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End-of-life Care Practice Patterns Among Patients Admitted To A Tertiary Care Facility

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Abstract

Aim and Background:

A dignified death, free from suffering, is the right of every dying patient. It is very difficult for the patient's relatives to determine which life support should be withdrawn and which support should be continued. The aim of this study is to understand the various practice patterns of EOLC (end-of-life care) and identify factors influencing EOLC decisions.

Methods:

This retrospective observational study included 126 patients whose surrogates provided DNAR (Do Not Attempt Resuscitation) consent in a multidisciplinary tertiary care ICU (Intensive Care Unit) and clinical data was collected from DNAR consent form which included eight major components of EOLC: 1) CPR (cardiopulmonary resuscitation), 2) Intubation or re-intubation, 3) NIV (non-invasive ventilation), 4) Vasopressors, 5) Hemodialysis, 6) Feeding, 7) Sedation, 8) Withdrawal of ongoing support. The choices made by patients' surrogates were documented and analyzed. Patient's quality of life before hospitalization and financial constraints for treatment were also documented to understand their impact on EOLC decisions.

Results:

The mean age of patients whose surrogates gave DNAR consent was 69.96 years, with a standard deviation of ±14.23 years. Major reasons for EOLC decision were prolonged bedridden condition and advanced age. Financial constraints played a role in EOLC decisions, with 31% of patients having limited financial support due to a lack of health insurance.

Conclusion:

DNAR consent with options to select major intervention individually can help patient's surrogates in taking decision about continuation of particular therapy or intervention. Prolonged bedridden condition, advanced age, CVA (cerebral vascular accident) and financial constraints can play major role for EOLC decision.

Keywords: End-of-life care, Do-not-resuscitate, Do-not-intubate, Withdrawal of life support

Introduction

Intensivists frequently encounter clinical scenarios where medical interventions prove futile. Communicating poor clinical outcomes despite appropriate treatment and interventions to patients' relatives becomes a challenging responsibility. In such instances, families must grapple with decisions on whether to continue or withdraw treatment. At times, it can be confusing for the patient's relatives to determine which life support should be withdrawn and which support should be continued in the ICU.

A dignified death, free from suffering, is the right of every dying patient. In some cases, patients or their relatives can express their preferences in advance regarding palliative and supportive care if the patient's condition worsens. Clear instructions, especially regarding CPR (Cardio-pulmonary Resuscitation), must be communicated to the treating physician beforehand. It is crucial for intensivists to guide patients and their relatives in navigating these complex decisions. When expected outcomes are explained in detail, futile interventions can sometimes be avoided if prior consent for DNAR (Do Not Attempt Resuscitation) has been obtained from the patient's relatives.

Globally, various hospitals use different abbreviations for end-of-life care (EOLC), such as DNR (Do Not Resuscitate), NFR (Not for Resuscitation), or DNAR (Do Not Attempt Resuscitation). Terminally ill patients often undergo invasive procedures during their ICU stay, including mechanical ventilation, central venous catheterization, arterial cannulation, hemodialysis, and tracheostomy. Despite the known negative outcomes, intensivists are compelled to offer these interventions unless patients' relatives fully understand their implications. This may lead to significant financial loss and mental trauma for the patients' relatives due to prolonged ICU care despite a poor prognosis. This situation can be prevented if patient's relatives can decide on the interventions they desire or do not want in the patient's care. If DNAR consent outlines these interventions separately, patients or their relatives can select the desired interventions based on the patient's clinical condition. Therefore, a DNAR consent form should be an essential document for end-of-life care, including provisions for withholding or withdrawing ongoing treatment. Notably, 78% of terminally ill patients leave hospitals against medical advice due to escalating treatment costs and the absence of an EOLC policy in some facilities [1].

In 2020, the Indian Council of Medical Research Expert Group published consensus guidelines on DNAR, including a DNAR Form [2]. The majority of hospitals in India use this form while obtaining consent for EOLC decisions. This document contains details about the patient's clinical condition, the rationale for DNAR decisions, and signatures of physicians and relatives. Modifying this form to include specific interventions like intubation, CPR, NIV, vasopressor support, dialysis, feeding, sedation, allows families to tailor their choices based on the patient's clinical condition, potentially averting futile interventions.

Although the Indian Society of Critical Care Medicine (ISCCM) issued its first EOLC guidelines in 2005, there is a lack of uniform practices across Indian hospitals [3]. Many physicians hesitate to initiate EOLC discussions with relatives, especially for conditions beyond malignancies. A comprehensive understanding of EOLC practices in Indian ICUs is lacking, emphasizing the need for detailed explanations of major interventions to raise awareness of treatment futility. A retrospective observational study on EOLC practice patterns aims to provide crucial information for standardizing EOLC practices. The purposes of this study were therefore as follows: (1) to look at the various practice patterns in patients who fit the do not attempt resuscitation profile; (2) to look at the understanding and choices of families about end-of-life care and the interventions opted in and out during such situations; and (3) to identify factors influencing end-of-life care decisions.

Materials And Methods

This retrospective observational study included 126 patients whose surrogates provided DNAR consent in a multidisciplinary tertiary care ICU between January 2022 and November 2022 at Medicover Hospitals-Hyderabad, India. Institutional ethical committee approval was obtained. Demographic and clinical data were collected, and DNAR consent form was utilized to capture patient details and reasons for opting for DNAR. The form was modified to include a table listing eight major components of end-of-life care: 1) CPR, 2) Intubation or re-intubation, 3) NIV, 4) Vasopressors, 5) Hemodialysis, 6) Feeding, 7) Sedation, 8) Withdrawal of ongoing support (Table 1).

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Patient surrogates' choices regarding these components were documented and analyzed. Additionally, patient's nutritional status, pre-hospitalization quality of life, and financial constraints for treatment were considered to understand their impact on end-of-life care decisions.All pertinent details were recorded by the critical care physician after obtaining DNAR consent from patients' surrogates. This data encompassed the patient's name, age, sex, comorbid conditions, diagnosis, date of admission, date and time of DNAR decision, payment mode (self-paying or insurance), nutritional status before admission, and ambulatory status before admission (active, requiring support for ambulation, or bedridden). Vital signs and blood investigation values were documented on the day of the DNAR decision to calculate the SOFA (Sequential Organ Failure Assessment) Score and APACHE-2 (Acute Physiology and Chronic Health Evaluation) Score, providing insights into the severity of the clinical condition on that specific day. It was explicitly documented whether an end-of-life care discussion was initiated by the intensivist or the patients' relatives. Furthermore, the documentation included whether patients' relatives agreed to DNAR, if the DNAR consent was revoked during the hospital stay, and the use of life-sustaining therapies (invasive mechanical ventilation, vasopressors, or renal replacement therapy) at the time of the DNAR decision. Additionally, it was noted whether the patient died during the hospital stay or was discharged at the request of the patients' surrogates. This information is crucial to grasp that end-of-life care does not necessarily signify the end of life.

The primary information was extracted from the DNAR consent form, explicitly outlining the choices made by patients' relatives in selecting end-of-life care for the patients. These choices encompassed CPR, intubation or re-intubation, NIV, vasopressors, hemodialysis, feeding, sedation, and withdrawal of ongoing support. This information provides insights into various end-of-life care practice patterns among patients admitted to a tertiary care facility (Graph 1).

Results

As this was a retrospective observational study, the collected data were analyzed to discern the choices made by patients' relatives for specific interventions when providing DNAR consent. Beyond uncovering diverse end-of-life care practice patterns, the study shed light on various factors influencing end-of-life care decisions, such as age, comorbid conditions, disease severity, financial constraints, ambulatory status, nutritional status before ICU admission, and existing life-sustaining supports at the time of the end-of-life care decision.

A total of 126 patients were included in this observational study. The mean age of patients whose surrogates gave DNAR consent was 69.96 years, with a standard deviation of ±14.23 years. The gender distribution revealed a higher percentage of men signing DNAR consent compared to women, with 57.9% of patients (73) being men and 42.1% (53) being women. End-of-life care discussions were initiated by intensivists in cases where treatment was deemed futile, but on multiple occasions, patients' relatives took the lead in initiating end-of-life care discussions (43.7% by relatives and 56.3% by intensivists). Financial constraints played a role in end-of-life care decisions, with 31% of patients having limited financial support due to a lack of health insurance. The mean hospital stay before making an end-of-life care decision was 5.5 days, with a standard deviation of ±7.65 days. Patients' comorbid conditions were documented in DNAR consent form. Most observed comorbid condition among these patients was hypertension, which was seen in 78.57% of patients who opted for DNAR followed by diabetes mellitus which was seen in 50% of patients. Prolonged bedridden status, age ≥ 80 years, and cerebrovascular accidents (CVAs) were the predominant reasons for choosing DNAR (Graph 2, Graph 3).

Among the patients, 40 patients had a prolonged bedridden condition before hospitalization, and 45 patients required assistance for ambulation before ICU admission. If a patient was already on life-sustaining support, it was explicitly documented in the DNAR consent form (35.7% on invasive ventilation, 30.2% on vasopressors, and 17.5% on hemodialysis). Malnutrition was observed in 56.35% of patients at the time of the DNAR decision. To assess the severity of the clinical condition, SOFA and APACHE-II scores were calculated, with mean scores of 6.91 (SOFA) and 19.69 (APACHE-II). Following DNAR consent, patients received care as specified in the DNAR form, and most of these patients eventually had cardiac arrest. However, a notable portion did not deteriorate further, leading to 61.9% of patients dying during their

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hospital stay, while 38.1% were discharged at the request of their surrogates for home-based care or hospice. Instances of revoked DNAR decisions were documented in 3 cases where patients' relatives changed their decision after initially giving DNAR consent.

To comprehend the diverse end-of-life practice patterns among these patients, each intervention chosen by patients' relatives was meticulously documented (Table 2, Table 3).

Discussion

The results of this study revealed that intensivists play a major role in communicating about end-of-life care with patients' family members. In this study, we observed that all DNAR consents were signed by patients' relatives rather than the patients themselves. Self-determination of patients regarding medical decisions is not well articulated in our constitution. Ideally, patients should give consent for DNAR if they are competent to make choices. However, critically ill patients who are mostly incompetent to make choices in the ICU might not be able to sign DNAR consent. In this scenario, the wishes of surrogates acting on the patient's behalf can be considered when making end-of-life care decisions. Physicians cannot be absolutely certain about the anticipation of death in the ICU, but mortality prediction can be made with the help of a variety of scoring systems based on physiological variables. The APACHE-II score and SOFA score can help identify patients with possible poor outcomes. Our study suggests that advanced age of patient and certain disease conditions are major factors which helped physicians to start discussions about end-of-life care. According to a multicenter, prospective, observational study in Europe, decisions for limitation were related to age and diagnosis, among other factors [4]. Age, poor prognosis, and poor quality of life were among the reasons cited in studies from France and Canada [5]. Prolonged bedridden status can be considered poor quality of life and was the major reason for opting for end-of-life care in our study. On many occasions, patients might already be intubated when their relatives make DNAR decisions, leading to confusion about the continuation of further treatment in the ICU. If end-of-life consent or DNAR forms include all components separately, allowing relatives to select or opt-out of particular therapies or interventions, it would be very helpful for the patients' relatives when making DNAR decisions. If a patient is already intubated and maintaining oxygen saturation with spontaneous breathing on pressure support mode, the patient can be extubated after obtaining DNAR consent, which should clearly mention not to re-intubate the patient even if they desaturate or deteriorate after extubation. By obtaining such consent with clarity, futile invasive ventilation can be avoided. DNAR consent with proper selection of therapies can help save hospital resources, which can be useful for patients in need. If the patient or family does not want to continue ongoing life-supporting interventions, the intensivist can discuss the available options for limiting support, including: 1. Do-not-resuscitate status (DNR) 2. Withdrawal of life support 3. Withholding of life support. However, withholding of life support requires more clarity about specific life support, including dialysis support, vasopressor support, or ventilator support. By including all these components in DNAR consent, it becomes easy for patients' relatives to understand which therapy they want to continue or withhold.

Sometimes, patients' relatives may think that DNAR patients might receive substandard care once they sign for DNAR. This concern was also shown in other studies [6]. To avoid this kind of confusion among patients' relatives, it is advisable to explain each aspect of end-of-life care when obtaining DNAR consent. Patients can receive palliative care in rooms or wards without compromising their care. Patients' relatives can spend more time with the patients if palliative care is given in rooms or wards rather than ICUs. In our study, we noticed that many patients did not deteriorate further after withholding life support and eventually were sent home for hospice care. In many countries, culture can become an obstacle for DNAR decisions, as shown in the ETHICUS, SUPPORT, and ETHICATT studies [7-9]. Empirical evidence from other cultures may not be applicable in India, where data on the impact of socio-cultural influences on family needs are sparse. In our study, we found that culture was not an obstacle for DNAR decisions because the majority of end-of-life care discussions were initiated by patients' relatives. Communication is a key component of end-of-life care because early and effective communication facilitates a smoother transition from curative to palliative care, reduces the frequency of futile care, and decreases conflicts and

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the potential for litigation between families and healthcare workers [10].

In India, intensivists observe various barriers to end-of-life care (EOLC) which include financial issues to continue EOLC, lack of clear EOLC policies in many hospitals, less importance to the needs of the dying and concerns over the legality of foregoing of life-sustaining treatments [11,12]. While explaining to patient's relatives about EOLC, it is very important to make them understand the meaning of DNAR. Do not attempt resuscitation (DNAR) is a considered decision by the medical team in patient's best interests, in consultation with the patient with capacity, or when without capacity, the family/appointed proxy to not perform CPR in the event of a cardiorespiratory arrest. "Do not attempt resuscitation" is frequent, occurring in at least 50–60% of hospital deaths in a survey of six European countries [13]. Identifying patients who need EOLC or palliative care is also an important task for intensivists. All possible triggers to identify patients potentially in need of end-of-life care or palliative care have been clearly mentioned in an expert consensus published by ISCCM [14]. Communicating EOLC decisions with patient's relatives is another important task for treating physicians. In our study utmost importance was given to multidisciplinary family meetings which should happen as early as possible once triggers for EOLC are identified by physician. Breaking bad news skillfully and supporting families through grief reaction at the anticipated loss is essential [15]. Critically ill patients and families have spiritual needs, and spiritual support is a key indicator of comprehensive healthcare delivery [16,17]. At present there is no specific legislation on EOLC in India but National Medical Commission has already issued a draft which also includes a directive to the Ethics and Medical Registration Board to form EOL guidelines [18]. Research in EOLC has not progressed as much as needed. Only 6% of 848 original studies were RCTs, and some studies included patients with very short survival [19,20]. Hence, more well-designed EOLC research is urgently needed.

Conclusion

End-of-life care or DNAR consent should include all different components like CPR, intubation, NIV support, vasopressor support, dialysis support, feeding, sedation and withdrawal of ongoing support. This can help patients' relatives in taking decision about continuation of particular therapy or intervention while giving DNAR consent. Prolonged bed-ridden status before ICU admission and advanced age (more than 80 years) were main reasons for DNAR decision. Even after obtaining DNAR order, many patients can be discharged for homecare or hospice care if their clinical condition does not worsen further after initiating end-of-life care.

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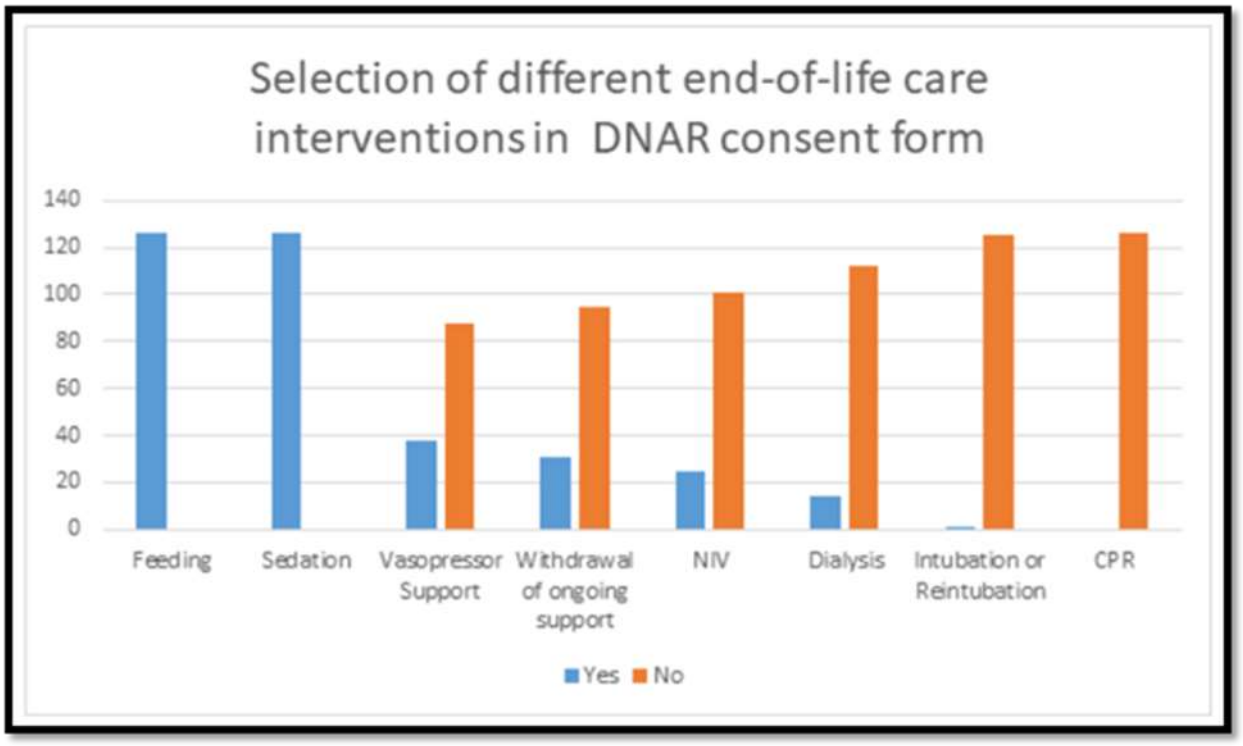
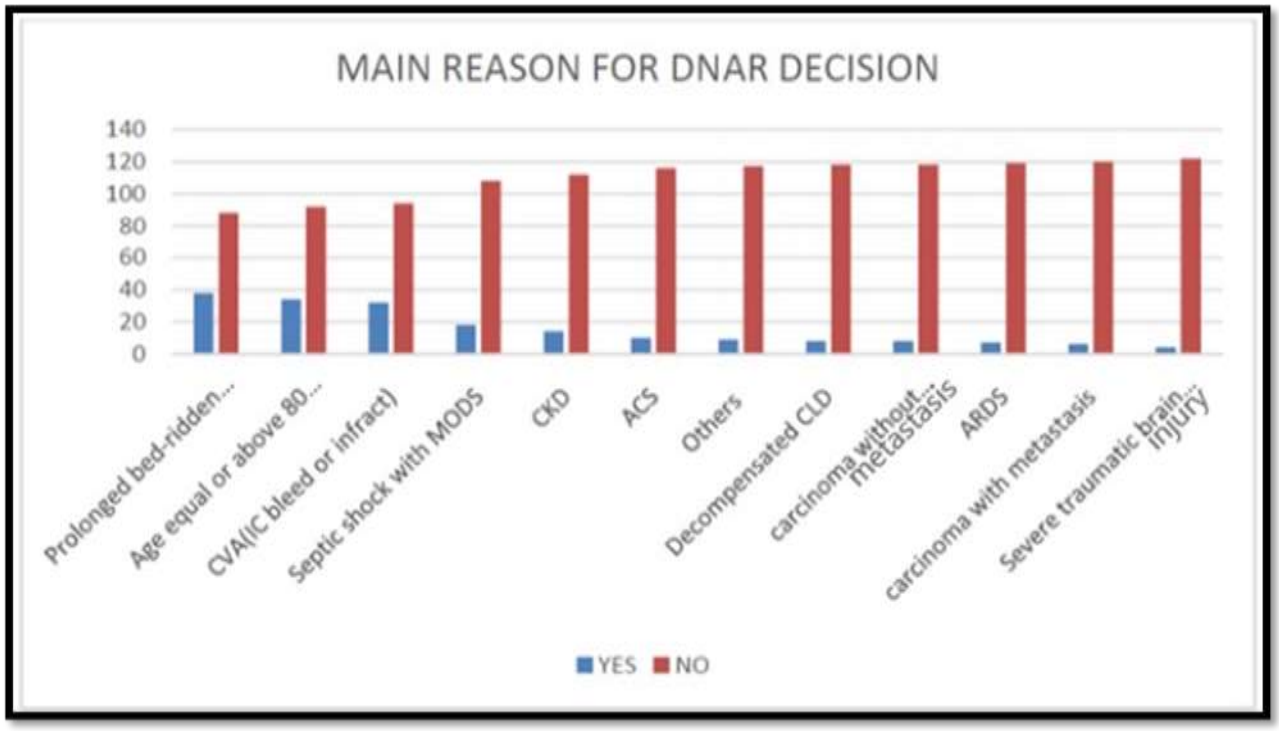
Graph 1: Selection of different end-of-life care interventions by patients' surrogates



(DNAR: Do Not Attempt Resuscitation, NIV: Non-invasive ventilation, CPR: Cardiopulmonary Resuscitation)

Graph 2: major reasons for DNAR decision



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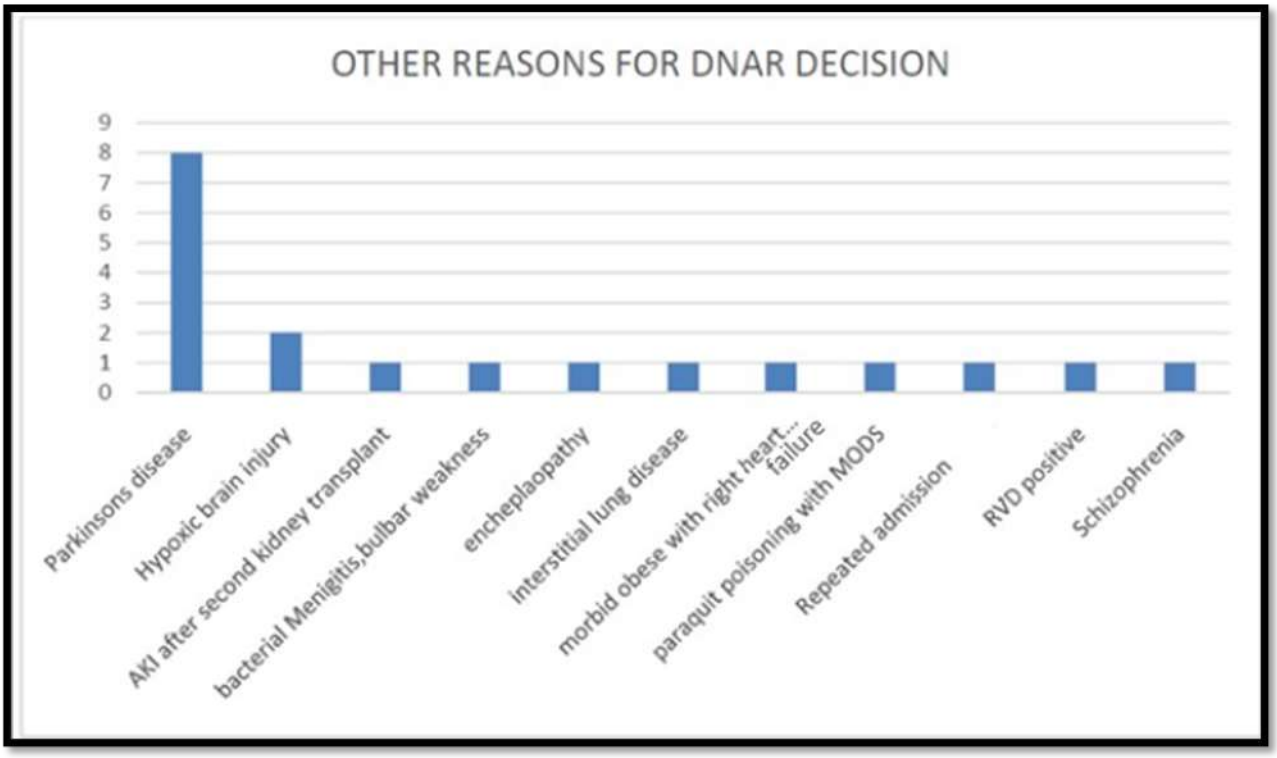
(CVA: cerebral vascular accident, IC bleed: intracranial bleeding, MODS: multiple organ dysfunction syndrome, CKD: chronic kidney disease, ACS: acute coronary syndrome, CLD: chronic liver disease, ARDS: acute respiratory distress syndrome)

Graph 3: Other reasons for DNAR decision



(MODS: multiple organ dysfunction syndrome, RVD: Retroviral disease)

Table 1: Different components of EOLC mentioned in DNAR consent form

No.	EOLC intervention opted by patient/surrogates	Yes	No
1	CPR		
2	Intubation or Re-intubation		
3	NIV		
4	Vasopressors		
5	Hemodialysis		
6	Feeding		
7	Sedation		
8	Withdrawal of ongoing support		

(EOLC: end-of-life care, DNAR: Do Not Attempt Resuscitation, CPR: cardiopulmonary resuscitation, NIV: non-invasive ventilation)

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Table 2: Data showing selection of different components of end-of-life care

End-of-life care interventions	Yes	No	Percentage
CPR	0	126	0.00
Intubation or Reintubation	1	125	0.79
NIV	25	101	19.8
Dialysis	14	112	11.1
Vasopressor Support	38	88	30.5
Sedation	126	0	100.0
Feeding	126	0	100.0
Withdrawal of ongoing support	31	95	24.6

(CPR: cardiopulmonary resuscitation, NIV: non-invasive ventilation)

Table 3: collected data with statistics

Total patients whose surrogates signed DNAR consent for EOL care		126 Patients
The mean age of the patients		69.96±14.23 years
End-of-life care discussion was initiated by	Intensivist	71(56.3%)
	Patient's surrogates	55(43.7%)
major reasons for opting end-of-life care	Prolonged bed-ridden status	38 (30.1%)
	Age more than 80 years	34(26.98%)
	CVA (intracranial bleed or infarct)	32 (25.39%)
Already intubated patients at the time of EOL care decision		45 (35.7%)
Patients requiring vasopressors at the time of EOL care decision		38 (30.2%)
Patients requiring hemodialysis at the time of EOL care decision		22 (17.5%)
Mean duration of ICU stay before taking end-of-life care decision		5.56 ± 7.65 days
Mean APACHE-2 score		19.69±6.58
Mean SOFA score		6.91± 3.18
Financial constraints for ongoing treatment		39 (31%)
end-of-life care decision was revoked by		3 (2.4%).
Patients who died in hospital		78 (61.9%)
Patients who got discharged at request for homecare/hospice		48 (38.1%)

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(DNAR: Do Not Attempt Resuscitation, EOL care: end-of-life care, CVA: cerebral vascular accident, ICU: intensive care unit, APACHE: acute physiology and chronic health evaluation, SOFA: Sequential Organ Failure Assessment)

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