91]	0	2 [9.09]	1.000
Review nutrition	15 [93.75]	0	1 [6.25]	49 [92.45]	1 [1.89]	3 [5.66]	19 [86.36]	0	3 [13.64]	0.700
Discuss care plan with Patient	6 [37.5]	0	10 [62.5]	25 [47.17]	6 [11.32]	22 [41.51]	12 [54.55]	1 [4.55]	9 [40.91]	0.477
Discuss care plan with relatives	8 [50]	0	8 [50]	46 [86.79]	0	7 [13.21]	21 [95.45]	0	1 [4.55]	0.001
Regular assessment	11 [68.75]	0	5 [31.25]	46 [86.79]	0	7 [13.21]	19 [86.36]	1 [4.55]	2 [9.09]	0.135
Palliative sedation	5 [31.25]	0	11 [68.75]	22 [41.51]	1 [1.89]	30 [56.60]	7 [31.82]	1 [4.55]	14 [63.64]	0.766
Terminology awareness	15 [93.75]	1 [6.25]	0	52 [98.11]	1 [1.89]	0	22 [100]	0	0	0.379
Consider withholding	1 [6.25]	3 [18.75]	12 [75]	22 [41.51]	9 [16.98]	22 [41.51]	11 [50]	3 [13.64]	8 [36.36]	0.036
Continue invasive intervention	3 [18.75]	9 [56.25]	4 [25]	1 [1.89]	33 [62.26]	19 [35.85]	1 [4.55]	12 [54.55]	9 [40.91]	0.166
Continue costly medicines	1 [6.25]	14 [87.5]	1 [6.25]	1 [1.89]	38 [71.70]	14 [26.42]	3 [13.64]	12 [54.55]	7 [31.82]	0.060
Address symptoms	13 [81.25]	1 [6.25]	2 [12.5]	45 [84.91]	0	8 [15.09]	17 [77.27]	1 [4.55]	4 [18.18]	0.387
Bereavement support	7 [43.75]	4 [25]	5 [31.25]	35 [66.04]	4 [7.55]	14 [26.42]	10 [45.45]	2 [9.09]	10 [45.45]	0.143
Dedicated team in ICU	1 [6.25]	15 [93.75]	0	8 [15.09]	45 [84.91]	0	2 [9.09]	20 [90.91]	0	0.740
Social workers involvement	5 [31.25]	11 [68.75]	0	23 [43.40]	30 [56.60]	0	5 [22.73]	17 [77.27]	0	0.220
Ask patient their last wish	5 [31.25]	11 [68.75]	0	22 [41.51]	31 [58.49]	0	9 [40.91]	13 [59.09]	0	0.797
Ask patient their will	4 [25]	12 [75]	0	19 [35.85]	34 [64.15]	0	6 [27.27]	16 [72.73]	0	0.703
Restriction on number of relatives	5 [31.25]	11 [68.75]	0	24 [45.28]	29 [54.72]	0	10 [45.45]	12 [54.55]	0	0.613
Allow children to meet	6 [37.5]	10 [62.5]	0	27 [51.94]	26 [49.06]	0	13 [59.09]	9 [40.91]	0	0.437
Use term dying	1 [6.25]	8 [50]	7 [43.71]	16 [31.19]	21 [39.62]	16 [30.19]	5 [22.73]	10 [45.45]	7 [31.82]	0.392
Allow relative to speak before intubation	12 [75]	4 [25]	0	48 [90.57]	5 [9.43]	0	21 [95.45]	1 [4.55]	0	0.163
Discuss Will of patient with relatives	5 [31.25]	7 [43.75]	4 [25]	20 [37.74]	20 [37.74]	13 [24.53]	9 [40.91]	9 [40.91]	4 [18.18]	0.962
Pain as distressing symptom	11 [68.75]	5 [31.25]	0	44 [83.02]	9 [16.98]	0	15 [68.18]	7 [31.82]	0	0.273
Fear as distressing symptom	7 [43.75]	9 [56.25]	0	26 [49.06]	27 [50.94]	0	8 [36.36]	14 [63.64]	0	0.646
Breathlessness as distressing symptom	8 [50]	8 [50]	0	30 [56.6]	23 [43.40]	0	14 [63.64]	8 [36.36]	0	0.672
Delirium as distressing symptom	9 [56.25]	7 [43.75]	0	27 [50.94]	26 [49.06]	0	7 [31.82]	51 [68.18]	0	0.246
Agitation as distressing symptom	5 [31.25]	11 [68.75]	0	19 [35.85]	34 [64.15]	0	10 [45.45]	12 [54.55]	0	0.659
Pharmacological support for distressing symptom	16 [100]	0	0	53 [100]	0	0	22 [100]	0	0	-
Psychological support for distressing symptom	13 [81.25]	3 [18.75]	0	40 [75.47]	13 [24.53]	0	17 [77.27]	5 [22.73]	0	0.942
Spiritual support for distressing symptom	5 [31.25]	11 [68.75]	0	18 [33.96]	35 [66.04]	0	7 [31.82]	15 [68.18]	0	1.000



**COLLABORATORS LIST**

Name	Affiliation	Name	Affiliation
Ravi Jain	Mahatma Gandhi medical College, Jaipur	Sumit Chaudhari	Galaxy Multi-Speciality Hospital, Surat
Ankur Luthra	PGIMER, Chandigarh	Senthil Kumaran S	Manian Medical Centre, Salem
Devachandran Jayakumar	Dr Kamakshi Memorial Hospital, Chennai	Tushar Yadav	Aditya Birla Memorial Hospital, Mumbai
Chayanika Kutum	G.B Pant Hospital, New Delhi	Murali T	KMCH, Coimbatore
Ziyokov Joshi	Tagore Heart Care Center, Jalandhar	Balasaheb D Bande	Noble Hospital, Pune
Amulya T Kumar	Sapthagiri Medical College, Bengaluru	Saurabh Bhargava	NIMS Medical College, Jaipur
Neeta Karmarkar	Nanavati Max Superspeciality Hospital, Mumbai	Shikha Mukhi	Apollo Hospital, Delhi
Anil kumar	Santosh Medical College & Hospital, Ghaziabad	Suhas S Dhole	Ruby Hall Clinic, Pune
Shalini Nair	Christian Medical College, Vellore	Ranvir Singh Tyagi	Synergy Plus Hospital, Agra
Vivek Bharti Sharma	Army Hospital R and R, Delhi	P Sivaraj	Dr MGR Medical University, Chennai
Gaurav Singh Tomar	Indian Spinal Injuries Center, Vasant Kunj, New Delhi	Zafer Khan	Noble Hospital, Pune
Ranjith HK	Medanta Hospital, Gurugram	Prajakta S Lanjewar	Ruby Hall Clinic, Pune
Kalavathy S	SIMS Hospital, Chennai	Hariharan M	KMCH, Coimbatore
Gunchan Paul	Dayanand Medical College and Hospital, Ludhiana	Nikhilesh Jain	CHL Hospital, Indore
Shreyas Chaudhari	Life Line Hospital, Gujarat	Amol Kulkarni	Seth Nandlal Dhoot Hospital, Aurangabad
Abhijeet Deshmukh	Ruby Hall Clinic, Pune	Amol Jadhav	Imperial Multispeciality Hospital, Pune
Bublee Khakhlary	AIIMS, Delhi	Asir Tamboli	Dr DY Patil Medical College and Hospital, Pune
A Shobhana	Institute of Neurosciences, Kolkata	Rakesh Tyagi	Synergy Plus Hospital, Agra
Paras Zunke	SS Multi Speciality Hospital, Nagpur	Jyoti Sharma	AIIMS, Bathinda
GJos Jasper	KMC, Chennai	Gaurav Pandey	Command Hospital Airforce, Bangalore
Nimisha Parker	Manipal Hospital, Goa	Chinmaya Panda	AIIMS, Raipur
Subhash Bajaj	Vishwaraj Hospital, Pune	Nandakumar P	Royal Care Super Speciality Hospital, Coimbatore
Srinivas Samavedam	Virinchi Hospital, Hyderabad	Dipak V Dhangar	Siddhivinayak Hospital, Amalner
Sunitha Varghese	Ruby Hall Clinic, Pune	Gopinathan T	KMCH, Coimbatore
Shrikant Kasar	Seven Orange Hospital, Pune	Nitin Busar	Fortis Hospital, Jaipur
Kuldeep Dalal	Bethany Hospital, Thane	Sathyamurthy G	G Kuppaswamy Naidu Memorial Hospital, Coimbatore
Anand M Tiwari	Ruby Hall Clinic, Pune	Urvi Shukla	Symbiosis University Hospital and Research Center, Pune
Srikanth Diddi	Yashoda Super Specialty Hospital, Hyderabad	Sivakumar MN	Royal Care Hospital, Coimbatore
Akshay Chhallani	Apollo Hospital, Mumbai	Ravindra Ghawat	Jupiter Hospital, Thane
Subodh Kumar	Government Medical College & Hospital, Chandigarh	Mathew Joseph	Christian Medical College, Vellore
Achal Gaidhar	Sterling Hospital, Ahmedabad	Rajiv K Patra	Apollo Hospital, Bhubaneswar
N Sridhar	Kauvery Hospital, Chennai	Bhabani S Mishra	Care Hospital, Bhubaneswar
Yuvaraj S	KMCH, Coimbatore	Nishant Gupta	Life Care ICU, Patan
Arun Kumar	Fortis Hospital, Mohali	Balaji Venkatachalam	Vijaya Medical and Educational Trust, Chennai
Rajeev K Dubey	Banaras Hindu University, Varanasi	Varun Jain	Fortis Hospital, Noida
Pramod Sood	Dayanand Medical College, Ludhiana		
Dona Saha	KIMS, Bhubaneswar		
N Selvarajan	KMCH, Coimbatore		
Deven Juneja	Max Super Speciality Hospital, Delhi		
Surya K Maddala	AIIMS, Bhubaneswar		
Manikandan S	SCTIMST, Thiruvananthapuram		
Nisha B	Apollo Hospital, Madurai		
Sukhadeo A Phule	SKN Medical College, Pune		
Upendra Kapse	Ruby Hall Clinic, Pune		
Raymond D Savio	Apollo Hospital, Chennai		
Srivatsa Nagachandan	Apollo Adlux Hospital, Ernakulam		

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**APPENDIX 1: QUESTIONNAIRE FOR THE SURVEY**

1. How often do you recognize that the patient is terminally ill?
  - a. Always
  - b. Sometimes
  - c. Never
2. Do you communicate with the patient (where possible), that the patient is terminally ill?
  - a. Always
  - b. Sometimes
  - c. Never
3. Do you communicate with the relatives of the patients, that the patient is terminally ill?
  - a. Always
  - b. Sometimes
  - c. Never
4. Do you help in providing spiritual care for the terminally ill patient?
  - a. Always
  - b. Sometimes
  - c. Never
5. Do you prescribe medicines in anticipation for symptoms such as pain, agitation, nausea, vomiting, dyspnea, and respiratory tract secretions?
  - a. Always
  - b. Sometimes
  - c. Never
6. Do you review clinical interventions that would be in the best interest of the dying patient?
  - a. Always
  - b. Sometimes
  - c. Never
7. Do you review the hydration status of terminally ill patient, including need for commencement and cessation?
  - a. Always
  - b. Sometimes
  - c. Never
8. Do you review the nutritional status of terminally ill patient, including need for commencement and cessation?
  - a. Always
  - b. Sometimes
  - c. Never
9. Do you carry out a full discussion of the care plan with the terminally ill patient?
  - a. Always
  - b. Sometimes
  - c. Never
10. Do you carry out a full discussion of care plan with the relatives or caregiver?
  - a. Always
  - b. Sometimes
  - c. Never
11. Do you carry out regular assessments of such terminally ill patients?
  - a. Always
  - b. Sometimes
  - c. Never
12. What are the commonest distressing symptoms you observe in terminally ill patients?
  - a. Pain
  - b. Fear/Anxiety
  - c. Breathlessness
  - d. Delirium
  - e. Agitation
13. How do you take care of the distressing symptoms of a terminally ill patient? (Tick all applicable)
  - a. Pharmacological support
  - b. Psychological support
  - c. Spiritual support
14. Do you provide palliative sedation to terminally ill patients?
  - a. Always
  - b. Sometimes
  - c. Never
15. If Yes to Q14, what drugs do you use to provide palliative sedation? [Tick all applicable]
  - a. Opioids
  - b. Benzodiazepines
  - c. Ketamine
  - d. Not applicable
16. Are you aware about withdrawing, withholding, do not resuscitate, and euthanasia advance will terminologies?
  - a. Yes
  - b. No
  - c. Never heard
17. Do you consider withholding or withdrawal of care in terminally ill patients?
  - a. Yes
  - b. Sometimes
  - c. No
18. If No to Q17, what are reasons?
  - a. Legal issues
  - b. No hospital policy
  - c. Not aware about it
  - d. Any specific reason
19. If Yes to Q17, then who decides the withholding or withdrawal of care?
  - a. Surgeon/Neurosurgeon
  - b. Intensivist/Neuro intensivist
  - c. Primary consultant
20. What challenges do you face when providing end-of-life care?
  - a. Space and staff
  - b. Nonavailability of hospital policy
  - c. Education and training of healthcare workers
  - d. Documentation
21. If impending death is diagnosed, do you continue invasive interventions and investigations?
  - a. Yes
  - b. No
  - c. Sometimes

*(Continued)*

**APPENDIX 1:** (Contd...)

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22. If impending death is diagnosed, do you continue costly definitive medications ?
- Yes
  - No
  - Sometimes
23. If impending death is diagnosed, do you address the symptoms of the patients?
- Yes
  - No
  - Sometimes
24. If impending death is diagnosed, do you provide bereavement support?
- Yes
  - No
  - Sometimes
25. Do you have a dedicated team in your ICU to deal with EOL issues?
- Yes
  - No
26. If Yes to Q25, please give details of all involved.
27. Does your hospital have social care workers involved in the handling of grief among the terminally ill patients and their relatives?
- Yes
  - No
28. Do you ever ask the patients their last wish or desire in such a situation?
- Yes
  - No
29. Do you ever ask the patient (where possible) about their health?
- Yes
  - No
30. Does your hospital impose any restrictions on the number of relatives or loved ones of the patients who can meet?
- Yes
  - No
  - If yes, specify
31. Do you allow children to meet terminally ill patients in your ICU?
- Yes
  - No
32. Do you ever use the term "dying" for the terminally ill patients during your conversation with their relatives?
- Yes
  - No
  - Sometimes
33. Do you allow relatives to speak to the terminally ill patient or meet them just before tracheal intubation, should the need arise for mechanical ventilation?
- Yes
  - No
34. Do you discuss the "Will" of the patient with the relatives?
- Yes
  - No
  - Sometimes
-