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# Ethics and end-of-life in pediatric and neonatal ICUs: a systematic review of recommendations

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## Abstract

**Background** Working in neonatal intensive care units (NICUs) or pediatric intensive care units (PICUs) entails making difficult decisions about children at the end of their lives that raise significant ethical issues. This review identified the ethical content of the papers containing expert guidelines and recommendations in relation to end-of-life decision-making in NICUs and PICUs, by analyzing ethical positions and ethical principles behind them.

**Methods** Systematic search was limited to the period from 1990 to 2023 and encompassed 6 bibliographic databases (Medline, PubMed, CINAHL, APA PsycINFO, Web of Science Core Collection, and Scopus), grey literature sources and relevant reference lists. The international, national, or institutional papers providing expert guidelines and recommendations comprehensively addressing either withholding/withdrawing of life sustaining treatment, palliative care, and/or intentional life terminating actions in NICUs and PICUs were included in analysis. Also, only papers published in English language were considered. Papers that were not developed by intensive care expert communities and those that were either too narrow (e.g., dealing with specific issues or specific patient groups) or broad (e.g., addressing issues of interest on general and abstract level) were excluded. The search data were gathered and deduplicated, partly by Mendeley software. Titles and abstracts were screened by three independent reviewers, and full-text papers further reviewed and assessed for eligibility. Subsequently, data of interest were extracted, and qualitative analysis was performed.

**Results** Initial search retrieved 6784 papers from bibliographic databases and 363 from other utilized sources. Titles and abstracts from 2827 papers were screened. 17 full texts were further assessed resulting in a total number of 9 papers (6 from bibliographic databases and 3 from other sources) which met the inclusion criteria and were included for analysis. The papers were published from 2001 to 2021. Four papers primarily focus on NICU setting, while five on PICU. A total of 38 ethical positions were identified and were grouped under 5 themes according to the content of the positions, relating to: patients, parents, medical team, decision-making and treatment options. A total of 12 ethical principles were mentioned in the papers. The principle of beneficence emerged as the most prominent one. It was explicitly mentioned in all included papers except one.

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**Conclusions** This review has shown that papers containing guidelines and recommendations on end-of-life decision-making in the NICU and PICU promote similar stances. The ethical principle of beneficence is at the core of the decision-making process, and all decisions are made focusing on the child's best interests.

**Keywords** NICU, PICU, End-of-life, Decision-making, Ethics

## Introduction

Working in neonatal intensive care units (NICUs) or pediatric intensive care units (PICUs) entails making difficult decisions about children at the end of their lives [1]. Currently, most deaths in PICU occur following withholding and/or withdrawing (WH/WD) life sustaining treatments (LST) [2, 3]. Similarly, limitation of LST is common in the NICU and has shown a steady increase over time [4]. These decisions, which form a core component of end-of-life care practices, involve not only the healthcare team but also the ailing child and their parents (or legal guardians), who are navigating one of life's most emotionally distressing experiences [5]. While physicians are generally willing to involve parents and children (when feasible) in the decision-making process, they often emphasize their critical role as advocates for the child's best interests [6].

The World Health Organization's report *Integrating palliative care and symptom relief into paediatrics* states that as many as 21 million children worldwide require pediatric palliative care (PPC) annually, and nearly 2.5 million children die each year while enduring serious health-related suffering [7]. These figures underscore the urgent need for palliative care for the youngest and most vulnerable patients. Pediatric palliative care encompasses support and care for all children with life-threatening or life-limiting conditions, including those unborn with severe health issues who may not live through birth or may live only briefly [8]. Effective palliative care also recognizes the profound need to support parents and close family members, offering comfort during times of extraordinary distress.

Despite the critical importance of pediatric palliative care, end-of-life decision-making in NICUs and PICUs remains fraught with ethical dilemmas and practical challenges. These include clinical uncertainty, the complexity of balancing the best interests of the child and family, navigating unequal power dynamics in decision-making processes, and a lack of supportive work settings [6, 9–11]. Existing guidelines and recommendations aim to assist healthcare professionals in addressing these challenges, yet there is limited clarity on how these frameworks are applied in practice and whether they sufficiently address the ethical principles at play.

A gap in the literature exists regarding the systematic identification, analysis, and synthesis of expert guidelines and recommendations on end-of-life decision-making in NICUs and PICUs. While individual studies provide

insights into specific ethical or procedural aspects, a comprehensive overview is lacking. This systematic review was therefore undertaken to address these gaps by identifying and analyzing expert guidelines and recommendations. Its objectives are to perform a qualitative analysis of their content and evaluate the ethical positions and principles they espouse, providing a foundation for more consistent and ethically robust practices in pediatric end-of-life care.

## Methods

This systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 guidelines [12].

### Information sources

A systematic search of 6 bibliographic databases for relevant papers was undertaken on Medline (R)ALL (Ovid), PubMed, CINAHL Complete (EBSCOhost), APA PsycINFO (EBSCOhost), Web of Science Core Collection (SCI-Expanded, SSCI, AHCI, ESCI) and Scopus. We also searched the following grey literature repositories: ProQuest™ Dissertations & Theses Citation Index (WOS), British Library EThOS, Networked Digital Library of Theses and Dissertations (NDLTD), OpenAIRE and Google Scholar. In addition, we searched the reference lists of the articles selected for inclusion to identify additional relevant papers.

### Search strategy

Our search strategy was based on a similar study previously conducted in adult intensive care units [13], now adapted for neonatal and pediatric intensive care units (see Appendix 1). The related keywords were used through electronic databases, with minor variations in using the thesaurus MeSH terms. In the grey literature search strategy, we focused on the recurring terms noticed when conducting bibliographic database searches. As in the previous study [13], we focused on the commonly known terms and their variations, such as “end of life”, “palliative care”, “pediatric/pediatric intensive care unit”, “neonatal intensive care unit”, and “newborn intensive care unit”. Due to search restrictions in grey literature sources, we had to use the most common and fundamental terms as search phrases.

All searches were limited to papers written in English. The search period covered publications from 1990 to

2023. The World Health Organization published a paper in 1990 that described the idea of palliative care, which was why 1990 was chosen as the starting year [14]. The search was performed on October 18 and from October 25 to 26, 2023.

### **Inclusion /exclusion criteria**

The papers had to comprehensively address at least one of the three topics: withholding/withdrawing of LST, palliative care or intentional life terminating actions in pediatric/neonatal populations, specifically PICUs and/or NICUs, or in pediatric/neonatal wards where PICUs/NICUs were included. Papers containing guidelines or recommendations at the international or at the institutional level were included. The papers needed to have been developed by professional health care institutions or panels of neonatal or pediatric intensive care experts and provide positions or recommendations on the end-of-life decision-making process in the NICU and/or PICU.

Papers from fields outside intensive care (e.g., cardiology), those addressing specific issues (e.g., only artificial respiration) or specific groups of infants (e.g., extremely preterm infants) were excluded. Papers in which it was unclear whether they were issued by an institution or expert panels and those developed by nonprofessional organizations were not included. Broader international professional codes dealing with end-of-life issues at the general and abstract levels were also excluded.

### **Screening and selection process**

The searches of six bibliographic databases retrieved 6784 papers. Searches of the grey sources identified 360 additional papers. Duplicates were removed using Mendeleev's duplicate identification strategy and manually. This process left 2827 (Fig. 1). Three researchers conducted the screening process independently from each other. The papers were first screened based on the title and abstract, resulting in 2,641 exclusions from bibliographic databases, leaving 14 papers for retrieval.

The next step involved reading the full text of these 14 papers to assess their eligibility. Three researchers read the full texts of 14 papers and reviewed the bibliographies for additional papers. In cases where uncertainty arose regarding whether a specific paper satisfied the inclusion criteria, two other researchers were consulted, and a mutual decision was reached. Of the 14 papers assessed for eligibility, 6 were ultimately included, and 8 were excluded. A total of 363 papers were identified via other methods (see Fig. 1). Three of those papers were assessed for eligibility and included in the final analysis. Thus, the final review included 9 papers: 6 detected through bibliographic databases and 3 via other methods. Only papers satisfying all inclusion and exclusion criteria were included in the review. Papers identified through

the snowballing technique were screened using the same criteria.

Decisions regarding the inclusion of all but two papers were straightforward. One paper was a report made by the Working Party with the Nuffield Council on Bioethics, which examined ethical issues in critical care decisions in fetal and neonatal medicine. It extensively explored the topic from an ethical standpoint and provided recommendations for critical care decisions for babies needing intensive care [15]. We decided to include this paper, analyzing only the parts pertaining to the recommendations. The second paper, written by Catlin and Crater, presents the creation of a protocol delineating the needs of patients, families, and staff necessary to provide a pain-free, family- and staff-supported death for newborns who cannot benefit from intensive, life-extending support [16]. This protocol was prepared with a 101-member panel using the Delphi research method. We included it in our analysis as it was developed by an expert panel of several US societies.

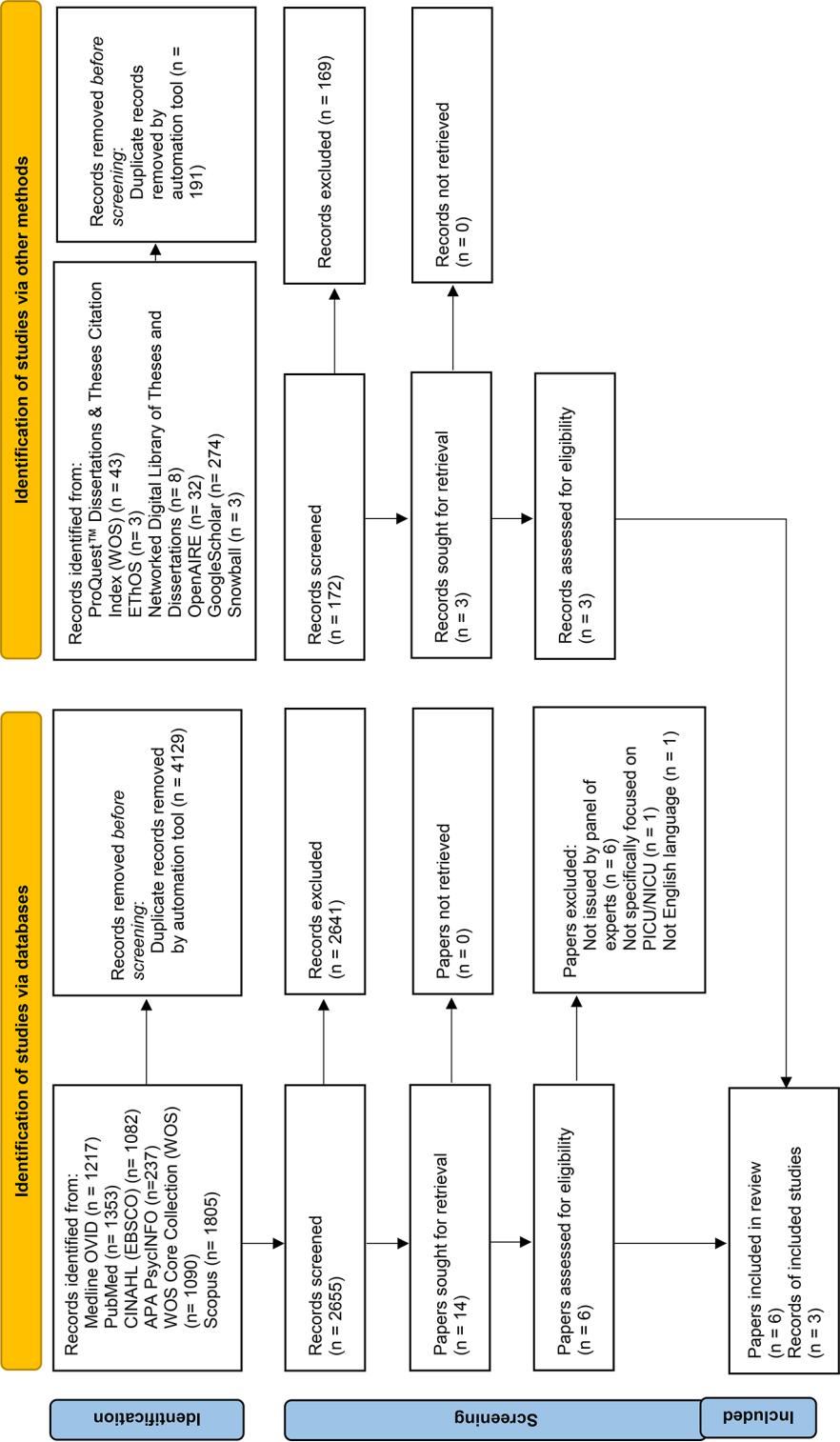
Several papers dealing with issues related to end-of-life decisions in children were seriously considered for inclusion. However, they were not included because it was unclear whether they were issued by professional institutions or panels of intensive care experts [17, 18], or they did not explicitly focus on NICUs/PICUs [19].

### **Data extraction and analysis**

Two researchers extracted and synthesized the data. To identify ethical content including ethical positions and ethical principles, the constant comparative method was used for the qualitative analysis [20, 21]. This inductive method enabled us to analyze the text by coding, categorizing, and comparing the data [22]. Two researchers read and analyzed the included papers. The relevant parts of the text were labeled, compared, refined, and categorized. The initial categories were revised as necessary, and ethical positions were developed. Subsequently, axial coding was performed, which involved considering connections between the categories of ethical positions and grouping them according to their content. The ethical principles associated with the identified ethical positions were noted.

It is important to emphasize that the boundaries between the ethical positions are not always strict, as some overlap, making clear distinctions challenging in certain cases. In cases of uncertainty, another researcher was consulted, and a mutual decision was reached.

The ethical content of the papers was analyzed by identifying ethical positions and principles. In this review, the term 'ethical position' refers to positions and recommendations emerging from qualitative analysis and pertaining to ethical aspects (e.g., all decisions should be focused on the best interests of the child), rather than practical



**Fig. 1** PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

aspects of end-of-life decision-making (e.g. doses of medications used). All identified ethical principles were mentioned in relation to specific ethical positions and analyzed in this review (a rather narrow definition of extracted principles, based on a broader (bio)ethical literature, is presented in Appendix Table 1).

## Results

### Characteristics of included guidelines

A total of 9 papers meeting the inclusion criteria were included in the analysis (see Table 1). The papers were published from 2001 to 2021.

Eight papers are country-specific, originating from France, Italy, Poland, Thailand, the Netherlands, the UK and the USA. One is international. Four papers pertain to the limitation of LST in the NICU [15, 16, 23, 24], and 5 papers focus on the PICU [25–29]. Since the included papers share the same positions regardless of whether they pertain to the NICU or PICU, we have presented the combined results, as separate analyses for NICU and PICU were deemed unnecessary.

### Ethical positions

We identified a total of 38 ethical positions, 25 of which were explicitly supported by one or more ethical principles in the papers. The remaining 13 positions are not explicitly connected to any ethical principle. However, it is evident from reading the papers that most positions stem from several overarching ethical principles, such as beneficence and professional duty.

Ethical positions were grouped into 5 themes according to their content, relating to: patients, parents, the medical team, decision-making and treatment options.

Five positions were mentioned in all included papers:

1. all decisions should focus on the best interest of the child;
2. decisions to limit LST should be made within a medical team and with the involvement of parents, whose opinion cannot be decisive;

3. conflicts between the medical team and the parents should be resolved;
4. optimal palliative care must be provided to the patient to ensure comfort;
5. pain and suffering of the child must be alleviated, even if it may hasten death.

Only one paper states that a decision to deliberately end the life of a newborn is morally and legally permitted in cases of severe suffering that cannot be relieved by excellent palliative care, including sedation [24], whereas 4 papers explicitly state that deliberate hastening of a patient's death is never acceptable [15, 23, 25, 29]. Table 2 lists the positions alongside references to the papers and the ethical positions and principles provided.

### Ethical principles

A total of 12 ethical principles were mentioned in the papers. The principle of beneficence emerged as the most prominent one. It was mentioned in all included papers except one and supports 13 different positions. The principle of futility is mentioned in six papers and supports 3 positions. The principle of professional duty is mentioned in 7 papers and supports 8 different positions. The principle of proportionality supports 9 different positions but is mentioned in only 2 papers. The principle of nonmaleficence supports 8 positions and is mentioned in 3 different papers. One paper uses the term 'right to own integrity', which was associated with the principle of autonomy, as referred to in other papers. Several principles are generally described in the papers without explicitly supporting specific positions. Table 3 summarizes the list of ethical principles and their related positions.

## Discussion

The aim of this systematic review was to analyze the ethical content of papers containing expert guidelines and recommendations addressing issues related to end-of-life decision-making in NICUs and PICUs. It explored ethical positions and supporting ethical principles.

**Table 1** List of included papers

Publication year and reference	Country	Constructed by	PICU/ NICU
2001 [23]	International	Ethics Working Group of the Confederation of European Specialists in Pediatrics (CESP)	NICU
2002 [16]	USA	American Academy of Pediatrics, National Perinatal Association, Society for Pediatric Research and the American Society for Bioethics and Humanities	NICU
2006 [15]	UK	Nuffield Council on Bioethics	NICU
2008 [24]	Italy	Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care (SARNePI)	PICU
2014 [25]	The Netherlands	National Dutch Committee	NICU
2017 [26]	USA	American Academy of Pediatrics	PICU
2020 [27]	Thailand	University hospital in northern Thailand	PICU
2021 [28]	Poland	Pediatric Anesthesiology and Intensive care Section of the Polish Society of Anesthesiology and Intensive Therapy	PICU
2021 [29]	France	Groupe francophone de réanimation et urgences pédiatriques (GFRUP)	PICU

**Table 2** List of positions with references to papers where positions and ethical principles are provided

Themes	Positions	Papers	Principles
Patient related	All decisions should be focused on the <b>best interests</b> of the child.	[15, 16, 23–29]	Beneficence [25, 26] Nonmaleficence
	<b>Child should receive honest information</b> about their condition, and their opinion should be sought and taken into account.	[24, 26–29]	Autonomy [26, 27, 29] Veracity [26] Fidelity [26]
	Ethical foundations for the decision-making process are the same in children with and without <b>developmental disabilities</b> .	[15, 23, 24, 26, 29]	Right to treatment [23] Dignity [24] Justice [29]
	<b>Child's psychological</b> , physical and spiritual needs should be met.	[24, 27–29]	Not explicitly linked to any ethical <i>principle</i>
	Every human being is unique, therefore different decisions may be taken in cases of identical diagnosis and prognosis.	[23, 24, 29]	Right to live own life [23] Right to optimal treatment [23] Proportionality [24] Singularity [29]
Parents related	<b>Parents must be informed</b> about child's diagnosis, prognosis, treatment options and decisions in an understandable way	[16, 23–29]	Autonomy [29] Proportionality of treatment [24] Nonmaleficence [29] Veracity [26] Fidelity [26]
	<b>Parents' wishes</b> should be considered, and respected if in child's best interest.	[15, 16, 23–25, 27, 29]	Autonomy [29] Nonmaleficence [25] Proportionality [24]
	<b>Parent's wishes</b> may be disregarded if not in the best interest of the child	[23–26, 28, 29]	Beneficence [23–25, 29] Dignity [28] Proportionality [24, 29] Futility [29]
	<b>Parents should be provided with psychological support</b>	[16, 24, 27–29]	Not explicitly linked to any ethical <i>principle</i>
	<b>Bereavement</b> support should be offered to the <b>family</b> .	[16, 27, 29]	Not explicitly linked to any ethical <i>principle</i>
	<b>Parents</b> should be able to <b>choose their level of involvement</b> in the decision-making process.	[24, 29]	Autonomy [29]
Medical team related	<b>Medical team</b> (within the team itself) should engage in open and honest <b>communication</b> and discussions.	[24–29]	Professional duty [26, 27] Proportionality [29]
	Members of <b>the medical team</b> should <b>be trained</b> in issues pertaining to end-of-life	[15, 16, 24, 26, 27, 29]	Beneficence [15]
	<b>Personal views of the members of the medical team</b> should not influence their decisions	[15, 16, 23]	Beneficence [15]
	<b>Psychological support</b> should be offered to the members off the <b>medical team</b> .	[16, 27, 29]	Not explicitly linked to any ethical <i>principle</i>
Decision-making related	<b>Conflicts</b> between the medical team and the parents should be resolved.	[15, 16, 23–29]	Dignity [28]



**Table 2** (continued)

Themes	Positions	Papers	Principles
Treatment options related	<b>Decisions to limit LST should be made within a medical team and with the involvement of parents</b> , whose opinion cannot be decisive.	[15, 23–26, 28, 29]	Beneficence [15, 23, 24, 26, 29] Proportionality [24]
	Treatment decisions should be noted in patient's <b>medical records</b> .	[16, 23, 24, 26–29]	Not explicitly linked to any ethical <i>principle</i>
	<b>A second expert opinion</b> should be sought in cases of unclear situations and to facilitate communication.	[16, 23, 26–29]	Not explicitly linked to any ethical <i>principle</i>
	Establishment of <b>advanced care plans</b> are recommended	[16, 24, 26, 28, 29]	Not explicitly linked to any ethical <i>principle</i>
	<b>Legal framework</b> must be respected while making decisions to limit LST.	[15, 24–26, 29]	Not explicitly linked to any ethical <i>principle</i>
	<b>Physician's primary responsibility</b> is the child's well-being.	[23, 25, 24, 28, 29]	Professional duty [23–25, 28, 29] Beneficence [23] Nonmaleficence [23, 29] Proportionality [24]
	In some situations, patients should be <b>referred to other wards</b> or institutions	[24, 26, 28, 29]	Professional duty [26]
	<b>Periodic assessments</b> of the balance of benefits and losses resulting from the treatment should be made.	[26–28]	Professional duty [28]
	<b>Treating physician bears the main responsibility</b> for the final decision.	[24, 25, 29]	Not explicitly linked to any ethical <i>principle</i>
	<b>The family must be allowed a delay</b> from the point when the decision to limit LST was made until it is implemented	[25, 26, 29]	Nonmaleficence [25]
	<b>LST must be provided</b> and maintained <b>in case of doubt</b> about the efficacy of the treatment.	[15, 24, 25]	Beneficence [15, 24] Proportionality [24]
	<b>Allocation of resources</b> should be fair, but not the deciding factor in decision-making.	[15, 24, 29]	Justice [15, 23, 29] Beneficence [15]
	In some situations, <b>patients should not be admitted to the ICU</b> .	[24, 28]	Justice [24]
	Optimal <b>palliative care</b> must be provided to the patient to ensure comfort.	[15, 16, 23–29]	Beneficence [15] Dignity [16, 24, 26, 28]
	<b>Pain and suffering of the child must be alleviated</b> , even if it may hasten death.	[15, 16, 23–29]	Beneficence [29] Professional duty [23, 25]
	<b>Futile and disproportionate treatments</b> should not be provided.	[15, 23–26, 28, 29]	Beneficence [15, 23, 25] Futility [15, 23, 25, 28, 29] Proportionality of treatment [24, 29] Professional duty [23–25] Dignity [29] Nonmaleficence [29]
	Withholding and withdrawing of LST are <b>morally equivalent</b> .	[23, 24, 26, 28, 29]	Not explicitly linked to any ethical <i>principle</i>
	<b>Deliberate hastening of patient's death</b> is never acceptable	[15, 23, 24, 29]	Not explicitly linked to any ethical <i>principle</i>
	<b>Artificial nutrition and hydration</b> can be regarded as LST and may be limited.	[16, 25, 26, 29]	Futility [25, 26] Beneficence [16]
	Oral nutrition and hydration can be stopped if causing discomfort.	[15, 25]	Not explicitly linked to any ethical <i>principle</i>
	<b>Palliative sedation</b> is permitted in cases of severe suffering and, otherwise, intractable symptoms.	[25, 29]	Not explicitly linked to any ethical <i>principle</i>
	A decision to deliberately end the life of a newborn ( <b>DELN</b> ) is morally and legally permitted in cases of severe suffering that cannot be relieved by excellent palliative care including sedation.	[25]	Nonmaleficence [25] Beneficence [25]

**Table 3** List of ethical principles and related ethical positions

Ethical principle	Positions	Papers reference
<b>Right to live own life</b>	- Every human being is unique, therefore different decisions may be taken in cases of identical diagnosis and prognosis.	[23]
<b>Right to optimal treatment and care</b>	- Every human being is unique, therefore different decisions may be taken in cases of identical diagnosis and prognosis.	[23]
	- Ethical foundations for the decision-making process are the same in children with and without developmental disabilities.	[23]
<b>Autonomy (Right to own integrity)</b>	- Child should receive honest information about their condition, and their opinion should be sought and taken into account.	[26, 27, 29]
	- Parents should be able to choose their level of involvement in the decision-making process.	[27, 29]
	- Parents' wishes should be considered, and respected if in child's best interest.	[27, 29]
	- Parents must be informed about child's diagnosis, prognosis, treatment options and decisions in an understandable way.	[27, 29]
	- <i>The principle is generally mentioned in the paper</i>	[23]
<b>Fidelity and veracity</b>	- Child should receive honest information about their condition, and their opinion should be sought and taken into account.	[26]
	- Parents must be informed about child's diagnosis, prognosis, treatment options and decisions in an understandable way.	[26]
<b>Beneficence</b>	- Decisions to limit LST should be made within a medical team and with the involvement of parents, whose opinion cannot be decisive.	[15, 23, 24, 26, 29]
	- Parent's wishes may be disregarded if not in the best interest of the child.	[23–25, 29]
	- Futile and disproportionate treatments should not be provided.	[15, 23, 25]
	- All decisions should be focused on the best interests of the child.	[25, 26]
	- LST must be provided and maintained in case of doubt about the efficacy of the treatment.	[15, 24]
	- Members of the medical team should be trained in issues pertaining to end-of-life.	[15]
	- Personal views of the members of the medical team should not influence their decisions.	[15]
	- Allocation of resources should be fair, but not the deciding factor in decision-making.	[15]
	- Physician's primary responsibility is the child's well-being.	[23]
	- Optimal palliative care must be provided to the patient to ensure comfort.	[15]
	- Pain and suffering of the child must be alleviated, even if it may hasten death.	[29]
	- Artificial nutrition and hydration can be regarded as LST and may be limited.	[16]
	- A decision to deliberately end the life of a newborn (DELN) is morally and legally permitted in cases of severe suffering that cannot be relieved by excellent palliative care including sedation.	[25]
	- <i>The principle is generally mentioned in the paper</i>	[28]
<b>Professional duty</b>	- Physician's primary responsibility is the child's well-being.	[23–25, 28, 29]
	- Futile and disproportionate treatments should not be provided.	[23–25]
	- Medical team should engage in open and honest communication and discussions.	[27, 26]
	- Pain and suffering of the child must be alleviated, even if it may hasten death.	[23, 25]
	- Periodic assessments of the balance of benefits and losses resulting from the treatment should be made.	[28]
	- In some situations, patients should be referred to other wards or Institutions.	[26]
<b>Justice (resource allocation)</b>	- Allocation of resources should be fair, but not the deciding factor in decision-making.	[15, 23, 29]
	- Ethical foundations for the decision-making process are the same in children with and without developmental disabilities.	[29]
	- In some situations, patients should not be admitted to the ICU.	[24]



**Table 3** (continued)

Ethical principle	Positions	Papers reference
<b>Nonmaleficence</b>	- Physician's primary responsibility is the child's well-being.	[23, 29]
	- Parents' wishes should be considered, and respected if in child's best interest.	[25]
	- The family must be allowed a delay from the point when the decision to limit LST was made until it is implemented.	[25]
	- Futile and disproportionate treatments should not be provided.	[29]
	- Parents must be informed about child's diagnosis, prognosis, treatment options and decisions in an understandable way.	[29]
	- A decision to deliberately end the life of a newborn (DELN) is morally and legally permitted in cases of severe suffering that cannot be relieved by excellent palliative care including sedation.	[25]
<b>Futility</b>	- Futile and disproportionate treatments should not be provided.	[15, 23, 25, 28, 29]
	- Artificial nutrition and hydration can be regarded as LST and may be limited.	[25, 26]
	- Parent's wishes may be disregarded if not in the best interest of the child.	[29]
	- <i>The principle is generally mentioned in the paper.</i>	[27]
<b>Dignity</b>	- Optimal palliative care must be provided to the patient to ensure comfort.	[16, 24, 26, 28]
	- Ethical foundations for the decision-making process are the same in children with and without developmental disabilities.	[24]
	- Parent's wishes may be disregarded if not in the best interest of the child.	[28]
	- Futile and disproportionate treatments should not be provided.	[29]
<b>Proportionality</b>	- Conflicts between the medical team and the parents should be resolved.	[28]
	- <i>The principle is generally mentioned in the paper.</i>	[27]
	- Parent's wishes may be disregarded if not in the best interest of the child.	[24, 29]
	- Futile and disproportionate treatments should not be provided.	[24, 29]
	- Every human being is unique, therefore different decisions may be taken in cases of identical diagnosis and prognosis.	[24]
	- Parents' wishes should be considered, and respected if in child's best interest.	[24]
	- Parents must be informed about child's diagnosis, prognosis, treatment options and decisions in an understandable way.	[24]
	- Medical team should engage in open and honest communication and discussions.	[29]
	- Decisions to limit LST should be made within a medical team and with the involvement of parents, whose opinion cannot be decisive.	[24]
	- LST must be provided and maintained in case of doubt about the efficacy of the treatment.	[24]
<b>Singularity</b>	- Physician's primary responsibility is the child's well-being.	[24]
	- Every human being is unique, therefore different decisions may be taken in cases of identical diagnosis and prognosis.	[29]

**Beneficence**

The principle of beneficence is at the core of end-of-life decision-making in neonatology and pediatrics. It underpins ethical support for end-of-life decisions [1–3, 5–8]. However, in everyday practice, the application of the principle of beneficence becomes more complex as the benefit of treatment is less certain [30].

The death of a child can have profound consequences for the physical and psychological health of the parents [5]. As children are expected to outlive their parents, the grief following child's death is markedly different from that experienced after losing a parent or spouse [31]. Parents may experience guilt over their decisions, and complex emotions such as guilt and regret can influence the decision-making process [32]. For some parents, being a good parent involves focusing on the child's quality of life

and prioritizing the child's needs over their own. Parents often hope for a peaceful death for their child in these, end-of-life situations [32]. Beneficence, in the context, aims to ensure that parents are presented with reasoned choices that balance the intended benefits and risks for a child, providing them with adequate closure through the support of the healthcare providers [33].

**Best interest of the child**

The notion of the 'child's best interests', inextricably linked to the principle of beneficence, is widely discussed in the reviewed papers, but also in other literature dealing with issues of LST limitation, end-of-life, and decision-making in the neonatal and pediatric care [26, 34]. While it is relatively straightforward that the child's

best interests are the primary focus, the challenge lies in defining these interests and identifying who determines them.

Clinical best interests are ascertained by weighing and balancing the benefits and burdens of treatment, considering the child and family's known wishes, beliefs, values, and cultural or religious perspectives. A study conducted in Slovenian ICUs revealed that the patient's best interest were one of the three top priorities in end-of-life care [35]. The views of parents, physicians and the medical team providing care should all be considered [34].

The treating physician holds the responsibility to make final decisions, ensuring the child's well-being remains paramount [6, 10]. They may provide objectivity that emotionally invested and involved parents cannot [36]. However, it can be challenging for physicians to separate the child's interests from the parents' [9].

Society grants significant discretionary decision-making authority to parents, assuming they act in their child's best interests due to their intrinsic parental love [36]. Parents also bear responsibilities towards their child. Their ability to discern the child's best interests is often inextricably linked with their capacity to provide care and support [15].

Both parents and physicians have duties toward a severely ill child who is at the end of life. When parents and physicians agree on the child's best interests, subsequent actions—no matter how difficult—are less morally distressing. Shared focus on a common goal reinforces certainty in the clinical and ethical soundness of the decision.

### Disagreements

Disagreement is easily conceivable, especially in situations where the medical team considers that the LST limitation is the appropriate next step, whereas parents hold the opposite opinion.

Engaging in effective, early communication with parents can foster open dialogue, reduce the trauma associated with aggressive medical interventions, and improve the likelihood that parents feel confident about reaching an informed decision [6, 37]. A systematic approach to identifying parental preferences and needs regarding decisional roles and information may reduce variability in parental involvement [6]. However, it is understandable that parents might struggle to accept the end of their child's life and fail to recognize the futility of treatment. Poor communication and disagreements over care plans are often cited as reasons behind physician-parent conflict [5].

The literature suggests several steps to be taken in such situations, with the primary emphasis on improving communication. Since disagreement may arise from a lack of information, continuing a process of respectful

and honest information sharing is recommended [26]. Effective communication should include using language that parents can understand, delivered in a culturally sensitive manner [31, 38]. Openly discussing uncertainty, coupled with appropriate emotional support, can positively affect parents' well-being and help them prepare for bereavement [39]. Reassuring parents that their decisions are thoughtful and consistent with choices other families might make in similar circumstances can also be helpful, particularly for those struggling with feelings of guilt or doubt [30].

It may be prudent to involve additional members of the medical team, including other physicians of the same specialty or specialties previously involved in the child's care. Ethics consultation and palliative care services can offer parents alternative perspectives and well-reasoned advice. Resorting to legal resolution of disagreements should remain the last resort [30].

### Parental inclusion

Shared decision-making involves a collaborative partnership between the health care team, parents and the child. This process requires regular and consistent communication between team members and parents to identify the child's best interests and alleviate parental anxiety [38]. Shared decision-making is associated with fewer conflicts, reduced unrealistic parental expectations, and improved collaboration between providers and family members [40].

Parental inclusion in the medical decision-making process is morally and, in many jurisdictions, legally obligatory. The reviewed papers recommend allowing parents to choose their level of involvement in decision-making [25, 27, 29]. However, physicians retain significant and even decisive influence, as they can shape parental engagement based on their perceptions of the child's and parents' best interests and their clinical expertise in recognizing and evaluating prognostic and treatment uncertainty [9].

Parental involvement varies across countries. For example, a study from Slovenia has shown that only 26% of intensivists agree that a child's legal guardian should participate in EOL care decisions [35]. In contrast, a study from Belgium reported that physicians consulted the parents regarding EOL decisions in 84% of cases involving the deaths of neonates and infants [41].

Allowing parents to determine their level of involvement acknowledges that some parents may find it too painful to actively participate in the decisions to limit LST, perceiving it as giving up on their child. In such cases, an informed non-dissent approach may be appropriate. Physicians can outline a treatment plan explaining which interventions are or are not reasonable, creating a context where parental permission to limit LST is not

explicitly solicited [30]. Some physicians may choose not to discuss certain treatment options with parents if they do not find those treatments to be appropriate unless specifically asked about them [9].

The ethical and legal obligation to include parents in the decision-making process for their children is widely recognized, yet navigating this responsibility across diverse contexts is complex. Parental inclusion is not only a moral imperative rooted in the need to respect principles of autonomy and family integrity but also legally mandated in many jurisdictions [6]. Such inclusion upholds the rights of guardians over their children's care. However, contextual factors such as cultural norms, institutional policies, and the urgency of pediatric critical care decisions may complicate adherence to this obligation [42]. For instance, Carnevale et al. emphasized that while legal frameworks universally advocate for parental involvement, such contextual challenges can hinder its consistent application [42]. Clinicians must balance these obligations with the child's best interests, particularly when cultural practices and parental disagreements conflict with medical recommendations. Literature underscores the importance of clear communication, ethical training, and institutional support to help clinicians to navigate these complex legal and moral intersections effectively [6, 42].

Providing emotional support to parents and alleviating pain and managing child's symptoms are core clinical skills for pediatric intensive care physicians [30]. Training and education in palliative care and communication are essential to equip healthcare providers with the tools needed to offer high-quality end-of-life care to patients and their families [8, 32, 38, 43, 44].

### Deliberate hastening of a child's death

Optimal palliative care and the alleviation of pain and suffering are conditions that must be met for all end-of-life patients, even if it may hasten death [13]. However, there are differing positions on the deliberate hastening of death. Four papers included in this review explicitly state that such actions are never acceptable [15, 23, 25, 29], whereas one paper presents a different stance [35].

In 2005, the Dutch Pediatric Society adopted the Groningen Protocol, which concerns the ending of life in gravely ill newborns suffering severely without any prospect of improvement [45, 46]. This practice of deliberately ending the life of newborns with lethal drugs (DELNs) is permitted only for a specific group of newborns and only after a satisfying a stringent set of requirements [45, 46]. The principles of beneficence and nonmaleficence are central to such decisions [36], as both parents and physicians agree that the prognosis is extremely poor, and that death would be more humane than continued suffering [45]. The process includes obligatory legal oversight,

based on medical team reports, followed by assessments conducted by criminal prosecutors.

The Nuffield Council on Bioethics rejects the deliberate ending of neonatal life and opposes the establishment of legal provisions for such practices [15]. However, the EURONIC study revealed that a certain percentage of neonatal physicians across several countries were involved in decisions to perform active euthanasia, and an even greater percentage considered active euthanasia as acceptable under selected circumstances [47].

Regardless of the legality of the practice, neonatal euthanasia occurs albeit rarely. This may reflect the immense emotional and moral distress associated with these tragic but unavoidable situations [48].

### Strengths and limitations

This is the first study that systematically reviewed the ethical content of papers containing guidelines and recommendations of end-of-life decision-making in NICUs and PICUs. It offers a comprehensive overview of the ethical positions and principles relevant to such decisions. However, the search was limited to English publications, which may have led to the omission of non-English contributions, thereby introducing a selection bias. Additionally, almost all reviewed papers originated from European countries and the USA, which share similar cultural backgrounds and socioeconomic context. This limitation is particularly significant in a field like pediatrics, where linguistic and cultural diversity influence clinical practices and guidelines.

For example, the 2005 GFRUP recommendations were originally published exclusively in French [49]. By contrast, the 2021 update [29] adopted a bilingual publication strategy, ensuring accessibility to both French- and English-speaking audiences. This decision highlights a growing trend where the use of English in medical literature serves as a *lingua franca*, facilitating broader dissemination, international collaboration and potential standardization of clinical guidelines across diverse contexts.

However, this linguistic convergence may have unintended consequences. While it increases global accessibility, it may inadvertently shape guidelines to align more closely with dominant Anglo-American perspectives and practices, marginalizing culturally specific approaches and ultimately reducing diversity of inputs. Striking a balance between accessibility and cultural specificity remains critical for the development of future guidelines.

This issue is especially significant when discussing ethics, as such homogenization of perspectives can profoundly impact the framing and shaping of ethical concepts, metaphors, principles and, ultimately, discourses [50]. English-language bioethics tends to reflect Western individualistic perspectives, often emphasizing autonomy

and personal choice over more collectivist or community-oriented values common in non-Western cultures. This is particularly relevant in pediatrics as, for instance, in various non-Western traditions, relationality and family-centered decision-making are emphasized, contrasting with the autonomy-focused frameworks prevalent in English-language bioethics [50]. All these issues require careful consideration, as addressing these disparities is essential to foster equitable, truly global bioethics, a notion that receives growing attention as the only valid kind of bioethics suitable for increasingly intertwined contemporary landscapes [51].

Moreover, guidelines, clinical guidelines, and practical guidelines or recommendations are problematic. Many guidelines as document type are not indexed in the commonly available bibliographic databases [52] or grey literature sources due to their nature. There are documents that typically provide context-specific information needed to make explicit and, ideally, transparent recommendations in the clinical soundings [53] as they may have limited availability and applicability only in the local context [54]. This review aimed to replicate the methodology used in prior study published by the same group, which examined the ethical content of expert recommendations for end-of-life decision-making in adult intensive care units [13]. However, adapting this methodology to NICU and PICU environments yielded significantly fewer eligible papers. In contrast to adult guidelines, the NICU/PICU papers often lacked detailed argumentation supporting ethical positions, limiting the scope of analysis. Another limitation of this study was the difficulty of applying specific, standardized criteria to assess the strength and quality of primary sources. While such methods are often recommended to enhance robustness and rigor, their application proved difficult to implement here due to the nature of the primary sources and the study objectives. Consequently, all papers meeting the inclusion criteria were included and analyzed on an equal basis, with careful documentation and discussion of the dilemmas encountered during the selection process.

## Conclusion

The findings of this systematic review highlight important implications for both clinical practice and future research. This study demonstrates that papers containing guidelines and recommendations on end-of-life decision-making in the NICU and PICU published in English adopt and promote similar stances. The ethical principle of beneficence is at the core of the decision-making process, ensuring all decisions prioritize child's best interests. This finding is of great clinical relevance as the emphasis on beneficence and the child's best interests underscores the necessity of comprehensive training for healthcare providers in ethical decision-making,

palliative care, and communication strategies tailored to the specific sensitivities of end-of-life care.

Clinically, practices should include structured frameworks for shared decision-making to promote and enhance transparency and trust among healthcare providers, families and a broader society. Variability in parental involvement across different settings, as highlighted in this review, suggests the need for standardized approaches that respect cultural and contextual differences while maintaining focus on the child's welfare.

For research, this review reveals significant gaps in understanding how these guidelines are implemented in diverse cultural and healthcare contexts as well as their alignment with local values and practices. Future studies should investigate the lived experiences of healthcare providers and families in applying these ethical principles, particularly in non-Western settings where familial or community-centered decision-making is more common. Additionally, exploring the impact of language and cultural specificity on the guideline formulation and acceptance could ensure a more inclusive, comprehensive perspective. These efforts could bridge existing knowledge gaps, fostering ethically robust and globally applicable and sustainable practices in neonatal and pediatric intensive care settings.

## Abbreviations

NICUs	Neonatal intensive care units
PICUs	Pediatric intensive care units
LST	Life sustaining treatment

## Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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## Author contributions

DŠ, MČ, CG, BG, and AB have made substantial contributions to the conception and design of the work; DŠ, SJ, DV, GM, MČ, MN, BFG, and SG have made substantial contributions to the acquisition, analysis and interpretation of data; DŠ, DV, MČ, CG, BG and AB have drafted the work and substantively revised it. All authors have approved the submitted version, and have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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## Data availability

All data generated or analysed during this study are included in this published article [and its supplementary information files].



## Declarations

### Ethical approval

Not applicable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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