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End-of-life decisions in an Indian intensive care unit

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Abstract *Background:* There is a paucity of data on end-of-life decisions (EOLD) for patients in Indian intensive care units (ICUs). *Objective:* To document the end-of-life and full-support (FS) decisions among patients dying in an ICU, to compare the respective patient characteristics and to describe the process of decision-making. *Design:* Retrospective, observational. *Patients:* Consecutive patients admitted to a 12-bed closed medical-surgical ICU. *Exclusions:* Patients with EOLD discharged home or transferred to another hospital. *Measurements and results:* Demographic profile, APACHE IV at 24 h, ICU outcome, type of limitation, disease category, pre-admission functional status, reasons for EOLD, interventions and therapies within 3 days of death, time to EOLD, time to death after EOLD and ICU length of stay.Out of 88 deaths among 830 admissions, 49% were preceded by EOLD. Of these 58% had withholding of treatment, 35% had do-not-resuscitate orders (DNR) and 7% had a withdrawal decision. Mean age and APACHE IV scores were similar between EOLD and FS groups. Functional dependence before hospitalization favored EOLD. Patients receiving EOLD as opposed to FS had longer stays. Fifty-three percent of limitations were decided during the first week of ICU stay well before the time of death. Escalation of therapy within 3 days of death was less frequent in the EOLD group. *Conclusions:* Despite societal and legal barriers, half the patients dying in the ICU received a decision to limit therapy mostly as withholding or DNR orders. These decisions evolved early in the course of stay and resulted in significant reduction of therapeutic burdens.

Introduction

Decisions to limit support in terminal illness have become routine in American and European ICUs [1, 2]. In a recent publication, European physicians were reported to have had no difficulty in making these decisions in 81–93% of cases [3].

These decisions have been perceived to be difficult in India due to a number of barriers: unawareness of ethical issues, culture of "fighting till the end," lack of palliative care orientation, and legal and administrative prejudices [4, 5]. Ironically, nowhere is it more pertinent to shift focus from curative to comfort care in the terminally ill than India with its enormous financial and resource limitations.

End-of-life decisions (EOLD) in the Indian context with its unique social, cultural, economic and legal complexities have not been adequately studied. There is a paucity of empirical data on the frequency and the manner of foregoing life support in Indian ICUs. The Indian physician's attitude, which would appear to favor limitation of therapies [5], is severely hampered in practice by

the lack of safeguards in the form of professional and legal guidance. The Indian Society of Critical Care Medicine (ISCCM) ethical position statement published in 2005 [6] ushered in significant steps towards improving end-of-life care in India.

Although this paper only reflects the practice in a small ICU in a private hospital, its purpose is to place on record that despite the difficulties mentioned above, EOLDs have been systematically implemented and documented. This was possible because, with the caregiver team, patient and family considerations outweighed the perceived risks of legal and administrative complications.

The paper describes the frequency and type of EOLD, explores the patient characteristics associated with EOLD, records the reasons for EOLD and compares the burdens due to full support (FS) as opposed to EOLD.

Parts of these data were presented in an oral form at the annual meeting of the European Society of Intensive Care Medicine at Lisbon and published as an abstract [7].

Materials and methods

The patients had been admitted to the Medical-Surgical ICU of a 170-bed tertiary care private hospital in India. Those admitted to the ICUs of other services, namely cardiology, nephrology and orthopedics, were not included in this study. The 12-bed closed unit of the Department of Pulmonology and Thoracic Surgery was comprised of a director, a chief surgeon, a pediatric intensivist, and nine physicians and surgeons. The nurse–patient ratio was 1:1–2.

Retrospective chart review of deaths was conducted among patients admitted from May 2006 to December 2007. The purpose of the review was to record the characteristics of the EOLD and FS patients as well as the process involved in decision-making and to compare the therapeutic burdens around the time of death. Data collected included age, gender, disease category, comorbidities, reasons for EOLD, ICU length of stay, acute physiology and chronic health evaluation score (APACHE) IV 24 h after ICU admission, pre-admission functional status, mode of EOLD, time to EOLD and time of death from EOLD. Details of the therapeutic interventions performed, an antibiotic or a vasopressor initiated and any diagnostic test ordered within 3 days of death were also collected.

Approval of the institutional review board was not sought considering it unnecessary in view of the retrospective and observational nature of the study. Patients' identities have not been disclosed.

Statistical analysis

Comparison between the FS group and EOLD was performed using the statistical tool SPSS, version 10. All P values <0.05 were considered significant.

Regression analysis among the FS and EOLD group in terms of age, comorbidity and APACHE IV at 24 h of admission were not significant.

Hazard ratio between the functional status of patients among EOLD and FS was comparable. Linear regression analysis of the frequencies of the reasons for EOLD showed a significant independent relationship to advanced chronic disease and unresponsiveness to treatment ($P < 0.001$).

Definitions

Full support (*FS*) involved provision of all measures needed to support hemodynamics, metabolism and ventilation.

Do-not-resuscitate (*DNR*) involved aggressive ICU management up to but not including attempts at CPR.

Withholding of life support (*WH*) was the decision not to institute new treatment or escalate existing treatments for life support.

Withdrawal of life support (*WD*) was the cessation and removal of an ongoing life-supporting treatment while not substituting an equivalent alternative treatment.

Left against medical advice (*LAMA*) indicated the unilateral decision by a patient's family to discontinue life support and remove a terminally ill patient from the hospital, usually without any prescription.

Functional status included: *independent*: no help needed for activities of daily living (ADL); *partially dependent*: help needed only for ADL; *dependent*: bed- or wheelchair-bound, needing help for toileting.

Procedure

Discussions for limiting life support were initiated by physicians as a part of "good medical practice," guided by the ISCCM ethical position statement [6]. Decision-making typically evolved over days to weeks as a physician–family consensus in accordance with international recommendations [8]. Family conferencing was a formal, daily activity with due attention to the adequacy of time and quality of content guided by previous publications [9, 10]. The meeting was conducted by the director of the unit (RKM) and included at least two family members and two or more of the other physicians of the treating unit, but no nurses.

Documentation

The proceedings of family conferences were recorded with signatures of two family members (not insisted upon). Documentation was in the form of a written account in the case records along with or without filling an end-of-life decision form.

Hospital policy

The hospital's stated policy endorses limitation of life support in the terminally ill.

Legality of decisions

Euthanasia has been declared illegal by the Supreme Court of India. No pronouncements exist in Indian law on DNR, WH or WD. Civil law recognizes negligence as a breach of obligation to provide care in accordance with ordinary professional standards. Protection against criminal liability can be sought through the provisions under Indian Penal Code sections 76, 81 and 88 [11].

Results

During the study period 830 patients were admitted to the ICU, of whom 88 (10.6%) died.

Of the deaths 45 patients had FS and 43 (48.8%) had EOLD. The EOLD group had DNR in 15 (35%), WH in 25 (58%) and WD in 3 patients (7%).

Patient characteristics are detailed in Table 1. There was no significant difference in the age or sex distribution between EOLD and FS.

Patients with respiratory failure more frequently had EOLD than FS, while those with sepsis or renal failure more frequently had FS. There was a trend towards more co-morbidity in EOLD as compared to FS. There was no significant difference between the two groups in the mean scores of APACHE IV at 24 h.

There was a significantly longer ICU stay for those who received EOLD as opposed to FS.

The day of EOLD from the day of ICU admission (mean, SD) was 9.44 ± 13.26 days [95% confidence interval (CI): 5.35–13.52]; 23/43 (53%) decisions were taken in the first week.

The day of death after an EOLD was (mean, SD) 6 ± 11.87 days (95% CI: 2.34–9.65), but this was longest in those who received WH (mean days, SD) [9.02 ± 14.90 median 3 as compared to DNR (1.9 ± 0.70), median 2 or WD (2.33 ± 0.577) median 1].

The patients were classified according to their preadmission functional status as independent, partially dependent and dependent (Table 2). The proportional hazard ratio in favor of EOLD as compared to FS was 0.48 for independent, 1.18 for partially dependent and 3.66 for dependent patients.

Underlying advanced chronic disease was significantly more common in respiratory and sepsis patients in the EOLD group as compared to those in the FS group (Table 3). Among those who received EOLD advanced chronic disease was significantly more frequent in respiratory patients as compared to sepsis patients.

Reasons for EOLD are listed in Table 4. The most frequent reasons recorded were advanced chronic disease followed by unresponsiveness to treatment. Advanced age (>75 years), advanced malignancy, severe neurological deficit and family's unwillingness to continue treatment were the other reasons. There were no statistically significant differences in the relative frequencies of the reasons for EOLD between the first

Table 1 Characteristics and outcomes of 88 deaths in the ICU over the study period

Sex	Full support		End-of-life decision		*P* value
	33 male	12 female	26 male	17 female	
Age (mean and range)	56.97 ± 17.22 (15–89)		61.74 ± 18.67 (26–93)		0.340
Primary organ of involvement at presentation (no., % of deaths)					
Respiratory	16 (35.6)		24 (55.84)		0.003
Sepsis	15 (33.3)		10 (23.25)		0.044
Neurological	7 (15.5)		6 (13.9)		0.323
Renal	5 (4.4)		0		0.024
Cardiac	1 (2.2)		0		0.323
Unclassified	1 (2.2)		3 (6.97)		0.160
Co-morbidities (no., % of deaths)	37 (82.2)		41 (93.5)		0.05
APACHE IV (mean)	81.418 ± 19.29		76.06 ± 26.38		0.055
LOS in ICU (mean and range)	7.24 ± 9.178 (CI = 4.48–10.00)		15.4 ± 22.12 (CI = 8.61–22.22)		0.041

Results are presented as mean, standard deviation and range or numbers of patients and proportions

Table 2 Impact of preadmission functional status of dying patients on life-support decisions

Functional status	Full support (*n*, %)	Hazard ratio	End-of-life decision (*n*, %)	Hazard ratio	Proportional hazard ratio
Independent	25 (55.5)	0.675	12 (27.9)	0.324	0.48
Partially dependent	17 (37.7)	0.459	20 (46.5)	0.540	1.1764
Fully dependent	3 (6.6)	0.214	11 (67.4)	0.785	3.66

Results are expressed as numbers, proportions and proportional hazard ratios

Table 3 Impact of advanced chronic disease on EOLD

Primary organ of involvement at presentation	Advanced chronic disease among patients with EOLD	Advanced chronic disease among patients with FS	*P* value
Respiratory*	19/24 (79.16%)	6/16 (37.5%)	<0.001
Sepsis*	6/10 (60%)	2/15 (13.33%)	<0.001

The numbers and proportions of patients with such diseases in EOLD and FS groups are compared

* Advanced chronic disease in EOLD respiratory patients versus EOLD sepsis patients: $P < 0.001$

EOLD end-of-life decisions

and second weeks of admission when most decisions took place.

The following supports were withheld: mechanical ventilation in 16, antibiotics in 7, vasopressors in 3, hemodialysis in 3, diagnostic tests in 9 and others (including drugs, transfusions and artificial feeding) in 9 patients.

Escalation of treatment towards the end of life (within 3 days prior to death) was analyzed (Table 5). Therapeutic interventions were performed significantly more frequently with FS than with EOLD. Initiation of or change to carbapenems, vasopressor use and diagnostic tests were more frequent with FS than with EOLD. Significantly more families who were self-paying opted to continue FS, while insurance beneficiaries were equally represented in both groups (Table 6). The majority of those dying were Hindu by religion (84/88), with Sikh (2), Christian (1) and Muslim (1) patients comprising numbers too small for analysis.

Seven patients with EOLD were not included in this analysis: two patients with WH transferred to another hospital, three patients with WH who had several subsequent admissions outside the ICU (one patient each of COPD, advanced cerebral glioma and vegetative state due to septic encephalopathy) and two patients with terminal discharges but lost to follow-up.

Discussion

This study in a closed medical-surgical ICU in an Indian tertiary care private hospital documents end-of-life decisions in 49% of deaths. The majority (58%) of these had WH. Foregoing of life support towards the end of life, as a concept, is unfamiliar to India. Moreover, most physicians appear to have adopted the uninformed view that limiting life support is a punishable offense [4, 5, 11]. Reports of the rates of EOLD in India are scarce. The first report was in 2003 as a single table in a review article [12]. It reported an unintentional foregoing of life support in 22% of deaths in a tertiary care hospital. Out of the 48 deaths preceded by some form of treatment limitation, 38 (79%) were discharged terminally as "left against medical advice (LAMA)." LAMA has been reported from several countries in the context of patients taking their own discharge for personal or financial reasons [13–16]. Planned discharges for terminally ill patients for ensuring "good death" have been reported from The Netherlands [17] and Tunisia [18, 19]. However, LAMA here refers to a unilateral withdrawal decision by the family usually because of unbearable financial and other burdens [4, 12]. LAMA is a common occurrence in India since the private sector dominates health-care delivery [20]. This often has the tacit approval of the physicians who in the process hope to circumvent moral accountability and perceived legal liability. The social and ethical implications of this practice have been discussed previously [4, 5, 21, 22]. Notably, in the present study no patient died through this practice since the caregiver team was fully sensitized to its ethical obligations in terminal care.

The second report from India, in 2005, culled from the international SAPS3 study data, revealed an average EOLD rate of 34% in four Mumbai hospitals [23]. EOLD preceded 41–50% of ICU deaths in two private hospitals and a cancer referral center that takes both paying and free patients. Most deaths in the cancer hospital and 44 and 27% in the private hospitals occurred outside ICUs. In the remaining public hospital that caters to free patients 23% deaths occurred in the ICU, with an EOLD rate of only 19%. These data reveal physician reluctance for EOLD but not for the rationing of ICU beds. No details of the patient characteristics or the process of decision-making were reported. Subsequently, two abstracts have reported varying EOLD rates of 19 and 91% in predominantly neurological patients [24] and elderly patients [25], respectively.

Reports of EOLD rates from the west have varied from high levels (>60% of deaths) in the US [1], Canada

Table 4 Reasons for EOLD in 43 patients and their distribution according to the timing of EOLD since admission in weeks

Reasons for EOLD	1st week (no., %) $N = 23$	2nd week (no., %) $N = 11$	3rd week (no., %) $N = 6$	4th week (no., %) $N = 1$	5th week (no., %) $N = 1$	11th week (no., %) $N = 1$	Total $N = 43$
Advanced chronic disease[a]	17 (73.90)	7 (64)	3 (50)	0 (0)	1(100)	1 (100)	29 (67.4)
Advanced age[b]	6 (26.0)	3 (27)	1 (16)	0 (0)	0 (0)	0 (0)	10 (23.2)
Unresponsive to treatment	11 (47.8)	5 (45)	3 (50)	0 (0)	1(100)	1 (100)	21 (48.8)
Advanced malignancy[c]	6 (26.0)	3 (27)	0 (0)	1(100)	0 (0)	0 (0)	10 (23.2)
Advanced neurological deficit[d]	5 (22)	3 (27)	2 (33)	0 (0)	0 (0)	0 (0)	10 (23.2)
Family unwilling to continue treatment	1 (4)	1 (9)	0 (0)	0 (0)	0 (0)	0 (0)	2 (4.65)

The results are expressed as number of times the reason was cited out of total EOLD in the week and its proportion

The proportions add up to more than 100 as in most patients more than one reason was found

[a] Included (no., disease): five interstitial lung disease/extensive pulmonary fibrosis, ten chronic obstructive pulmonary disease, two bronchiolitis obleterans and organizing pneumonia, two end-stage sarcoidosis, one severe chronic heart failure, one advanced rheumatoid arthritis, one systemic amyloidosis, one bronchiectasis, two panresistant tuberculosis, one morbid obesity, two lymphatic and veno-occlusive disease of the lung, one acquired immunodeficiency disease state

[b] Regarded as >75 years

[c] Included (no., disease): one carcinoma tongue, one lymphoma, two multiple myeloma, one carcinoma breast, one carcinoma colon, one nasopharyngeal carcinoma, one carcinoma thyroid, one carcinoma prostate, one bronchogenic carcinoma

[d] Included (no., disease): two cerebrovascular accident, one Alzheimer's disease, one tubercular meningitis, two septic encephalopathy, three hepatic encephalopathy, one postanoxic encephalopathy

Table 5 Therapeutic burdens within 3 days of patients' death in the ICU

	Full support (n, %)	End-of-life decision (n, %)	P value
Interventions[a]	44 (97.7)	29 (67.4)	<0.001
Antibiotic change[b]	14 (31.1)	5 (11.6)	0.02
Vasopressors	9 (20)	1 (2.3)	0.001
Diagnostic tests[c]	28 (62.2)	7 (16.3)	<0.001

Results expressed as numbers and proportions

[a] Included ventilation, hemodialysis, chest tube drainage, cardioversion, bronchoscopy and surgery

[b] Refers to initiation of carbapenems

[c] Included blood, bacteriological and radiological tests

Table 6 Impact of the mode of payment on the type of decisions for 88 patients who died

Mode of payment	End-of-life decisions	Full support	P value
Self-paying	33/43 (76.74%)	40/45 (88.89%)	0.005
Insurance beneficiary	10/43 (23.26%)	5/45 (11.11%)	0.867

The results are expressed as numbers of patients and their proportions

[26], UK [27], South Africa [28] and Northern and Central Europe [2] to lower levels of 11–59% from Brazil [29], Lebanon [30], Spain [31], Southern Europe [2] and Hong Kong [32]. The lower levels may reflect conservative physician attitudes or societal and legal barriers to EOLD. The present study shows that reasonable levels of limitation are achievable in India despite the perceived barriers.

The low WD rate of 7% in the present study contrasts with the 45% reported in the ETHICUS study [2], 71% in an American survey [1] and 70–80% reported from a large British survey [27] and from a combined study in London and Cape Town [28]. The WD rate is also low in Israel [33], Lebanon [30] and Southern Europe [2], where religious beliefs, ethical values and unclear legal position appear to discourage the practice.

In our study DNR was documented in 17% of deaths—a rate markedly lower than that reported from elsewhere [27]. CPR rates are very low in Australia and very high in Japan, reflecting different cultural attitudes towards the practice [34]. The earliest report from India showed a DNR rate of only 1.6% [12]. DNR still continues to be prohibited in many Indian hospitals [21]. The reluctance to make these decisions in India [4, 5] is attributable to the confusion with respect to their ethical and legal status in the country.

WH, being the most frequent, was evidently the easiest to implement. The mean time to EOLD was 9.4 days, half the decisions being made within the first week of ICU admission, compared to 11.2 days in London, 9.6 days in Cape Town [28] and 7.6 days in France [35]. In a study in Canada DNR directives were established in half the patients by day 8 [36]. Where health care is free and ICU beds are limited, reported days to EOLD are as low as medians of 2.8 [2] and 2 [27]. The time from initiation of end-of-life discussions to decision-making was not recorded in this study. In a private hospital setting where the majority is self-paying, autonomy would be expected to prevail over physician paternalism, although genuine

autonomy as opposed to assent may be difficult in practice [37]. The data from this study seem to indicate that decision-making was not rushed, providing sufficient opportunity for a considered opinion by the family. Further, the mean time of death after an EOLD was 6 days, suggesting that these decisions were taken reasonably early in the clinical course. However, in earlier large surveys where WD was frequent, the reported average times of death were 4 [2] and 2 [27] h following EOLD. Similar to an earlier study [38], patients with EOLD in our study had more than twice the length of ICU stay as with FS, implying that prolonged stay tended to favor such decisions.

Futility of care, failure of prolonged trial of intensive care, non-surgical reason for admission, poor premorbid functional status, poor long-term prognosis, advanced age, financial cost and family request are some of the reasons cited for EOLD [27, 30, 39]. In the present study pre-hospital fully dependent functional status was associated with EOLD. Age, APACHE 4 at 24 h and comorbidity did not independently favor EOLD. Analysis of a multinational database revealed that patients having EOLD tended to be older, had higher admission SOFA scores and more severe co-morbidity [40]. In the present study, presentation with respiratory failure more frequently led to EOLD, while that with sepsis or acute renal failure more frequently led to FS. As the treating unit received highly selected pulmonary patients, the majority among the former category had underlying chronic disease as opposed to the latter. Also, advanced chronic disease constituted one of the reasons for EOLD in 67% of the patients, and, as with unresponsiveness to treatment independently related to EOLD. This would suggest that physicians favored EOLD for acute-on-chronic organ failure while tending to continue FS for catastrophic, acute conditions. EOLD significantly reduced the therapeutic and cost burdens towards the last 3 days of life. Notably, the use of carbapenems, which could amount to 50% of the expenditure on drugs [20], was curtailed.

All decisions were taken jointly by the physicians and patients' families as an essential requirement of hospital policy. This is in contrast to the family's involvement in EOLD reported as 48% in the southern, 70% in the central and 88% in the northern European regions [41].

In the present study all were private patients, of whom most were self-paying as opposed to third-party payees. As a policy, care was taken not to initiate EOLD based solely on financial considerations, but nonetheless the latter is expected to significantly affect family decisions. Though high cost of care would be expected to drive families towards EOLD, in our data the latter group surprisingly had fewer self-paying patients. In this cohort of patients the mode of payment thus had no significant impact on end-of-life decisions.

The limitation of the study is that the practices described are not representative of the whole country given the variability of health-care standards in India. Differences are likely to be significant between private and public hospitals [4, 23], among metropolitan cities and even within the same hospital. Wide variations in end-of-life practices have been reported within the same country or region [1, 2, 26]. Surveys must therefore have a mix of hospitals catering to different socioeconomic and cultural groups.

India, being a multicultural society, affords ample opportunity to explore the impact of religion on EOLD. In the present study the majority of patients practiced Hinduism. Representations of other religious groups were too small for interpretation.

Conclusions

About half the deaths among ICU patients involved decisions to limit life support. WHs were the most frequent, while WDs were few. Most decisions were taken in the first 2 weeks of ICU stay. EOLD was associated with a longer ICU stay but with reduced burdens around the time of death. Ethical decision-making in the terminally ill is achievable in India despite the perceived legal and societal barriers.

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