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Barriers to end-of-life decisions and care objectives in intensive care units

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ABSTRACT

Aims: Technological advancements have played a crucial role in the advanced development of organ support systems in intensive care units (ICUs). While the utilization of support systems enhances patient discharge rates, it also extends the ICU stay of patients with terminal comorbidities who have no chance of survival. This elongation of the dying process, which is the inevitable outcome, results in a suspension of life in a sense. Hence, the effective implementation of end-of-life decisions and care stands as one of the crucial steps in the intensive care process. The objective of this study is to identify barriers to end-of-life decision-making and care in intensive care settings. Its aim is to facilitate a comprehensive, suitable, and peaceful experience for patients at the end of life and their families by making the necessary arrangements.

Methods: This survey study involved physicians and nurses evaluating the prepared questionnaire questions concerning the challenges encountered in intensive care settings.

Results: The most important barriers to making end-of-life decisions in intensive care were; among clinician-related factors, concern about legal liability for withholding life-sustaining treatments was 98 (79.7%), among institutional and ICU-related factors, the lack of regulated protocols and standards for end-of-life decisions and care was 96 (78%), among family-related factors, unrealistic expectations of patients and/or families about the prognosis or effectiveness of ICU treatment was 83 (67.5%), and disagreements among family members about end-of-life decisions was 80 (65%). Regarding end-of-life care, the admission of patients to the intensive care unit who would not benefit from treatments in the intensive care unit was rated as 110 (89.4%) and the absence of palliative care services to which a dying patient could be transferred was rated as 108 (87.8%).

Conclusion: Providing unavailing treatments to patients who will not benefit from intensive care interventions results in a decline in quality of life, increased distress among family members, and burnout among intensive care staff. Therefore, end-of-life decisions and care should be effectively implemented in intensive care units. Ensuring adequate training, fostering effective communication between clinicians and families, and maximizing collaboration and communication with the ICU team and other medical departments can facilitate prompt and effective decision-making regarding end-of-life care.

Keywords: Intensive care, intensive care health surveys, communication, end of life decision, end of life care

INTRODUCTION

Intensive care units are specialized units where critically ill patients with multiple organ failure are monitored. Technological advances have been effective in the advanced development of organ support systems in intensive care units. Thanks to these support systems, critically ill patients can hold on to life more in the intensive care unit. While the utilization of support systems enhances patient discharge rates, it also extends the ICU stay of patients with terminal comorbidities who have no chance of survival. This elongation of the dying process, which is the inevitable outcome, results in a suspension of life in a sense. In this way, technology-laden end-of-life care is associated with reduced quality of life, lower satisfaction with end-of-life care, and increased family anxiety and depression.[1]

Many patients admitted to the intensive care unit (ICU) have unknown end-of-life decision and care preferences. As a result, clinicians and substitute decision makers are tasked with making decisions on their behalf.[2] Today, especially in developed countries, most deaths in hospitals occur in intensive care units. Severely ill patients admitted to intensive care are increasingly exposed to unwanted interventions.[3,4] The desire of physicians, patient's relatives, or both to continue interventions that will not benefit the patient can strain healthcare professionals, exhaust limited resources, deprive

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the patient of a peaceful end-of-life experience, and potentially result in a poor quality of life during the final days.

The objective of this study, which we conducted with the participation of intensive care workers, is to identify barriers to end-of-life decision-making and care in intensive care settings. Its aim is to facilitate a comprehensive, suitable, and peaceful experience for patients at the end of life and their families by making the necessary arrangements. The study also aims to ensure that intensive care beds are used more effectively.

METHODS

Study Design and Inclusion Criteria

The survey study, focusing on end-of-life decision-making and care in the intensive care unit, was conducted on 22/5/2023 with the approval of the Clinical Research Ethics Committee of Haydarpaşa Numune Training and Research Hospital (HNEAH-KAEK 2023/84). It involved the participation of volunteers, including physicians and nurses working in the 3rd Step intensive care unit of the same hospital. All procedures were carried out in accordance with the ethical rules and the principles of the Declaration of Helsinki. A literature review was performed to inform the questionnaire study, aiming to identify the challenges associated with end-of-life decisions and care. Subsequently, the identified challenges encountered in your intensive care unit were compared, and based on this comparison, the questionnaire form was revised and recreated.

End-of-life decision and care challenges in intensive care were assessed using a 26-question questionnaire divided into three sections: patient and family-related factors (8 questions) in section 1, institutional and intensive care-related factors (9 questions) in section 2, and clinician-related factors (9 questions) in section 3. Participants were asked to evaluate the significance of the problems by assigning values from 1 to 5 to the questions (1=No barriers, 2=Minimal barrier, 3=Moderate barrier, 4=Significant barrier, and 5=Very significant barrier).

Data Collection

The intensive care unit consists of a total of 156 employees, including 77 physicians and 79 nurses. Out of the 123 participants who voluntarily filled out the forms for the study, 59 were physicians and 64 were nurses.

Primary and Secondary Endpoints

To determine the importance and priority order of the problems encountered in intensive care in line with the answers given by the participants and to ensure that necessary measures are taken to solve the problems. The secondary endpoint is to ensure that intensive care beds are used more efficiently by ensuring more effective implementation of end-of-life decisions.

Statistical Analysis

IBM SPSS Statistics 22 program was used for statistical analyses while evaluating the findings obtained in the study. The suitability of the parameters for normal distribution was evaluated by Kolmogorov-Smirnov test and it was found that the parameters did not exhibit normal distribution. In addition to descriptive statistical methods (mean, standard deviation, frequency), Mann Whitney U test was used to compare quantitative data. Significance was evaluated at $p<0.05$ level.

RESULTS

The study was conducted with a total of 123 intensive care workers aged between 22 and 60 years. The mean age was 31.17±7. 35 years (**Table 1**).

Table 1: Demographic characteristics

		Min-Max	Avg±SD
Age		22-60	31.17±7.35
		n	%
Gender$_{n(\%)}$	Female	73	59.3
	Male	50	40.7
ICU Task$_{n(\%)}$	Nurse	64	52.0
	Physician	59	48.0
Duration of Employment$_{n(\%)}$	Shorter than 1 year	41	33.3
	1 year and longer	82	66,7

59.3% of the participants were female, 40.7% were male, 52% were nurses and 48% were physicians (**Table 1**).

Duration of employment ranged between 2 days and 30 years, with a mean of 4.38±5.76 years. 33.3% had shorter than 1 year of employment, while 66.7% had 1 year or longer (**Table 1**).

The most important obstacles for the participants to make end-of-life decisions in intensive care is firstly the admission of patients who will not benefit from intensive care treatments to the intensive care unit 110 (89.5%), and secondly the absence of palliative care service to which a dying patient can be transferred 108 (87.8%) (**Table 2**).

Physicians' ratings of the questions "No prior statement about the end of life of patients and No palliative care service to which a dying patient can be transferred" were statistically significantly higher than nurses' ratings (p:0.001 and p:0.016; $p<0.05$) (**Table 3**).

Nurses' ratings of the questions "Insufficient recognition of the importance of end-of-life decisions and care by colleagues or institutional management, Inadequate care in the intensive care unit due to physician staffing patterns, Inadequate care in the intensive care unit due to nurse staffing patterns" were statistically significantly higher than those of physicians (p:0.002, p:0.001, p:0.001; $p<0.05$) (**Table 3**).

Nurses' ratings for the questions "Inadequate support services for bereaved families, inadequate clinician training on end-of-life decisions and care, and clinicians' inability to allocate sufficient time to the patient/family due to busyness" were statistically significantly higher than physicians' ratings (p:0.001, p:0.001 and p:0.001; $p<0.05$) (**Table 3**).

Nurses' ratings for the questions "Inadequate communication between the intensive care team and patients/families regarding end-of-life decision and care goals, inadequate communication between the intensive care team and other clinicians regarding end-of-life decision and care goals, and inadequate communication (disagreement) within the intensive care team regarding end-of-life decision and care goals" were statistically significantly higher than physicians' ratings (p:0.035, p:0.006 and p:0.036; $p<0.05$) (**Table 3**).

Nurses' rating of the question "The current health policy limits the role of nurses in making these discussions." was statistically significantly higher than that of physicians (p:0.001; $p<0.05$).

There is no statistically significant difference between physicians and nurses in terms of the scores they received from other questions ($p>0.05$) (**Table 3**).

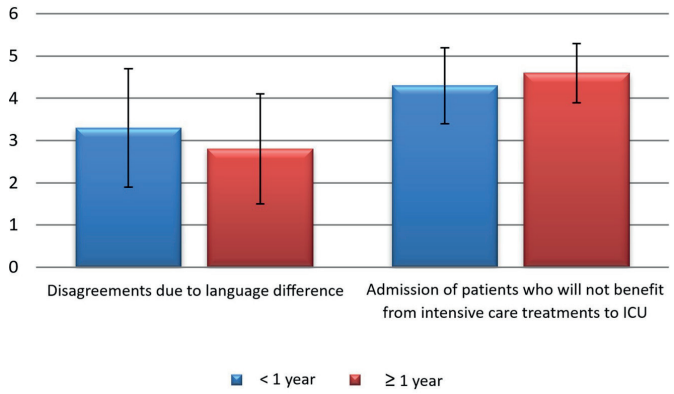

Figure 1. Comparison in terms of the scores obtained from the answers given to the end-of-life decisions questions according to the duration of working in the ICU

The score evaluation of ICU employees with less than 1 year of working experience in response to the question "Disagreements due to language differences" was statistically significantly higher than those with longer than 1 year of working experience (p: 0.034; p<0.05) (**Figure 1**).

The point evaluation of ICU staff with longer than 1 year of employment to the question "Admission of patients who will not benefit from intensive care unit treatments" was statistically significantly higher than those with shorter than 1 year of employment (p:0.041; p<0.05) (**Figure 1**).

There is no statistically significant difference between the working hours in terms of the scores they received from other questions (p>0.05) (**Figure 1**).

DISCUSSION

Our study aimed to identify the key barriers to end-of-life decisions and care in the ICU. Our findings revealed that the primary obstacles to end-of-life decisions in the ICU are the absence of legal and administrative infrastructure, as well as the lack of established protocols and standards. Additionally, the major barriers to care include admitting patients who will not benefit from intensive care treatments and the insufficient availability of suitable palliative centers.

Table 2: Distribution of answers to end-of-life decisions questions

	No barriers	Minimal barrier	Moderate barrier	A big barrier	A very big barrier
	n (%)	n (%)	n (%)	n (%)	n (%)
Factors related to patients/family members					
Unrealistic patient and/or family expectations about the prognosis or effectiveness of ICU treatment	1 (0.8%)	11 (8.9%)	28 (22.8%)	56 (45.5%)	27 (22%)
Many patients are unable to participate in treatment discussions	10 (8.1%)	28 (22.8%)	43 (35%)	29 (23.6%)	13 (10.6%)
Patients do not make any prior statements about the end of life	10 (8.1%)	29 (23.6%)	31 (25.2%)	30 (24.4%)	23 (18.7%)
Disagreements between family members about end-of-life decisions	3 (2.4%)	10 (8.1%)	30 (24.4%)	34 (27.6%)	46 (37.4%)
No proxy to make decisions on behalf of patients who lack decision-making capacity	5 (4.1%)	13 (10.6%)	30 (24.4%)	38 (30.9%)	37 (30.1%)
Refusal by patients/families to give up life-sustaining treatments for religious reasons	7 (5.7%)	23 (18.7%)	20 (16.3%)	21 (17.1%)	52 (42.3%)
Disagreements between patients/families and ICU team about end-of-life decisions	4 (3.3%)	16 (13%)	24 (19.5%)	37 (30.1%)	42 (34.1%)
Conflicts due to language differences	16 (13%)	40 (32.5%)	20 (16.3%)	25 (20.3%)	22 (17.9%)
Institutional/ICU factors					
Lack of adequate legal and administrative infrastructure for end-of-life decisions	3 (2.4%)	4 (3.3%)	17 (13.8%)	40 (32.5%)	59 (48%)
Lack of a suitable environment for visits by families of critically ill ICU patients	5 (4.1%)	15 (12.2%)	29 (23.6%)	31 (25.2%)	43 (35%)
Lack of palliative care services to which a dying patient can be transferred	1 (0.8%)	6 (4.9%)	8 (6.5%)	45 (36.6%)	63 (51.2%)
Admission of patients who will not benefit from intensive care treatments to the intensive care unit	0 (0%)	4 (3.3%)	9 (7.3%)	28 (22.8%)	82 (66.7%)
Insufficient recognition of the importance of end-of-life decisions and care by colleagues or institutional management	2 (1.6%)	13 (10.6%)	33 (26.8%)	47 (38.2%)	28 (22.8%)
Inadequate care in the intensive care unit due to physician staffing patterns	10 (8.1%)	28 (22.8%)	22 (17.9%)	36 (29.3%)	27 (22%)
Inadequate care in the intensive care unit due to nurse staffing patterns	7 (5.7%)	22 (17.9%)	27 (22%)	31 (25.2%)	36 (29.3%)
Inadequate support services for bereaved families	3 (2.4%)	12 (9.8%)	33 (26.8%)	42 (34.1%)	33 (26.8%)
Lack of regulated protocols and standards for end-of-life decisions and care	1 (0.8%)	2 (1.6%)	24 (19.5%)	35 (28.5%)	61 (49.6%)
Clinician factors					
Inadequate clinician training on end-of-life decisions and care	4 (3.3%)	21 (17.1%)	35 (28.5%)	39 (31.7%)	24 (19.5%)
Clinicians cannot allocate enough time to the patient/family due to busy schedules	4 (3.3%)	6 (4.9%)	32 (26%)	47 (38.2%)	34 (27.6%)
Inadequate communication between the intensive care team and patients/families regarding end-of-life decisions and care goals	1 (0.8%)	14 (11.4%)	32 (26%)	50 (40.7%)	26 (21.1%)
Concern about legal liability for forgoing life-sustaining treatments	3 (2.4%)	5 (4.1%)	17 (13.8%)	44 (35.8%)	54 (43.9%)
Clinicians' unrealistic expectations about patient prognosis in terms of treatment or the effectiveness of the intensive care unit	4 (3.3%)	16 (13%)	36 (29.3%)	34 (27.6%)	33 (26.8%)
Inadequate communication between the intensive care team and other clinicians regarding end-of-life decisions and care goals	4 (3.3%)	17 (13.8%)	40 (32.5%)	30 (24.4%)	32 (26%)
Inadequate communication (disagreement) within the intensive care team regarding end-of-life decision and care goals	5 (4.1%)	31 (25.2%)	32 (26%)	29 (23.6%)	26 (21.1%)
Psychological/emotional stresses of providing care to dying patients	6 (4.9%)	31 (25.2%)	26 (21.1%)	34 (27.6%)	26 (21.1%)
Current health policy limits the role of nurses in these discussions.	4 (3.3%)	20 (16.3%)	26 (21.1%)	32 (26%)	41 (33.3%)

Table 3: Comparison of nurses and doctors in terms of the scores they received from the answers they gave to the questions of end-of-life decisions

	Nurse	Doctor	
	Avg±SD (median)	Avg±SD (median)	p
Factors related to patients/family members			
Unrealistic patient and/or family expectations about the prognosis or effectiveness of ICU treatment	3.6±1.0 (4)	3.9±0.8 (4)	0.112
Many patients are unable to participate in treatment discussions	3.1±1.2 (3)	3.0±1.0 (3)	0.725
Patients do not make any prior statements about the end of life	2.8±1.3 (3)	3.6±1.0 (4)	0.001*
Disagreements between family members about end-of-life decisions	3.7±1.2 (4)	4.1±0.9 (4)	0.182
No proxy to make decisions on behalf of patients who lack decision-making capacity	3.6±1.1 (4)	3.9±1.1 (4)	0.142
Refusal by patients/families to give up life-sustaining treatments for religious reasons	3.7±1.4 (4)	3.7±1.3 (4)	0.848
Disagreements between patients/families and ICU team about end-of-life decisions	3.8±1.2 (4)	3.8±1.1 (4)	0.883
Conflicts due to language differences	3.0±1.3 (3)	3.0±1.4 (3)	0.898
Institutional/ICU factors			
Lack of adequate legal and administrative infrastructure for end-of-life decisions	4.2±0.9 (4)	4.2±1.0 (4)	0.705
Lack of a suitable environment for visits by families of critically ill ICU patients	3.6±1.3 (4)	3.9±1.0 (4)	0.446
Lack of palliative care services to which a dying patient can be transferred	4.2±0.9 (4)	4.5±0.8 (5)	0.016*
Admission of patients who will not benefit from intensive care treatments to the intensive care unit	4.5±0.9 (5)	4.6±0.7 (5)	0.609
Insufficient recognition of the importance of end-of-life decisions and care by colleagues or institutional management	4.0±1.0 (4)	3.4±1.0 (3)	0.002*
Inadequate care in the intensive care unit due to physician staffing patterns	3.8±1.1 (4)	2.8±1.3 (2)	0.001*
Inadequate care in the intensive care unit due to nurse staffing patterns	4.1±1.0 (4)	2.9±1.2 (3)	0.001*
Inadequate support services for bereaved families	4.1±0.9 (4)	3.3±1.0 (3)	0.001*
Lack of regulated protocols and standards for end-of-life decisions and care	4.3±0.9 (5)	4.2±0.8 (4)	0.684
Clinician factors			
Inadequate clinician training on end-of-life decisions and care	3.9±1.0 (4)	3.0±1.0 (3)	0.001*
Clinicians cannot allocate enough time to the patient/family due to busy schedules	4.1±0.8 (4)	3.5±1.1 (4)	0.001*
Inadequate communication between the intensive care team and patients/families regarding end-of-life decisions and care goals	3.9±1.0 (4)	3.5±0.9 (4)	0.035*
Concern about legal liability for forgoing life-sustaining treatments	4.1±1.0 (4)	4.2±0.9 (4)	0.396
Clinicians' unrealistic expectations about patient prognosis in terms of treatment or the effectiveness of the intensive care unit	3.8±1.1 (4)	3.5±1.1 (4)	0.141
Inadequate communication between the intensive care team and other clinicians regarding end-of-life decisions and care goals	3.8±1.1 (4)	3.3±1.1 (3)	0.006*
Inadequate communication (disagreement) within the intensive care team regarding end-of-life decision and care goals	3.5±1.2 (4)	3.1±1.1 (3)	0.036*
Psychological/emotional stresses of providing care to dying patients	3.5±1.3 (4)	3.2±1.1 (3)	0.073
Current health policy limits the role of nurses in these discussions.	4.2±1.0 (4)	3.2±1.2 (3)	0.001*

With the aging population and advancements in medicine, there will be an increasing number of end-of-life decisions made in intensive care units (ICUs).[5] The absence of a specific standard leads to the emergence of various problems during the implementation of these decisions.

Communication between the intensive care team is one of the important factors in making end-of-life decisions in intensive care units. In a study conducted by Ferrand et al.[6], it was found that a majority of both nursing staff (91%) and physicians (80%) emphasized the importance of collaborative decision-making in end-of-life decisions. However, only 27% of nurses and 50% of physicians stated that this practice could be achieved in actual implementation. In our study, 73 (59.3%) found that current health policies limit the role of nurses in making these decisions in cooperation. Ethically, interdisciplinary collaboration in the ICU improves clinical outcomes.[7-9] In our study, inadequate communication between the intensive care team and other clinicians was identified as a significant factor, with a rate of 62 (50.4%). In conclusion, maintaining high levels of both intra- and extra-clinical communication in the ICU is believed to significantly enhance the effective implementation of end-of-life decisions and care. The lack of recommendations from scientific bodies and legislation on the withdrawal of life-sustaining treatments in intensive care medicine in many European countries likely contributes to conflicts among ICU caregivers.[6] In our survey study, a significant percentage of respondents (96, or 78%) identified the lack of organized protocols and standards for end-of-life decisions and care as an important factor contributing to the failure to make these decisions effectively.

One of the most important elements in making end-of-life decisions is family members, who are often the decision-makers. Many recent studies have shown that surrogate decision-makers for critically ill patients often have optimistic expectations regarding prognosis.[10,11] This is a serious problem because optimistic expectations are associated with increased use of invasive treatments and delayed integration of palliative care in dying patients.[12-14] In the study conducted by You JJ et al.[15], it was found that the most significant barriers to making end-of-life decisions originate from family members and patients. Among these factors, they found that the most prominent reasons were family members' or patients' difficulty in accepting a poor prognosis (mean [SD] score, 5.8 [1.2] and 5.6 [1.3] respectively), family members' or patients' difficulty in understanding the limitations and complications of life-sustaining treatments (5.8 [1.2] for both groups), disagreement among family members about the

goals of care (5.8 [1.2]). JE. Nelson et al.[16] found that the most important barriers to end-of-life decisions and care in their study were unrealistic patient and/or family expectations about the prognosis or effectiveness of ICU treatment 272 (48.7%) and the inability of a significant proportion of patients to participate in treatment discussions 259 (46.6%). S Iranmanesh et al.[17] found that the most important barrier was "families not accepting the poor prognosis" (5.04). In our study, the most prominent problems encountered among family-related factors were unrealistic patient and/or family expectations about the prognosis or effectiveness of ICU treatment 83 (67.5%), disagreements among family members regarding end-of-life decisions 80 (65%), and disagreements between patients/families and the ICU team regarding end-of-life decisions 79 (64.2%). Effective communication between clinicians and family members is crucial for decision-making in the ICU, especially since most critically ill patients lack decision-making capacity.[18] Improved communication with family members has been shown to enhance patient care and improve outcomes for both patients and their families. End-of-life care extends beyond the patient's death, and intensive care units should consider developing comprehensive psychological support programs to meet the needs of both families and clinical staff.[19]

One of the most important elements of effective implementation of end-of-life decisions and care is the ability of the intensive care team to speak a common language. It is important that the whole team can find common ground on end-of-life decisions. HU Bucher et al.[20] found that the most frequently reported problems related to end-of-life decision-making by nurses in their study were difficulty in fully interpreting parents' attitudes (92% vs. 82%), insufficient time for decision-making (81% vs. 54%), legal restrictions (80% vs. 54%), and lack of a consistent unit policy (73% vs. 36%). In our study, the problems that nurses rated higher than doctors were; Clinicians not being able to allocate enough time to the patient/family due to busy schedules (mean [SD] score 4.1±0.8 (4) 3.5±1.1 (4) respectively), Inadequate communication between the intensive care team and patients/families regarding end-of-life decisions and care goals (mean [SD] score 3.9±1.0 (4) 3.5±0.9 (4), respectively), Current health policy limits the role of nurses in these discussions (mean [SD] score 4.2±1.0 (4) and 3.2±1.2 (3), respectively), and Insufficient recognition of the importance of end-of-life decisions and care by colleagues or institutional management (mean [SD] score 4.0±1.0 (4) and 3.4±1.0 (3), respectively). In addition, nurses were more likely than physicians to emphasize the inadequacy of communication within the team, with other clinicians and with family members.

Studies have shown that language may affect communication with the patient and family and may be a negative factor in making end-of-life decisions.[21-23] In our study, 47 (38.2%) disagreements due to language differences were detected and this opinion was found to be significantly higher especially in ICU team working less than 1 year.

CONCLUSION

Unavailing treatments administered to patients who will not benefit from intensive care can result in poor quality of the patients' final moments, depression, anxiety, and restlessness among family members, and burnout among intensive care staff. Therefore, end-of-life decisions and care should be effectively implemented in intensive care units. Ensuring adequate training, fostering effective communication between clinicians and families, and maximizing collaboration and communication with the ICU team and other medical departments can facilitate prompt and effective decision-making regarding end-of-life care. In addition, ICU nurses should be more involved in the decision-making process regarding end-of-life decisions and care.

ETHICAL DECLARATIONS

Ethics Committee Approval: The study was carried out with the permission of Clinical Research Ethics Committee of Haydarpaşa Numune Training and Research Hospital (Date:22.05.2023, Decision No: HNEAH-KAEK 2023/84).

Informed Consent: Written consent was obtained from the patient participating in this study.

Referee Evaluation Process: Externally peer-reviewed.

Conflict of Interest Statement: The authors have no conflicts of interest to declare.

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Author Contributions: All of the authors declare that they have all participated in the design, execution, and analysis of the paper, and that they have approved the final version.

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