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Medical futility at the end of life: the first qualitative study of ethical decision-making methods among Turkish doctors

Esra Aksoy[1*] and Ilhan Ilkilic[2]

Abstract

Background The swift advancement of intensive care medicine, coupled with technological possibilities, has prompted numerous ethical inquiries regarding decision-making processes concerning the withholding or withdrawal of treatment due to medical futility. This study seeks to delineate the decision-making approaches employed by intensive care physicians in Türkiye when faced with medical futility at the end of life, along with an ethical evaluation of these practices.

Methods Grounded theory, a qualitative analysis method was employed, conducting semi-structured, in-depth interviews with eleven intensive care physicians in Türkiye. The subsequent text analysis was carried out using MAXQDA software.

Results Participants assert that the decisions made by Turkish physicians determine whether treatment is futile, rely on medical consensus, and lack a standardized decision-making process. The decisions are influenced by legal and social pressures, resource constraints, and occasional conflicts of interest. The significance of professional hierarchy is notable, with limited consideration given to the opinions of nurses and other staff. The unstructured medical consensus processes are shaped by normative concepts such as benefit, age, justice, and conscience. Furthermore, it was observed that the conscientious opinions of physicians carry more weight than adherence to ethical principles and guidelines.

Conclusion To create optimal conditions for doctors to make ethically justifiable decisions, the dynamics within the treatment team should be improved, emphasizing the minimization of hierarchy, and ensuring the active participation of all team members in the decision-making process. Additionally, efforts should be directed toward narrowing the gap between the conscience of the individual doctor and established ethical principles. A potential solution lies in the nationwide implementation of clinical ethics committees and the establishing of clinical ethics guidelines, aiming to address, and overcome the identified challenges.

Keywords Intensive care ethics, End-of-life decisions, Medical futility, Conscience, Culture, Grounded theory

Introduction

The issue of futile treatment has been a subject of ethical literature for over three decades [1–3]. Initially, scholars explored a functional definition of futility, which resulted in various categories, such as qualitative and quantitative futility or physiological futility [4, 5]. Alongside this, definitions related to the quality of life were also established [6, 7]. Over time, the concept has evolved and been

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shaped by diverse factors, including medical goals, sociocultural values, religious beliefs, and personal characteristics and emotions of physicians and patients [8]. This complexity suggests that the concept is difficult to define, leading ethical research on decision-making processes to shift focus to later periods [9]. Studies have highlighted the adverse effects of persisting with futile treatment, categorizing them into impacts on patients, their relatives, other patients, healthcare professionals, and economic outcomes [10–12]. Consequently, some countries have developed policies and guidelines to prevent futile treatment, emphasizing shared decision-making involving patients and their relatives. In acknowledgement of the epistemological challenges in defining the concept, some have suggested that the absence of a purposeful indication serves as a guiding factor in assessing the possibility of futile treatment [13, 14].

Türkiye currently lacks ethical guidelines delineating how end-of-life decisions should be approached. Studies on futility in Türkiye have mostly been reviews [15–17] or surveys primarily involving nurses [18–21]. To address this knowledge gap, this study aims to investigate the ethical decision-making processes of physicians in Türkiye's intensive care units regarding futile treatment. However, surveying futility poses additional challenges in countries with no clearly defined or equivalent term for the concept [22]. In Turkish, five different words—'yararsız, faydasız, nafile, boşuna ve beyhude tedavi'—are used to express futile treatment. The lack of precise definition, along with multiple words for the same concept, has a detrimental impact on operationalizing the concept in Türkiye. For this study, medical futility is defined as "when a specific intervention provides no benefit to a particular patient, and the medical treatment proves unsuccessful in curing the disease or enhancing the patient's quality of life in any manner." The interviews conducted align with this defined understanding of medical futility.

Methods

Study design

The research employed a qualitative analysis method called grounded theory to explore the processes and actions involving numerous individuals [23]. The aim was to develop a theory that explains the observed processes or actions. Grounded theory was chosen as the methodological framework for the study because the focus was on investigating the decision-making processes of physicians in intensive care units. Charmaz's constructivist approach was applied to this study [24]. The limitation of this study, due to the nature of qualitative methodology, it does not claim to provide a comprehensive representation of clinicians' perspectives on medical futility at the end of life. Ethical guidelines established by the Istanbul University Social Sciences and Humanities Research Ethics Committee were followed by the researchers, and the Ethics Report Number was E-35980450–663.05–1412175.

Participant sampling and data collection

In grounded theory, research involves selecting a purposive sample based on the assumption that it provides the most relevant information to address the research question [23]. This study aims to examine physicians working in intensive care units in Türkiye who demonstrate ethical awareness regarding end-of-life decisions. The following inclusion criteria for the purposive sample were established (satisfying one criterion considered sufficient):

- Having conducted studies on futile treatment or intensive care ethics
- Educated in intensive care ethics
- Demonstrating awareness of intensive care ethics (confirmed through pre-interviews)

Participants were assigned random numbers using the letter "D," representing the word "doctor," and conversations were recorded anonymously. Table 1 provides an overview of the sociodemographic characteristics of the interview participants.

In the study, each participant underwent a single in-depth interview, lasting between one and three hours. To comply with quarantine measures during the COVID-19 pandemic, the interviews were conducted via Zoom. The data collection process began with ethics committee approval on April 5, 2021, and concluded with the

Table 1 Characteristics of participants ($n=11$)

Characteristics	n of physicians
Gender	
Female	6
Male	5
Title	
Professors	3
Specialists	5
Assistants	3
Work Experience in ICU	
< 4 Years	5
4 – 10 Years	3
> 10 Years	3
City	
Istanbul	5
Metropolis	4
Little town	2

eleventh interview on October 11, 2021. When data saturation was achieved, meaning no new codes were generated, the interview phase of the study was concluded. The researcher transcribed a total of 190 pages of recorded content. The interviews were conducted in Turkish, and the article's citations were translated into English by the authors.

Analyzing methods

Text analysis was performed using the MAXQDA 2022 Analytics Pro program, specifically designed for computer-assisted qualitative methods. The data coding process commenced with the first interview, and data collection and analysis were carried out simultaneously. Alongside the coding procedure, a research diary documenting the activities and analytical memos containing notes on the research were maintained. The text underwent analysis in accordance with the initial coding, focused coding, and theoretical coding stages as outlined by Charmaz [25].

Results

After analyzing the decision-making process of Turkish physicians on medical futility at the end of life in the ICU, three primary themes emerged. These themes were illustrated in Fig. 1. The physicians stated that they do not make challenging end-of-life decisions alone, but as part of a team. However, the specifics of how this team-based decision-making process works remain unclear. There are differing practices and opinions on whether nurses or

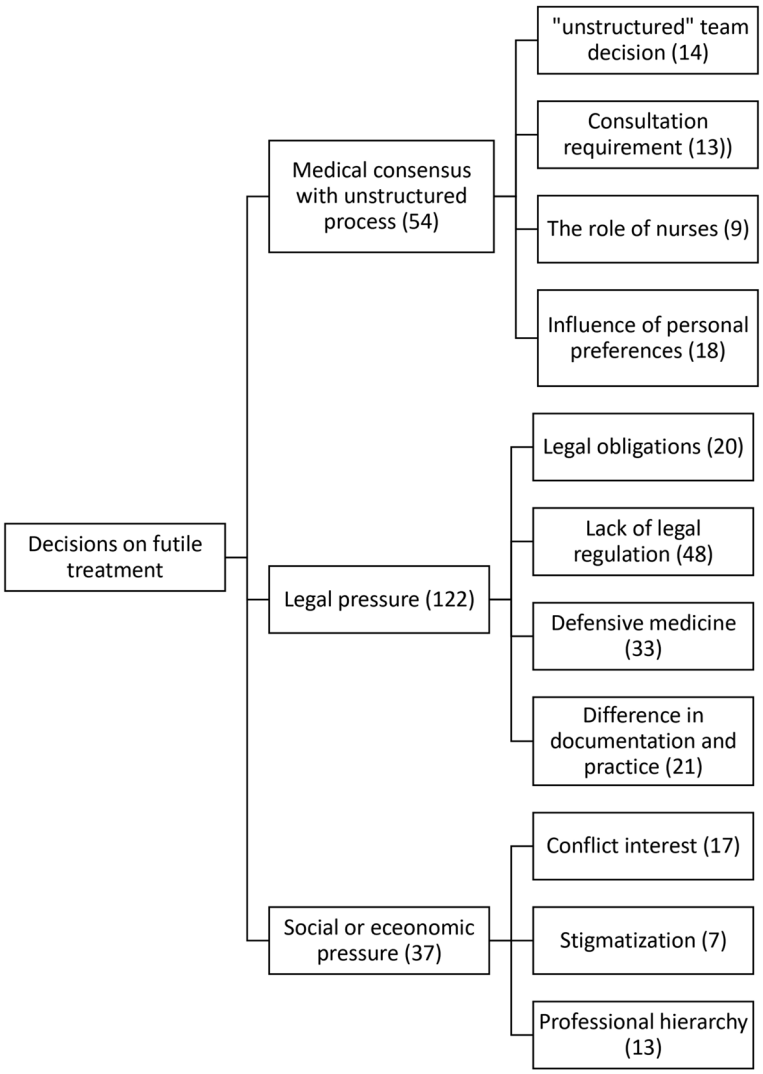

Fig. 1 Categories Found in Interviews Regarding Decisions on Futile Treatment at the End of Life in Intensive Care. (Numbers in parentheses indicate the coding frequency for each category in the interview transcripts.)

other healthcare personnel should be involved in these processes. While participants mentioned that consultations are routinely conducted with relevant departments, these consultations are often perceived as procedures to complete patient files or to provide legal protection. Legal influence emerged as the most influential factor in decision-making processes, consistently emphasized by all participants. "Legal pressure" is an umbrella term that encompasses both the challenges arising from legal obligations and uncertainties due to gaps in legislation and physicians' biases and fears of litigation. Addressing this issue requires legal reforms, providing physicians with psychological support, and increasing their legal awareness. This theme was mentioned 122 times, making it the most frequently coded theme.

> *"A 40-year-old terminal patient presents with complaint and upon examination, a tumor is detected. The surgeon assesses it and says that it is an advanced stage with metastasis, and surgery is not an option. (…) The patient goes to the oncologist, and he/she may or may not give treatment, indicating that this patient will not benefit from oncological treatment. Then the patient gets worse at home, comes to the emergency room, and is admitted to intensive care. (…) Now, the surgeon has done nothing, the oncologist has done nothing, too. But as an intensive care physician in Türkiye, I cannot say that nothing can be done to this patient, I am not taking him/her. Neither the patient's relatives nor other doctors are ready for this, and even most doctors do not accept it either." (D9).*

Physicians may face various legal influence depending on the case. They may feel obligated to follow legal regulations, or they may be uncertain about how to establish advance directives for end-of-life care due to a lack of legal guidance. Sometimes, physicians may practice defensive medicine to protect themselves legally. They may document their practices differently in patient files, such as recording CPR for a patient even if CPR was not performed if they believe it would be deemed futile. Besides legal pressure, physicians may struggle with social pressure and economic conflicts of interest. Social pressure can come from colleagues and patients' relatives. Decisions may be influenced by supervisors due to the hierarchical structure of the medical profession. Additionally, well-known figures or influential individuals might exert influence to ensure their relatives receive improved or more specialized care.

Physicians' decision-making processes in the context of futility

Regarding futility at the end of life, physicians have three critical 'points of no return' in their decision-making processes. Figure 2 illustrates these points and the measures that can prevent their occurrence. The figure highlights that the insufficient number of palliative care centers is the most crucial factor, and exceeding these critical points depends on individual preferences. Figure 3 details the intricate process of a patient's hospitalization, starting from the emergency department and ending in ICU admission. This delineation underscores the direct impact of physicians' ethical awareness in the context of futility and the preferences expressed by the patients' families on the decision to admit a patient to the ICU.

Factors in decision-making in the context of futility

The decision-making process at the end of life in the context of futility involves various factors such as the patient's city of residence, the physician's ethical awareness regarding futility, and the characteristics and

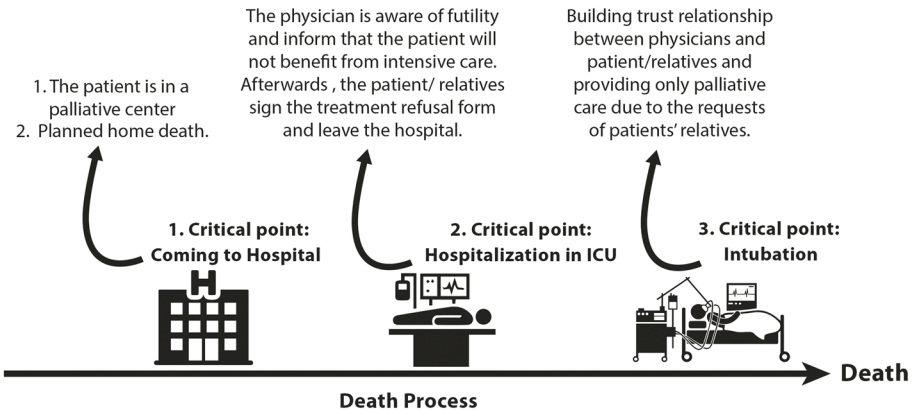

Fig. 2 The critical points of no return in physicians' decision-making processes in the context of futility

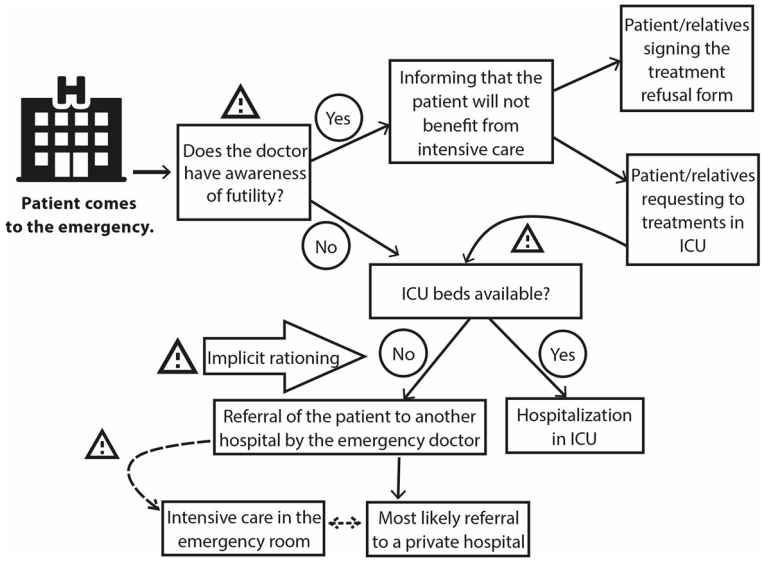

Fig. 3 Process of decision-making around ICU admission of patients in the context of futility

preferences of both patients and their relatives. The geographical location of the patient plays a significant role, as the number of private hospitals and the presence of an operational palliative center in the city affect the decision-making process. Physicians note that they are compelled to admit patients to intensive care when there are no alternative options due to a lack of sufficient palliative centers. They also claim that patients with futile treatment prospects may more readily secure a bed in the ICU of private hospitals. These parameters vary between metropolises and small cities, with larger cities, especially Istanbul, facing more significant organizational challenges.

Physicians' ethical awareness is crucial in informing patients and their relatives about futility. While some medical professionals advocate for allocating all available resources to every patient without considering futility, there is often resistance to referrals from palliative care to intensive care. Patients are initially categorized based on their medical conditions. Patients receiving futile treatment in the ICU are classified into three categories: those at the end of life, long-term care patients, and victims of medical malpractice. In this context, having an adequate number of not only palliative care centers but also nursing homes and hospices is crucial. It is noteworthy that there are currently no hospices in Türkiye. Only one participant mentioned that maximal treatment was provided due to considerations of medical malpractice without concern of futility.

Building trust between the medical team and patients/relatives is crucial. However, the trust established by the patient or their relatives within the professional community plays a significant role. For instance, if a patient or their relative is a health worker, especially a physician, the medical team is more likely to accept their request not to be intubated during ICU admission. This is because the status of a patient (or their relative) as a health worker helps establish a level of trust within the professional community. Physicians have pointed out that there are no legal regulations on advance directives in Türkiye. Therefore, they decline requests made by patients not to be intubated. However, they emphasize that if the patient or their family members sign a refusal of treatment form and choose to return home, there will be no legal complications. Unfortunately, the legal regulations for a hospitalized patient to provide advance directives are not clearly defined. Consequently, many hospitalized patients, even those receiving futile treatment, continue to receive care. Physicians fear potential legal repercussions for not providing care to a patient without a clear medical indication. As a result, the right to withhold care from a patient lacking a medical indication is often not exercised.

Normative concepts affecting decision-making in the context of futility

In our study, we identified several normative concepts that influence physicians' decision-making processes at the end of life. These concepts include benefit, patient age, justice, and conscience. The term "benefit" is commonly used in the context of "medical benefit." However, upon analyzing the meaning attributed to the concept of benefit, we found that a detailed exploration was lacking.

Evaluation primarily occurred with regards to the success of treatment.

Physicians noted that age has a significant impact on decision-making, with a focus on old age often being interpreted in relation to comorbidity. Physicians stated that elderly individuals, even in good health, are less likely to respond positively to treatment compared to younger patients. The concept of chronological age, therefore, functions as a criterion with physiological impacts rather than possessing direct and absolute influence. That is, age is considered a hypothetical criterion that necessitates evaluation based on medical consequences and ethical implications. [26] The absence of guidelines on the interpretation of old age or the classification of comorbidity raises concerns about potential discrimination against the elderly.

In relation to the concept of justice, participants highlighted the wastage of resources due to futile treatment, making fair allocation challenging. Although physicians expressed motivation to assess resources in decision-making processes and allocate them fairly, they emphasized that the primary responsibility in this regard lies with politicians and directors. Physicians underscored the importance of making decisions in accordance with legal regulations and health policies, emphasizing that fair distribution is primarily guided by these regulations.

Conscience is a normative concept that plays a significant and crucial role in the decision-making process for physicians considering end-of-life treatment choices. Unlike other normative concepts, physicians consider conscience as the most important strategy for resolving ethical conflicts during end-of-life care. They may be motivated by religious beliefs or seek to avoid future regrets while making these decisions. The concept of deciding conscientiously is essential for physicians while making difficult decisions during end-of-life care.

> *"If you turn off the inotrope or significantly reduce the oxygen support for a terminal patient, then at that moment, probably their heart will stop. They will probably pass away very shortly. [pause] This, you know, is something that is left to the conscience of that individual doctor; in my view, it is a bit like killing. If I were in that situation and someone were to cut off my support, I would certainly not take offense, feel hurt; I wouldn't do anything of that sort. But it is different when you do it to someone else." (D6).*

Conscientiousness is unquestionably a virtue that health professionals should have [27]. However, some individuals believe that making decisions based on conscience is sufficient to resolve ethical dilemmas. As a result, they do not feel the need to use any guiding principles or frameworks when making end-of-life decisions.

Discussion

Futility has been characterized as a 'perennial issue' due to the absence of a definition applicable and operationalizable without doubt in clinical ethics [28]. Despite medical knowledge relying on statistical evidence, establishing a minimum statistical threshold for determining futility poses challenges in providing ethical justification [14]. Additionally, differing opinions among doctors in various medical branches on the necessity of a treatment further complicates the issue [9] and the delay and challenges physicians face in making difficult decisions or informing patients and/or their relatives can lead to futile treatment [29]. Moreover, socio-cultural factors influencing the decisions of physicians and patients, coupled with variations in decision-making processes across countries, contribute to the complexity of defining futility [30, 31]. Studies have revealed that the factors causing futility vary between countries [31]. Decisions based solely on medical evidence may not suffice to avoid futile treatment. Studies have also indicated the prevalence of futile treatment in ICU settings across many countries, with varying factors contributing to futility, leading to different rates in different regions [8, 32, 33]. The findings of this study are specific to Türkiye; however, we believe that the proposed solutions derived from these results have broader significance. They may offer valuable insights not only for addressing similar challenges in Türkiye, but also for other countries that share a comparable social state model, provide universal health insurance to all citizens, or have similar social structures [34]. Therefore, the recommendations based on our findings are not only relevant to resolving issues in Türkiye but also hold significance for other countries facing analogous challenges.

This study highlights the various factors that influence physicians' end-of-life decisions in the ICU. Although physicians claim to base their decisions on medical consensus, it is unclear how such consensus is achieved. Legal and social pressures also significantly shape the decision-making process. The use of clinical-ethical guidelines is deemed unnecessary by participants. Physicians stress the conscientious nature of their decisions, insisting that they must be made thoughtfully. However, this can lead to ethical challenges as the process may be influenced by personal preferences.

A significant concern is that many people who are involved in end-of-life decision-making processes do not fully understand the importance of using clinical-ethical guidelines. There is a misconception that such guidelines limit decision-making, but this is not the case. These

guidelines are actually valuable tools that aid in ensuring ethically justifiable decisions and transparent processes based on specific criteria. They also serve as warnings to prevent common mistakes identified in ethical studies [35]. Guidelines published by health ministries or professional organizations are crucial given the legal pressure that physicians face. Institutional policies specific to end-of-life decision-making, such as a DNR protocol, have contributed to a more ethical process [36].

The concept of conscience plays a crucial role in the decision-making process of Turkish physicians when it comes to end-of-life situations. Unlike in other countries, particularly in Western contexts, the perspective of using conscience as a key concept for problem-solving is more emphasized. Conscience refers to an internal foundation of morality that enables an individual to judge whether an action is morally required or forbidden. However, being conscientious alone is not enough to make ethically justified decisions [27]. Various factors, especially socio-cultural and religious influences, have a considerable impact on the development of conscience. Moreover, conscience is shaped individually and requires adaptation with *Zeitgeist* [37]. The study highlights that participant, despite being motivated by the same conscientious considerations, such as religious beliefs, made different decisions regarding the continuation of treatment in cases of futile treatment. Hence, relying solely on conscience as a guide for clinical-ethical decisions is considered problematic.

In Türkiye, there are currently no specific clinical ethical guidelines addressing futile treatment. However, the Turkish Medical Association's "Ethical Declaration on End of Life" includes a section on "futile treatment" [38]. Although it serves as a basis for discussion, this ethical declaration lacks the theoretical background required to guide ethical discussions effectively. Furthermore, the availability of hospital ethics committees is crucial to support professional teams as needed [39]. Studies have demonstrated that ethical consultation not only reduces futile treatment [40] but also prevents the emergence of burnout syndrome in healthcare professionals [41]. Nevertheless, the number of hospital ethics committees in Türkiye is currently less than five, and their effectiveness remains unclear [42]. The absence of clinical ethical guidelines and hospital ethics committees in Türkiye poses a significant challenge to ethical functioning. In addition to legal and ethical regulatory deficiencies, structural and organizational deficiencies are also crucial. In Türkiye, where universal health insurance is provided, one of the main reasons for the challenging decision-making processes related to futility is the lack of sufficient palliative care and nursing homes, as well as the ineffective use of existing facilities. Palliative care is especially important for reducing patient overcrowding in intensive care units, which can lead to futile treatments, and for preventing the initiation of certain processes.

Conclusion

This study reveals that physicians in Türkiye frequently make decisions about futile treatment without a standardized decision-making process and often under legal or social pressure. The concept of conscience emerged as a crucial factor in these decision-making processes. Therefore, optimization measures are essential to create conditions conducive to ethically justifiable decisions within the treatment team. This involves minimizing hierarchical structures and ensuring the active participation of all team members in the decision-making process. Implementing necessary legal regulations, establishing hospital ethics committees, and developing clinical ethics guidelines are integral components of these optimization measures. It is crucial to manage decision-making in complex processes transparently and involve a professional team in making decisions [35]. Furthermore, the tendency of Turkish physicians to prioritize the concept of conscience over established ethical principles requires a solution. While the role of conscience in medical ethics is often discussed in the context of physicians' conscientious objection or preferences, in Türkiye, physicians perceive conscience as a fundamental and operational ethical principle. In conclusion, although conscience plays a significant role, it cannot be the sole guide for clinical-ethical decisions.

This initial qualitative study in Türkiye provides a starting point for future research to uncover statistical patterns in the decision-making processes of intensive care physicians. Future studies should focus on conducting high-participation quantitative analysis and normative investigations to address the challenges identified in this initial study. Legal regulations are crucial in Türkiye to prevent unnecessary treatments and reduce defensive medicine practices. Physicians must be aware of their legal rights and responsibilities, which is why medical law courses should be included in medical education. Providing ongoing training and counseling to physicians regarding legal regulations is equally important. Additionally, it is essential to foster ethical awareness and decision-making skills within the medical team, free from hierarchical pressures, to optimize healthcare practices.

As a result of our study, we recommend a three-stage action plan to address the identified issues:

- Systemic and Organizational Steps: Minimization of cases without medical indication in the intensive care unit. Ensure the establishment of a sufficient number of functional palliative care centers and nursing homes.

- Ethical steps: Develop and establish ethical guidelines for end-of-life care. These guidelines should be periodically reviewed and updated considering ongoing studies and emerging evidence. Increase ethical awareness through education and training of doctors and healthcare professionals. Nationwide establishment and implementation of clinical ethics committees in hospitals.
- Legal Steps: Based on the ethical guidelines established in the previous step, formulate new regulations to govern end-of-life decisions legally.

The action plan is designed to address end-of-life care management issues in a systematic, ethical, and legal manner. All three levels of action are equally important, and measures at these levels should be implemented as closely in parallel as possible. However, it is important to note that legal steps often take longer to implement.

Abbreviations

CRP Cardiopulmonary Resuscitation
DNR Do Not Resuscitate
ICU Intensive Care Unit

Supplementary Information

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Supplementary Material 1.

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Authors' contributions
EA and Il conceived and designed the project together. EA conducted in-depth interviews and analyzed the data. EA and Il wrote the paper together.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Ethical guidelines established by the Istanbul University Social Sciences and Humanities Research Ethics Committee were followed by the researchers. (Ethics Report Number: E-35980450–663.05–1412175). The Istanbul University Social Sciences and Humanities Research Ethics Committee approved the current study. Participation in the study was entirely voluntary. Prior to their involvement, written informed consent was obtained from each participant, indicating their voluntary agreement to take part in the study.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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