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Ethical aspects of limiting end-of-Life treatment of adult patients at the primary healthcare level in family and emergency medicine: a systematic review

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Abstract

Background Decisions to limit treatment near the end of life are challenging and common in primary healthcare, especially in family and emergency medicine.

Objectives This review aimed to [1] examine the evidence on the decision-making process regarding treatment limitation in end-of-life care in family and emergency medicine [2], identify associated ethical considerations, and [3] compare the evidence between family and emergency medicine.

Methods A systematic search of PubMed and Embase was conducted for studies published between 2004 and 2024. Eligible studies focused on ethical aspects of limiting treatment in end-of-life care in family and emergency medicine, such as decision-making processes, influencing factors, and ethical considerations. Quality was assessed using adapted Critical Appraisal Skills Programme checklists.

Results Of the 477 identified studies, 12 met the inclusion criteria. Eight papers reported research on treatment limitations in emergency medical care, two in family/general medicine, one on medication discontinuation in end-of-life care, and one on goals-of-care conversations in emergency departments. Patients, families and colleagues were involved to varying degrees. Family physicians were rarely included in emergency care decisions, despite their potential to align care with patient preferences. Decision-making in emergency medicine was characterized by rapid, protocol-driven processes, often constrained by time and workload, while decisions in family medicine relied on longitudinal patient relationships and clinical judgment, though lacking formalized guidelines. Key factors influencing decisions on limiting treatment included patient and family wishes and values, illness severity, prognosis, previous functional limitation, age, poor predicted quality of life and cultural and religious contexts.

Conclusion Our review showed that decisions regarding treatment limitations in primary care settings remain underexplored, particularly in family medicine. More research and development of clearer guidelines, as well as enhanced collaboration between family and emergency physicians, could improve primary end-of-life care.

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Keywords Ethics, End-of-life care, Treatment limitation, Primary care, Family medicine, Emergency medicine, Systematic review

Introduction

The discussion about non-beneficial or futile interventions and the ethical necessity to limit them started over half a century ago. As McCormick put it in 1974, discussing the dilemmas of modern medicine, the decision of whether to treat the "hopelessly ill" patient or not raises one of the most delicate moral problems [1]. Decisions on treatment limitation include withholding and withdrawing life-sustaining treatment, as well as withholding and withdrawing artificial nutrition and hydration, drug deprescription, non-referral decisions and limitation of diagnostic procedures [2–5].

Ethical aspects of treatment limitation have been mostly researched in intensive medical care, where different national and international guidelines try to support one of the most challenging decision-making processes in medicine [6–10]. However, according to the World Health Organisation (WHO), most health care (around 90%) can be delivered in primary healthcare. Primary healthcare is characterized by equitable and accessible healthcare that focuses on people's needs and preferences, and is delivered across a continuum from prevention to treatment, rehabilitation, and palliative care [11]. It serves as the first contact between patients and HCPs and is mainly delivered through family (general) medicine, general pediatrics, primary obstetrics and gynaecology, emergency medicine, and in some contexts, general internal medicine, geriatrics, and similar [12]. Because primary healthcare systems have diverse structures across the globe, this review will focus on family (general) and emergency medicine as the two very important and at the same time most universal parts of primary healthcare for adults. Family medicine has a vital role in serving not only as a gatekeeper to regulate access to specialist treatments but also as a provider of comprehensive care within the patient's local environment. Emergency care complements family medicine by offering 24-hour services and pre-hospital care in medical emergencies (in many countries, family physicians/GPs are also involved in providing emergency care).

With developments in medical sciences, we are increasingly aware of the potential harm that over-diagnosis and over-treatment can cause to the patient, their closest ones, and society. Limiting the burden of unnecessary treatments and referrals is essential for both the patients and the healthcare system and does not mean only passive abstinence from treatment.

A group of patients who are particularly in need of care in their local area and who are especially at risk of being burdened by referrals or excessive treatments are those approaching the end of life. This is why decision-making on treatment limitation in end-of-life (EOL) care is urgent, difficult, and relatively common in primary care, especially in family medicine and emergency services. EOL care lacks a universally accepted definition. Some sources define it based on a specific time frame before death (commonly within six weeks), others equate it with care provided to actively dying patients, while some describe it as care for individuals diagnosed with incurable illnesses and a life expectancy of less than six months [13]. For the purposes of this review, we did not adopt a strict definition; instead, we applied a broad interpretation to capture a wide range of relevant literature.

To date, no systematic review has been carried out that would gather the available literature on ethical aspects of decision-making about treatment limitation in EOL care at the primary level of healthcare. This review aims to [1] examine the evidence on the decision-making process regarding treatment limitation in end-of-life care in family and emergency medicine [2], identify associated ethical considerations, and [3] compare the evidence between family and emergency medicine.

Methods

Search strategy

We conducted a systematic review and narrative synthesis of existing studies published in English, following the recommendations issued in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [14]. The review was not registered.

Studies were retrieved from the PubMed and Embase databases, which were last consulted at the end of July 2024. The search was restricted to the two databases after consultation with methodological experts, as they cover the vast majority of scientific papers in medical ethics. The search string was developed together by an experienced librarian and composed of text and/or MESH terms adapted to the selected databases. The full search string is available in Supplementary Materials. The search was performed separately in the two databases. The results were imported into Zotero 6.0.36, and the duplicates were manually removed.

Study selection

We sought studies that focused on the ethical aspects of decision-making regarding treatment limitations in end-of-life care in adult patients (over 18 years) at the primary level of healthcare. To capture the wide variety of end-of-life decisions in primary care, we included both family medicine and emergency medicine (including physicians-led prehospital care), aiming to compare the two settings. We included studies from both high-income and low-/middle-income countries in order to capture the diversity of end-of-life practices across healthcare systems and cultural contexts, as highlighted in the Ethicus-2 study [15].

We included the articles that reported research on decisional tools, influencing factors on decision-making, the decision-making process, ethical considerations and similar. By decisional tools, we refer to structured aids used to guide or support treatment limitation decisions in primary care settings. These may include clinical protocols, decision-making algorithms, or guidance documents developed to assist healthcare professionals in navigating complex end-of-life choices with patients and families.

We did not provide a narrow definition of decisions on treatment limitation but rather took the authors' definitions of the decisions. The decisions were worded, for example, as "withholding and withdrawing life-sustaining treatment" or "life-support (therapy)", "non-treatment decisions", "forgoing life-sustaining measures", "deprescribing", "medication discontinuation during the last phase of life", "limitation of therapeutic and diagnostic procedures", "goals-of-care discussions focusing on limitations of treatment", "the decision to perform life-extending treatment or to allow natural death".

A further criterion for inclusion was that the article focused on the physicians' views of the decision-making process, rather than that of the nurses, paramedics or the patient's relatives (but who may be involved in the decision-making). In our review, we included primary empirical research articles, defined as original studies in which data were collected directly by the authors. This encompassed both qualitative research—studies, which use non-numerical data (e.g., interviews, focus groups, participant observations) to explore concepts, experiences, or social phenomena (e.g [16]). —and quantitative research, which involves numerical data and statistical analysis to examine hypotheses or measure variables (e.g [17, 18]). We included studies published in English between 2004 and 2024. Following the approach of similar systematic reviews [19], we set the 20-year time frame arbitrarily, with the rationale that older studies may no longer reflect current practice due to societal shifts and recent developments in end-of-life care.

The exclusion criteria were the following: the article discussed decision-making about the limitation of treatment in secondary or tertiary hospitals and in long-term facilities like nursing homes (due to their different organizational structures, staffing, and regulatory frameworks, which warrant separate investigation in future research); the decision-makers in the focus of the research were not physicians and their teams, but family surrogates or paramedics; the decision-making in end-of-life care did not focus on the limitation of the treatment itself but rather on the process of advanced care planning, palliative care or euthanasia; the article was concerned more with the legal aspects than with the ethical aspects of decision-making; the article discussed only the prevalence of different types of end-of-life decisions and not the associated variables or ethical aspects; research in paediatric end-of-life care; the topic of limitation of treatment was only marginally mentioned; the article was a case report, editorial, review, commentary, or a secondary paper. Studies that focused exclusively on Do-Not-Resuscitate (DNR) orders were also excluded. While DNR decisions are an important part of end-of-life care, they are typically relevant to institutional settings (e.g., hospitals, long-term care facilities), which were not the focus of our research, and represent a distinct area of study. Our review aimed to adopt a broader perspective by exploring treatment limitation decisions within home-based primary care, where advance resuscitation decisions are typically less central to clinical decision-making. Including DNR-focused studies—which represent a substantial and specific body of literature—could have shifted the focus away from the wider range of treatment limitation decisions relevant in primary care. These include, for example, non-referral decisions, deprescribing, and other anticipatory choices that are part of advance care planning.

A total of 477 studies were retrieved from both databases after the duplicates had been manually removed (Fig. 1). The first author performed the initial screening of titles and abstracts to exclude irrelevant studies. Subsequently, all three authors independently assessed the full-text articles for inclusion, with disagreements resolved through discussion.

Quality assessment and data synthesis

To assess the quality of the included studies, The Critical Appraisal Skills Programme (CASP) checklist for Cross-Sectional Studies was used and slightly adapted by the CASP checklist for Qualitative Studies to cover the most critical aspects of the included papers [20]. An extra question was added to assess the article's relevance for our review (see Supplementary Materials). The papers' quality was assessed manually by the first author and checked for disagreements by the other authors.

The relevant information from the articles was collected in Table 1. The items of information extracted were the country in which the study was performed, research design, patient population, respondents and response rate, treatment that was limited, and the contents regarding the process of decision-making on treatment limitation, the factors influencing the decision-making (with the challenges encountered), and the arguments or

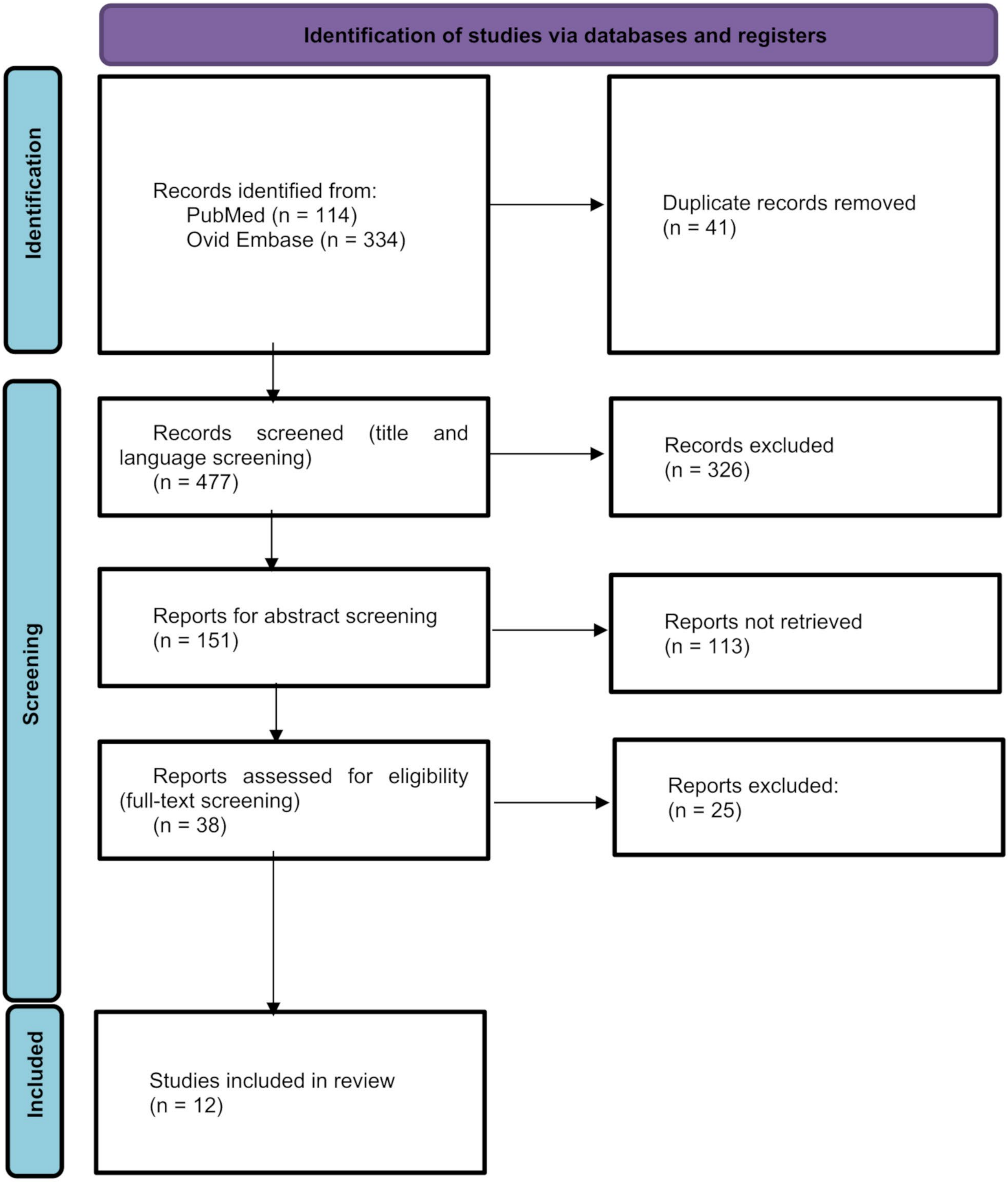

Fig. 1 PRISMA flow diagram of the selection process

ethical considerations, i.e. relevant principles, values or norms.

The first author carried out the initial qualitative data synthesis, which was further developed by the other authors. Due to the wide variability of research design in the included papers and differences in reported measures and approaches to ethical reflection, descriptive synthesis has been carried out. OpenAI's GPT 4.0 was used for AI-assisted copy-editing to improve readability and style.

Table 1 Characteristics and main findings of the selected studies

Authors (year), Title	Country	Research design and methods	Target population	Participants	Decision about limiting treatment	Main findings on the practices and ethical considerations regarding treatment limitation
Abela J. (2015), GPs and end of life decisions: Views and experiences	Malta	A cross-sectional survey	End-of-life patients	396 physicians, of which 160 were GPs	withdrawing or withholding treatment, sedation and euthanasia	• The study highlights a practical approach to EOL decision-making. • Most GPs support WH/WDT but are hesitant about euthanasia. • GPs prioritize preserving life while accepting intensified analgesia when needed. • 89.8% of GPs consider religion/philosophy crucial in EOL decisions. • C.: GPs require clearer legal and moral guidance in EOL care.
Bilsen et al. (2004), The incidence and characteristics of end-of-life decisions by GPs in Belgium	Belgium	Death certificate study and a survey	End-of-life patients cared by GPs	1067 deaths certified by GPs	end-of-life decisions, including non-treatment decisions	• EOL decisions occurred in 39.5% of primary care deaths, with 15.6% involving non-treatment decisions. • Their frequency varied by cause, location of death, patient education, and GP's religion and age. • C.: GPs often fall short of prudent EOL practices and call for international research to underscore their vital role.
Damghi et al. (2011), Withholding and withdrawing life-sustaining therapy in a Moroccan Emergency Department: An observational study	Morocco	An observational study	patients who died in an ED	177 patients	Withdrawing and withholding life-support therapy	• WH/WDT decisions preceded 30.5% of ED deaths. • Key reasons included lack of improvement after active treatment and expected irreversibility within 24 h. • Decisions were made by a single physician in 42.6% of cases, with patients and relatives participating in 11.1% and 70%, respectively. • C.: Religious beliefs and the absence of guidelines or Moroccan laws pose ethical challenges in decision-making.
Douplat et al. (2019), Difficulty of the decision-making process in emergency departments for end-of-life patients	France	A prospective multicenter study in three EDs	non-communicating patients in EDs, who required a WH/WDT decision	109 patients	withholding and withdrawing life-sustaining treatments	• Decisions of WH/WDT concerned 85.3% of patients, occurring more often when surrogate decision-makers were present (88.1%). • Key reasons included prior functional limitations, age, poor expected quality of life, and a fatal prognosis within six months. • C.: Early discussions of EOL wishes with patients during chronic disease management are essential.
Douplat, Daoud et al. (2020), Poor Involvement of General Practitioners in Decisions of Withholding or Withdrawing Life-Sustaining Treatment in Emergency Departments	France	Prospective observational multicenter study	adult patients nearing end of life unable to communicate	54 patient's associated general practitioners	withdrawing or withholding life-sustaining treatments	• Only 7.4% of GPs participated in WH/WDT decisions in EDs, though most agreed with the outcomes. • While 94% valued their involvement, 68% wished to participate consistently in future EOL decisions for ED patients. • GPs did not perceive time as a barrier. • C.: GPs can offer valuable insights into patients' premorbid conditions and wishes, aiding ED providers in setting appropriate treatment goals.

Table 1 (continued)

Authors (year), Title	Country	Research design and methods	Target population	Participants	Decision about limiting treatment	Main findings on the practices and ethical considerations regarding treatment limitation
Douplat, Fraticelli et al. (2020), Management of decision of withholding and withdrawing life-sustaining treatments in French EDs	France	a retrospective chart review study combined with a survey study	patients dying in the ED that required decision-making about withholding or withdrawing life-sustaining treatments	145 patients, 287 ED staff members	withholding or withdrawing life-sustaining treatments	• Three of ten EDs had a written WH/WDT procedure. • EDs with written procedures showed better collegial discussions, prognosis traceability, pain management, comfort care, and communication with patients and relatives. • Staff experience was not improved by the written procedure. • C.: Standardizing WH/WDT management in EDs per international guidelines could benefit from implementing written procedures.
Ferrand, Marty (2006), Prehospital withholding and withdrawal of life-sustaining treatments. The French LATASAMU survey	France	retrospective study	patients with end-of-life decision in the prehospital setting	1069 physicians	Treatment withholding and withdrawal	• 76% of ambulance-based emergency physicians recently participated in prehospital EOL decisions, primarily withholding life support. • The most common reason was the expectation of imminent death. • Informed consent was obtained from one-third of competent patients and 73% of relatives; half the decisions were made solely by the physician. • Ethical challenges in prehospital care mirror those in EDs and ICUs. • C.: WH/WDT decisions in prehospital emergencies remain highly contentious.
Geijteman et al. (2018), Medication Discontinuation at the End of Life: A Questionnaire Study on Physicians' Experiences and Opinions	the Netherlands	Questionnaire study, including a vignette	patients who are in the last phase of life	321 physicians	medication discontinuation during the last phase of life	• 73% of physicians believe patients in the last phase of life use excessive medications. • Most physicians prioritize patients' views on discontinuing unnecessary drugs. • Few physicians acknowledge factors driving the continuation of potentially futile or harmful medications. • C.: The persistence of inappropriate medication use remains unclear. An important reason could be a lack of awareness. Further research is needed.
Le Conte et al. (2010), Death in emergency departments: a multicenter cross-sectional survey with analysis of withholding and withdrawing life support	France and Belgium	4-month prospective survey in 174 emergency departments	Patients that died in the EDs	2,512 patients	decisions to limit life-support therapies: withdrawal and withholding	• WH/WDT decisions were made for 78.8% of patients, primarily those over 80 with metastatic cancer or prior functional limitations. • Family discussions occurred in 58.4%, while a single ED physician made the decision in 19.9% of cases. • Key reasons included illness severity, irreversibility of the condition, age, and prior functional limitations. • C.: Training for ED physicians should focus on enhancing care for dying patients, emphasizing collegial decision-making and palliative care.

Table 1 (continued)

Authors (year), Title	Country	Research design and methods	Target population	Participants	Decision about limiting treatment	Main findings on the practices and ethical considerations regarding treatment limitation
Levinson et al. (2019), Medical perspectives regarding goals-of-care consultations in Emergency Departments	Australia	the qualitative component of a mixed methods study	adult ED patients nearing end-of-life	18 ED physicians	goals-of-care discussions focusing on limitations of treatment	• Emergency physicians view goals-of-care discussions as relevant and frequent in their practice. • These discussions typically focus on medical outcomes, shifting to prevent non-beneficial treatments when death seems imminent. • ED physicians prefer long-term practitioners to initiate such discussions before patient deterioration. • C.: Standardized language, education, collaboration, and further research are needed to better equip ED physicians for these conversations.
Saban et al. (2019), Emergency department mortality: Fair and square	Israel	A retrospective archive study	patients that died in the ED.	674 patients	the decision to perform life-extending treatment (LET) or to allow natural death (AND)	• Among the three main variables affecting treatment in EDs: patient, medical staff, and ED setting, patients most strongly influenced therapeutic approaches. • The proportion of EOL patients receiving LET rose from 18.1–30.3% over three years, despite more palliative-care patients. • An association was found between Jewish physicians and nurses and AND approach. • Heavier ED workloads correlated with more aggressive treatments. • C.: National programs are needed to prevent external factors from impacting EOL decisions.
Sedillot et al. (2008), A five-step protocol for withholding and withdrawing of life support in an emergency department: an observational study	France	An observational study in single ED of a general hospital	terminally ill patients in an emergency department	98 patients	withholding and withdrawing of life support	• Treatment limitation was guided by a "five-step protocol" based on patient classification. • Factors considered included death probability, survival quality, and patient or family views. • Inclusion in groups 3, 4, or 5 (higher treatment limitation) required agreement from the full team and family. • Physicians were more hesitant to withdraw therapies than to withhold them. • C.: The five-step protocol could enhance EOL decision-making in EDs.

C.– conclusion; ED– emergency department; WH/WDT– withholding and withdrawing of life support treatment, ICU– intensive care unit, EOL– end-of-life; GP– general practitioner

Results

Study characteristics, quality and main findings

The selection process of our systematic review is presented in Fig. 1. We identified 12 eligible articles that met our inclusion criteria and followed the review's objectives [16, 17, 21–29]. Results of quality assessment according to the adapted Critical Appraisal Skills Programme (CASP) checklist are provided in the Supplementary File. Five articles were assessed as very valuable for our review and seven as valuable. Research in eleven articles was recognized as valuable in general and in one as partly valuable.

Eight papers reported research on treatment limitations in emergency medical care [18, 21, 22, 24–26, 28, 29], two in family/general medicine [17, 23], one on medication discontinuation in EOL care [27], and one on goals-of-care conversation in emergency department (ED) [16]. Characteristics and main findings of the selected studies are gathered in Table 1. The majority of the included studies originated from high-income countries (half of them from France). This distribution could reflect the current research landscape in the field and may influence the generalizability of the findings. A detailed discussion of this imbalance is provided in the Limitations section.

Table 2 Colleagues, patients and family involvement in decision-making

Context of treatment limitation decision	Consultation of colleague(s)	Involvement of GPs	Involvement of nursing staff	Participation of patients	Inclusion of relatives or surrogates
Patients who died in a Moroccan ED [29]	57%	N/A	89%	11%	70%
Non-treatment decisions made by Belgian GPs [17]	30% of cases	N/A	46%	Explicit request by the patient: 17%; discussion with the patient: 7%	61%
Non-communicating patients in French EDs [22]	73%	1.8%	28.4%	N/A	88%
End-of-life decision-making in French EDs– involvement of GPs [26]	N/A	7.4% (The majority of GPs wished to contribute to EOL decisions)	N/A	N/A	N/A
Prehospital end-of-life decisions [28]	50%	N/A	55%	33% of competent patients	73%
Patients who died in French EDs [24]	80%	4.8%	N/A	32% of competent patients	58%
Terminally ill patients in an ED with WH/WDT decision (groups 2–5) [21]	100%	N/A	100%	none	92%

N/A– not available; ED– emergency department; WH/WDT– withholding and withdrawing of life support treatment; GP– general practitioner

The decision-making processes

Frequency and Characteristics of Treatment Limitation Decisions:

Decisions to limit life-sustaining treatments were common in family and emergency medicine. In primary care in Belgium, about 39.5% of deaths involved a treatment limitation decision [17]. In a Moroccan ED, 30.5% of patients who died had life-sustaining treatments withheld or withdrawn [29]. The study among noncommunicating patients in French EDs found that the decisions to withhold life-sustaining treatment concerned 85.3% of patients and were more frequent when a surrogate decision maker was present [22]. In a large-scale survey in French and Belgian EDs, 78.8% of patients who died had a treatment limitation decision, primarily elderly patients with chronic diseases [24]. The study in Israeli EDs found that the percentage of EOL patients who died naturally, without life-extending treatments and intensive diagnostics, decreased over the three-year observation period, from 60.6% in 2015 to 46.5% in 2017 [18].

Three articles reported the median time interval between ED admission and the decision to limit the treatment (withholding or withdrawing), which was 162 min [22], 118 min [24] and 117 min [21].

Patient, family and colleagues involvement

Patient, family and colleagues' involvement in decision-making was prioritised in both settings but often faced practical limitations, especially in emergency contexts. Since patients in EOL situations were often unable to communicate, their inclusion in decision-making about the limitation of treatment was rare. Levinson et al. pointed out that ED physicians recognize the importance of discussing goals of care with patients or relatives but may limit these discussions to immediate care directives due to time constraints [16]. This contrasts with family medicine, where GPs have more established relationships with patients and their families, facilitating discussions on patient preferences, though these discussions are not always systematic [17].

The reported proportions of colleagues, patients and family involvement in decision-making are gathered in Table 2.

Role of protocols and structured decision-making

In emergency medicine, structured protocols for treatment limitation are still quite common, mainly to streamline rapid decision-making. Sedillot et al. presented a five-step protocol in the ED, which facilitated structured decisions ranging from full intervention to the active withdrawal of life support. The authors concluded that the protocol could offer some guidance for EOL decision-making in EDs and improve collaboration in the decision-making process while facilitating dialogue and transmission of information between staff and families [21]. A study by Douplet et al. found that written procedures in EDs enhanced the traceability of the prognosis assessment and the communication between the staff members, the patient and the relatives. However, the written procedure did not improve the experience of the healthcare personnel in these situations [25].

On the other hand, GPs in family medicine typically have less standardized protocols available, relying instead on individual clinical judgment and personal understanding of the patient and the situation. Abela, Bilsen et al. and Geijteman et al. highlighted the lack of formalized guidelines for GPs' decision-making on treatment limitations, indicating a need for establishing them to reduce variability based on GPs' personal background [17, 23, 27].

Ethical considerations in decision-making

The most common reasons for deciding on treatment limitation

The most commonly cited reasons for making the decision on treatment limitation were the severity of illness, the expected irreversibility of the acute disorder, the absence of improvement following a period of active treatment, previous functional limitation, age, poor predicted quality of life, underlying disease expected to be fatal in the following months, and the involvement of the patient in palliative care (i.e., the receipt of specific palliative care treatments or formal enrolment in palliative care services, as defined in the individual studies) [22, 24, 28, 29]. As the research settings and methods varied considerably between studies, we did not compare the frequency of the cited reasons between them.

According to Le Conte et al., physicians justified their decisions to withhold or withdraw life-sustaining treatments using a combination of criteria. Neither "expected quality of life unacceptably poor" nor age was used alone [24]. According to Saban et al., among the three main variables affecting treatment in EDs– the patient, the medical staff, and the ED setting– patient characteristics contributed most crucially to the therapeutic approaches [18].

Balancing patient autonomy with medical judgment

In EOL care, when the benefit of intensive treatments is questionable, patients' values are gaining ethical weight in judgment about the approach to treatment. However, there are inherent differences between family and emergency medicine in how to approach respect for patients' autonomy and their values.

Emergency medicine is characterized by a high frequency of patients, time constraints and unpredictable workflow. Emergency physicians should generally select the treatment option that maximizes overall benefit while minimally constraining the patient's future choices [26]. Although a shared approach to end-of-life decision-making is advocated to reach a consensus on a treatment that is in accordance with the patient's values [21], medical paternalism still drives some decision-making in acute care settings [16]. Saban et al. found a correlation between increased ED workload and more intensive treatments in EOL care. The authors suggest that in increased workload scenarios, "teams must focus on doing rather than on being" [18].

Researching goals-of-care discussions in EDs, Levinson et al. found that physicians are strongly oriented towards medical outcomes, which changes when a patient's death is recognised as imminent. In such instances, the goals-of-care conversations have been recognized as particularly important and aimed at preventing non-beneficial treatments [16]. Douplat et al. report that in EDs with a written procedure, the evaluation of the level of autonomy was improved in departments with a procedure, as well as the search for advance directives and communication with the patient about their state of health [25]. As most EOL patients are not able to express their wishes and do not have completed advance directives, their relatives have been recognized as having an important role in expressing patients' wishes and are, as such, often involved in decision-making [22, 28]. Patients' GPs could have a similar role, as they have long-term relationships with patients and families, which facilitates greater alignment of the treatment approach in EOL care with patient values. However, they are rarely involved in the decision-making process in EDs [22, 26]. Douplat et al. suggest that general practitioners should discuss the wishes of chronic patients with them in advance to avoid sending them to the ED [26].

Cultural and religious influences

The cultural and religious backgrounds of both patients and providers influence EOL decisions in primary healthcare. Saban et al. documented differences in the intensity of treatment in EOL patients among different demographic groups within Israeli ED settings, with Jewish patients experiencing more natural death than Arab patients did. Jewish nurses were also more inclined toward "allowing natural death" approaches compared to Arab nurses [18]. Similarly, Abela found that in Malta, personal religious beliefs play a significant role in GPs' decision-making in EOL care, which, according to the author, indicates a need for standardized ethics training to support consistent EOL care across diverse populations [23]. According to Bilsen et al., most EOL decisions varied significantly depending on the GP's religion. Non-treatment decisions were more frequent among patients treated by non-religious GPs and GPs who were older [17]. On a broader scale, Damghi et al. found similarities regarding treatment limitation in EOL care between Islamic physicians in Morrocco and Western physicians, suggesting that the three monotheistic religions (Judaism, Christianity and Islam) share the same code of morality despite some doctrinal differences among them [29].

Withholding and withdrawing treatment

In both settings, there is an ethical debate around the distinction between withholding and withdrawing treatment. The included articles report that withholding treatment is more common than withdrawing [22–24, 28, 29]. Sedillot et al. found that ED physicians often consider withholding treatment ethically less burdensome than withdrawing [21]. Similarly, Abela reports a higher percentage of GPs in Malta who would consider withholding treatment than withdrawing it. However, a quarter of respondents would consider both and almost half of them would neither withdraw nor withhold treatment [23].

Discontinuation (i.e. withdrawal) of medications in EOL care is discussed only in a paper by Geijtman et al. In the vignette study, physicians preferred stopping several medications if the patient's life expectancy was limited. Three groups of medications have been distinguished: preventive medications, medications for chronic diseases and medications to alleviate symptoms. If there was an agreement to stop preventive medications quite early, a huge variability between physicians was found regarding discontinuation of medications for chronic diseases. The observed preference of physicians for discontinuing medications in EOL care differed from the actual situation (as reported in other studies). Only a minority of physicians identified possible factors contributing to the continued use of potentially inappropriate or harmful medications in the last stages of life. The authors conclude that it remains unclear why such continuation is common practice and suggest that a possible reason is a lack of awareness [27].

Discussion

Our systematic review identified mostly studies about treatment limitations in EOL care in emergency healthcare settings; only two semi-relevant studies investigate the incidence and characteristics of EOL decisions in family medicine [17, 23]. However, none of the two deepens the ethical reflections or reasons behind these decisions, which represents a significant research gap. Since evidence for family medicine is limited, comparing the two settings is less plausible.

Regarding the characteristics of the **process of treatment limitation**, in both emergency and family medicine, decisions to limit treatments in EOL care are common but vary in frequency and approach based on the setting and country. Family involvement is prioritized but is exercised in various degrees. In EOL care in acute care settings, including also patients' GPs in decision-making and discussing goals of care with the most appropriate stakeholders have been recognised as ethically valuable processes [16, 22, 26]. Structured protocols, more common in EDs, provide guidance and enhance coordination, whereas family physicians often rely on clinical judgment without standardized guidelines, which can lead to more significant variability in decision-making. In emergency medicine, recommendations for end-of-life care also exist [30].

To discuss **ethical considerations in decision-making**, treatment limitation decisions are generally based on factors related to medical conditions, such as illness severity, lack of improvement, and poor quality of life prognosis. Withholding treatment is more common than withdrawal, and the former is often viewed as less ethically burdensome than the latter. The cultural and religious backgrounds of both patients and providers influence EOL decisions.

Our review suggests the ethical relevance of the physician-patient relationship, which is different between emergency and family medicine. In emergency medicine, ethical considerations frequently lean toward preserving life and minimizing harm, often at the expense of patient autonomy due to the urgency of decisions [16, 18, 21]. The challenge of emergency physicians is to establish a trustworthy relationship with unknown patients (or their proxies) in a limited time, from which patient's values and treatment preferences can be discerned. Family physicians, by contrast, are better positioned to discuss patient preferences, as they have a long-standing relationship with patients. They play an important role in EOL care, especially in discussing patients' values and preferences for EOL care in advance (and formulating advance directives or advance care plans). This can help avoid sending patients to emergency services, where treatment by protocols may easily overlook patients' values and goals of care [26]. However, since emergency services will always have some role in caring for patients at the end of their lives, emergency physicians' consultation with GPs can be an ethically advisable and underused option [26].

Both family medicine and emergency medicine typically have limited diagnostic and therapeutic options, meaning **diagnostic uncertainty** is unavoidable and prognostication difficult (the management of diagnostic uncertainty in primary care has been well reflected in a systematic review by Alam et al. [31]). The decision regarding the limitation of treatment often means the decision to refer or not to refer the patient to the hospital, where additional diagnostic and therapeutic options are available. However, the included papers discuss neither the issue of diagnostic uncertainty nor the non-referral decisions, which may be due to the lack of available research or the shortcomings of our search process (or both).

Looking beyond primary healthcare, different authors have recognised a pressing need to understand EOL care better. To our knowledge, two systematic reviews have been conducted on the factors influencing end-of-life decision-making. Frost et al., analysing the influencing factors for critically ill patients in general, concluded that different variables such as religious beliefs, racial and cultural backgrounds, and geographic location shape the expectations and preferences of patients and clinicians. Understanding these factors, which correlate with varying levels of technological intervention in end-of-life care, may enhance awareness, facilitate effective communication, and guide clinicians in EOL discussions [32]. Schildmann et al., in their review, focused on the limitation of treatment in patients with advanced cancer. They distinguished three categories of influencing factors: sociodemographic variables, health- or treatment-related variables, and patients' preferences with the role of relatives in decisions about the limitation of treatment. They concluded that several criteria associated with limiting treatment in clinical practice are value-laden and appeal for further research to understand them better [33].

Study limitations

Our systematic review has several limitations. First, the review question is quite broad without a hypothesis, which means that relatively diverse articles have been included, which are difficult to compare. We decided on this approach because the scoping review revealed limited existing research in that field, and a narrow research question (e.g. including only family medicine) would not give sufficient results. Due to the diversity of included articles, data synthesis has been qualitative without directly comparing different quantitative results, which allows more research bias in drawing conclusions.

Our literature screening algorithm predominantly identified studies from high-income countries. This imbalance may reflect limitations in our systematic search strategy or, alternatively, a broader lack of high-quality studies on this topic from low- and middle-income countries. As a result, our findings may not fully capture the global diversity of practices and perspectives. Furthermore, comparing end-of-life decision-making across different cultural, legal, and healthcare contexts remains inherently complex. The differences and comparisons between countries deserve more targeted research in the future.

Further, our review did not include potentially relevant papers, such as philosophical, non-empirical reflections on treatment limitations in EOL care. The search process also excluded articles published before 2004, grey literature, non-English publications, and studies not indexed in the selected databases, which often include research from other disciplines such as the social sciences, nursing, or psychology, and could have offered additional insights.

Conclusions

Our review showed that decisions regarding treatment limitations in EOL care in primary care settings remain underexplored, particularly in family medicine. Further, it showed that decision-making on treatment approach in EOL care is common in primary care and varies significantly between emergency and family medicine. Emergency departments prioritize rapid decision-making, often with structured protocols, while family medicine relies more on personal clinical judgment and patient history, though it lacks standardized guidelines. Ethical considerations, including patient autonomy, family involvement, and cultural influences, are central to treatment limitation decisions but are shaped by the immediate demands of the ED versus the relational depth in family medicine. Enhanced collaboration between emergency and family physicians, alongside clearer guidelines, could improve the consistency of end-of-life care.

Abbreviations

AND	Allow Natural Death
CASP	Critical Appraisal Skills Programme
DNR	Do-Not-Resuscitate
ED	Emergency Department
EOL	End-of-Life
GP	General Practitioner
ICU	Intensive Care Unit
LET	Life-Extending Treatment
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
WH/WDT	Withholding and Withdrawing Life-Sustaining Treatment
WHO	World Health Organization

Supplementary Information

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Supplementary Material 1

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Author contributions

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Data availability

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Declarations

Ethics approval and consent to participate

Not applicable.

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Competing interests

The authors declare no competing interests.

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