

# An Observational Study on the Effects of Delayed Initiation of End-of-Life Care in Terminally ill Young Adults in the Intensive Care Unit

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## Abstract

**Introduction:** The early initiation of end-of-life (EOL) care in terminally ill patients in the intensive care unit (ICU) offers distinct advantages but requires the consent and cooperation of the patients or their relatives. The terminally ill young adults pose distinct set of challenges. The present study was conducted to measure the prevalence and identify and compare the risk factors for the delayed initiation of EOL in terminally ill young adults. **Methods:** The retrospective study was conducted in a mixed medical-surgical 7-bedded ICU after extracting the medical records of all terminally ill young adults in the age group of 20–40 years admitted between June 2014 and November 2018. Only “treatment futile” patients were eligible for inclusion. The patients already on EOL care or with unproven diagnosis were excluded from the study. The commencement of EOL care was divided into (a) normal group (N) and (b) late group (L). The two groups were compared with respect to the demographic factors, outcome, and patient satisfaction level. The factors responsible for the delay were investigated. All statistical analyses were performed using software SPSS 21.0 (SPSS, Inc., Chicago, IL, USA). **Results:** Out of 66 terminally ill young adults with treatment futility, 23 (38.9%) were in the N group and 36 (61.1%) were in the L group ( $0.8 \pm 0.4$  days vs.  $3.1 \pm 1.6$  days;  $P = 0.01$ ). The education level and social and family support of the relatives of the N group were higher ( $P = 0.03$ ;  $P = 0.04$ ). The N group had lesser drug consumption of ICU resource usage (14.7% vs. 36.1%,  $P = 0.01$ ; 18.5% vs. 24.7%,  $P = 0.04$ ). There was no difference in the duration of mechanical ventilation, ICU stay, and satisfaction level at the time of discharge (or death) from the ICU. **Conclusions:** Our study found a high prevalence of delayed initiation of EOL care in terminally ill young adults and identified the factors responsible for them. The normal initiation of EOL care reduced the usage of medications and resources without affecting the level of patient satisfaction.

**Keywords:** Delayed initiation, end-of-life, intensive care unit

## INTRODUCTION

Early integration of end-of-life (EOL) care in the intensive care unit (ICU) is advocated for judicious distribution of health-care resources. However, the acceptance of EOL care by the patients’ family members varies considerably depending on a complex interplay of various medical and social factors.<sup>[1]</sup>

The initiation of EOL care in terminally ill young adults is offset with numerous challenges.<sup>[1]</sup> The quantification of the prevalence and identification of the risk factors for such delay have not been established with certainty to the best of our knowledge.

The present study was conducted to measure the prevalence of delayed initiation of EOL care in “treatment futile” terminally

ill young adults and identify the factors responsible for such delay in the ICU.

## METHODS

The retrospective observational study was conducted in the 7-bedded mixed medical-surgical ICU of a tertiary care

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university teaching hospital in India. After obtaining approval for waiver of informed consent from the institutional ethics committee, the medical records of all consecutive young adults in the age group of 20–40 years, who were admitted between June 2014 and November 2018, were recognized as terminally ill at any time after the ICU admission and these medical records were extracted from the ICU database. The patients who were identified for treatment futility after ICU admission were only eligible for inclusion. The patients already under EOL care before their ICU admission and those with unknown primary disease were excluded from the study.

For the study purpose, “young adults” were defined as individuals in the age group of 20–40 years. The treatment futility was based on a joint decision between the primary physician and the intensivist after considering the nature and stage of the disease, presence of comorbid illnesses, available therapeutic options, and the likelihood of response to treatment.

The commencement of EOL care after recognition of treatment futility was divided into (a) normal group (N) – within 24 h of decision of treatment futility and (b) late group (L) – after 24 h of recognition of treatment futility. The cutoff value of 24 h was calculated on the basis of median time for the initiation of EOL among all patients.

The groups were compared with regard to their primary disease, comorbid illnesses, level of education, economic status, available social support, number of counseling sessions required from recognition of treatment futility to consent for EOL, need for psychiatric consultation for aiding consent, and satisfaction level with EOL at the time of discharge (or death) from the ICU. The social and family support was considered as available when the patients’ family members expressed their ability to provide EOL care at home in case of his discharge from the hospital.

The satisfaction level of the family members was classified as “satisfied” or “dissatisfied” based on medical records noted after counseling the family members at the time of discharge (or death) from the ICU. The family members who expressed satisfaction with their decision to consent for EOL and were happy with the EOL care provided in the ICU were categorized as “satisfied” and those who regretted their decision for EOL consent and/or were unhappy with EOL care were categorized as “dissatisfied.” In case of variable opinion, the opinion of the legal guardian was considered.

All statistical analyses were performed using software SPSS 21.0 (SPSS, Inc., Chicago, IL, USA). The mean standard deviation (SD) and percentage values were used to summarize baseline characteristics and outcome data. Results were expressed as the mean  $\pm$  SD and percentage when appropriate.  $P < 0.05$  was considered statistically significant. Chi-square test was used to compare proportions. Paired  $t$ -test and Fisher’s exact test were used to compare outcomes in the two groups.

## RESULTS

A total of 66 terminally ill young adults were recognized for treatment futility during this period, of whom 23 patients (38.9%) underwent normal initiation of EOL (N) against late initiation (L) in 36 (61.1%) patients ( $0.8 \pm 0.4$  days vs.  $3.1 \pm 1.6$  days;  $P = 0.01$ ) [Table 1]. A total of seven patients died before consenting for EOL care. The baseline and demographic characteristics of both the groups were similar [Table 1].

The level of education was higher in the N group (45.3% vs. 69.5% and 49.2% vs. 21.4%;  $P = 0.03$  and  $0.04$ ) [Table 2]. More patients in the N group had social and family support to pursue EOL care at home if discharged from the hospital, although the economic status was similar. The L group needed multiple sessions of counseling in comparison to the N group [Table 2].

There was significantly lesser drug consumption (antibiotics, vasopressors, cardiac medications, etc.) and ICU resource utilization (ventilators, monitors, infusion pumps, etc.) in the N group [Table 2].

The mortality at 28 days and the satisfaction level at discharge (or death) from ICU were similar in the two groups [Table 1].

The delayed initiation of EOL was caused due to nonacceptance of EOL care, belief in a miraculous recovery, lack of adequate family and social support, and need for more time for decision-making [Figure 1].

## DISCUSSION

Our study has found a delay in the initiation of EOL care among most of the terminally ill young adults in the ICU. It is known that challenges in implementing EOL in children

**Table 1: Comparison of the baseline and demographic characteristics between normal (N) and late initiation (L)**

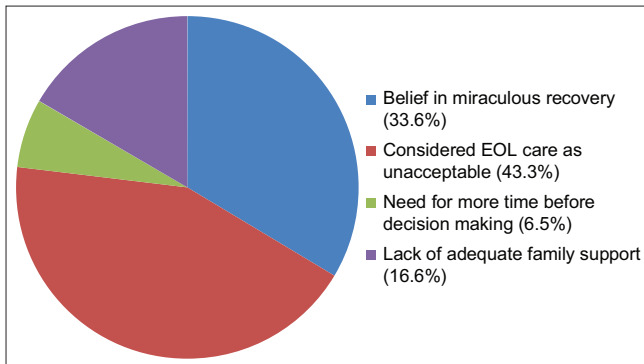
	Normal initiation (N) (n=23)	Late initiation (L) (n=36)	P
Age (years), mean $\pm$ SD	23 $\pm$ 2.7	25 $\pm$ 3.6	0.08
Sex (male/female)	17/6	23/13	0.09
Primary disease			
Malignancy	21.7	25.0	0.12
Sepsis	8.6	11.1	0.14
TBI	21.7	16.6	0.07
Stroke	4.3	2.7	0.12
Heart failure	13.0	13.8	0.16
Liver failure	17.3	13.8	0.14
Respiratory failure	13.0	16.6	0.09
Length of ICU stay (days), mean $\pm$ SD	14 $\pm$ 4.9	12 $\pm$ 5.6	0.08
Duration of mechanical ventilation (days), mean $\pm$ SD	4 $\pm$ 2.2	6 $\pm$ 3.9	0.07
28-day mortality (%)	86.9	86.1	0.14
Satisfaction level (%)	82.6	81.9	0.12

TBI: Traumatic brain injury, ICU: Intensive care unit, SD: Standard deviation

**Table 2: Comparison of the risk factors between the normal (N) and late initiation (L) group**

	Normal initiation (N) (n=23)	Late initiation (L) (n=36)	P
Level of education (%)			
Uneducated	45.3	69.5	0.03*
Matriculation/10 <sup>th</sup> class	49.2	21.4	0.04*
Above 10 <sup>th</sup>	6.5	9.1	0.06
Economic condition (%)			
Lower	54.8	59.5	0.09
Middle	30.5	26.8	0.12
Upper	14.7	13.7	0.07
Available social and family support (%)	54.2	21.8	0.03*
Need for multiple counseling sessions (%)	44.6	76.7	0.01*
Psychiatric reference required for securing consent (%)	42.6	51.9	0.07
Reduction in the drug consumption (antibiotics, vasopressors, cardiac medications etc.) (%)	36.1	14.7	0.01*
Decrease in ICU resource utilization (%)	24.7	18.5	0.04*

ICU: Intensive care unit. \*P<0.05

**Figure 1:** Causes for late initiation of end of life

and young adults are different than in elderly patients.<sup>[1-3]</sup> The difference is primarily due to nonacceptance of EOL care as a denial phenomenon and a hope for miraculous recovery.<sup>[4]</sup> While spiritual and religious beliefs are responsible for such behaviors to some extent, largely this is on account of a lack of understanding of the basic principles of EOL.<sup>[5,6]</sup> Besides these two factors, lack of validation from close family members to support such decision and apprehensions about the continuity of home care in the event of discharge from the hospital, etc., are other common causes for refusal of EOL.

It is reported that a single session of counseling for EOL is grossly inadequate as most people need time for decision-making.<sup>[7]</sup> The requirement of multiple counseling sessions in the late initiation group in our study supports this view. This also shows that the time period required to arrive upon a decision can be variable in patients and depend on their educational level and societal background. Studies have suggested that while some degree of “depression” may be common as patients approach toward EOL, patient screening tools need to be invented for the identification of those who are “demoralized” and treat them for “demoralization” before counseling them for the acceptance of EOL.<sup>[8,9]</sup> Since most of our patients are counseled initially by the senior physician and

by resident doctors and nurses in the subsequent sittings, there is a scope for some gap in the quality of counseling resulting in a refusal of EOL care. We often overlook to measure the quantum of psychological distress that the patient and their relatives experience on account of anxiety, depression, delirium, existential concerns etc., Since our physicians and nurses are not adequately trained in exploring the existential problems surrounding the fear of death, the time taken for decision-making is prolonged.

Our study also found a reduced usage of drugs and ICU resources in the early initiation group. While this is naturally expected and has been corroborated in many other studies, the implications of this finding are far reaching.<sup>[10-13]</sup> A considerable saving can thus be made for drugs and consumables for their better utilization in treatable conditions in the ICU.

The significant finding in our study was that in both the early and late initiation groups, the satisfaction level of the family members at death (or discharge) was comparable. This would mean that allowing more time for decision-making may be a more prudent approach toward patients who are unlikely to consent for EOL in the first sitting rather than postponing EOL care altogether. Since the preservation of patients’ autonomy is of fundamental importance, repeated counseling fulfills such obligations and allows easier acceptance of EOL care at the subsequent sessions. Many studies have reported twining of “Do not resuscitation” orders with EOL care in order to facilitate benefit.<sup>[14,15]</sup> However, since most of the patients in our setting have poorer comprehensive ability and are at risk of misinterpreting the concepts, we chose to secure the consent separately.

There are several limitations to our study. First, our study was a single-centered study in a public sector teaching institute and may not reflect practices in the private sector. There are no large databases, and the approach for EOL consent remarkably varies from hospital to hospital in our country. Second, the median time from counseling to consent might

be delayed due factors such as the doctor being on leave and patient requesting discharge against advice and hence cannot be representative of ideal situations. However, these data can be used to investigate the time interval between initial counseling and final counseling before decision-making which can be used to study the decision-making course of EOL care in India. Finally, this being a retrospective study did not include any valid quality of life questionnaire. Nevertheless, this study is the first to identify the risk factors for late initiation of EOL in young adults.

## CONCLUSION

To conclude, our study found late initiation of EOL care in a large proportion of young adults in the ICU after recognition of treatment futility and identified the factors causing late initiation. The consumption of drugs and ICU resources were lesser in the early initiation group. There was no difference in the satisfaction level between the two groups at the time of discharge (or death) from the ICU.

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## Conflicts of interest

There are no conflicts of interest.

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