



# Scoping review of end-of-life care for persons with anorexia nervosa

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**Background:** End-of-life (EOL) care is the part of palliative care intended for persons nearing death. In anorexia nervosa (AN), providing EOL care instead of coercing life-sustaining measures is controversial. The existing literature has not been synthesized yet. To clearly delineate differing views and identify open questions as well as areas of possible consensus, we conducted the first-ever synthesis of the existing literature.

**Methods:** We searched EMBASE, PubMed, PsycInfo, and Web of Science for scientific publications on forgoing coerced life-sustaining measures and/or providing EOL care for persons with AN who refuse life-sustaining measures, typically artificial nutrition. Palliative care outside of the EOL context and medical assistance in dying were not reviewed. As very little quantitative studies were identified, we qualitatively analyzed conceptual questions, ethical reasoning, legal aspects, stakeholder attitudes, practical aspects, stakeholder needs, and outcome.

**Results:** We identified 117 eligible publications from 1984 to 2023, mainly case reports (n=26 different cases) and ethical analyses. Conceptualizations of key terms such as terminality, futility, and decision-making capacity (DMC) in AN varied widely and were often value-laden and circular. Ethical reasoning centered on weighing the preservation of life versus quality of life in the context of uncertainty about DMC and likelihood of clinical remission. Studies on stakeholder attitudes reflected this challenge. In some cases, courts ruled against coerced life-sustaining measures and/or in favor of EOL care for persons with AN. While eligibility criteria were contested, recommendations for deliberating about and providing EOL care were consistent. We identified only one study on stakeholder needs and none on outcome. Case reports described quality of life under EOL care as good and death as the most frequent outcome but engagement in voluntary treatment and (partial) clinical remission in some.

**Conclusions:** The debate around EOL care in AN needs consented, coherent terminology whose

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value base is reduced to a minimum and made transparent. While more empirical research into decision-making in AN and predictors of outcome might help reduce uncertainty, fundamental normative questions need to be addressed, for example regarding the ethico-legal significance of treatment refusals, the weighing of quantity versus quality of life and the appropriateness of diagnosis-based ethico-legal exceptionalism such as hard paternalism. More research is needed on outcome of and stakeholder needs in EOL care for persons with AN.

**Keywords:** End-of-life care (EOL care); anorexia nervosa (AN); severe and persistent mental illness; palliative psychiatry; clinical ethics

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## Introduction

### Background & knowledge gap

At some point in their life, between 1 to 4 out of 100 women in high-income countries suffer from anorexia nervosa (AN) (1). AN is characterized by emphasis on fear of becoming fat, striving to achieve a lower than normal body weight by starvation (AN restricting subtype) or restriction plus purging (AN binge/purge subtype) (2). It is

associated with a range of medical complications (3). With evidenced-based treatments, most persons with AN achieve at least partial remission (4,5). A significant portion of AN patients do not access, drop out of or do not respond to treatment, or experience relapse afterwards (6-8), resulting in 20% of patients developing a severe and enduring form of AN (SE-AN). The mortality risk is five times higher than in a healthy same-age sample (9), corresponding to one of the highest mortality rates among mental disorders besides opioid use disorder (10).

Despite these risks, patients with AN are often very reluctant to seek the life-saving treatment of weight gain, which is critical to the success of treatment (11). Here, coercion can come into play. In US legislation, for example, coercion rests on the assumption that the individual either lacks decision-making capacity (DMC) regarding treatment for his/her AN (guardianship) or is a danger to himself/herself and/or gravely disabled (civil commitment). Guardianship and certification differ in terms of the type of treatment that can be provided under each statute (medical care *vs.* psychiatric care), as well as the venue for that treatment. Guardians can make decisions regarding a ward's emergent medical care (such as artificial nutrition). Once the ward is no longer medically unstable, coerced inpatient psychiatric care and further nutritional rehabilitation can only be authorized by the courts under civil commitment laws (12).

However, despite the risk of morbidity and mortality from untreated AN, there is often reluctance to use coercion. Such concern may be well founded in that such treatment may not necessarily be recognized in retrospect as helpful, especially by individuals with SE-AN whose ultimate goal is quality rather than quantity of life (13). This underscores the need

### Highlight box

#### Key findings

- Conceptualizations of terminality, futility, and decision-making capacity in anorexia nervosa (AN) vary widely and are often value-laden and circular. Open normative questions include the ethico-legal significance of treatment refusals, the weighing of quality versus quantity of life and the appropriateness of diagnosis-based ethico-legal exceptionalism. In some cases, courts have ruled in favor of end-of-life (EOL) care for AN patients. While eligibility criteria are contested, recommendations for deliberating about and providing EOL care for persons with AN are consistent. Data on stakeholder needs and outcome is scarce.

#### What is known and what is new?

- The controversial question of whether and when EOL care for persons with AN can be appropriate is reviewed here for the first time.

#### What is the implication, and what should change now?

- The debate around EOL care in AN needs consented coherent terminology whose value base is reduced to a minimum and made transparent. Fundamental normative questions need to be addressed. Outcome of and stakeholder needs in EOL care for persons with AN need to be studied.

to develop innovative treatment options for patients with SE-AN. If clinical remission<sup>1</sup> is in all likelihood unreachable, one possibility could be shifting the goal of care towards harm reduction and improved quality of life (14-16). This was studied in a seminal randomized controlled trial which showed high retention rates and improvements in quality of life (14). Focusing on quality of life and relief of suffering is a hallmark of palliative care (17) whose implementation in mental health care is known as palliative psychiatry (18). Palliative psychiatry also includes end-of-life (EOL) care. EOL care is the portion of palliative care that is directed towards persons nearing death (19) as is the case for patients with life-threatening AN in the absence of life-sustaining measures. EOL care has been proposed as alternative model of care for extremely ill AN patients (16,20-22) but strongly opposed by others (23-25). Leading eating disorders experts have called for the development of guidelines, eligibility criteria, and protocols (26). However, this process is hampered by the debate around EOL care for AN not having been synthesized yet.

### Rationale and objective

To clearly delineate differing views and identify open questions as well as areas of possible consensus, we conducted a scoping review in accordance with the PRISMA-ScR reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-522/rc>) (27). The review focusses on EOL care as alternative to coerced life-sustaining measures (typically artificial nutrition) in patients with life-threatening AN who refuse them. While we appreciate the need to make high-quality care available to all AN patients (including, when needed, coercive life-sustaining measures), our aim is to explore whether, when and how EOL care could and should play a role in providing optimal care in rare cases of extremely ill AN patients. The review does neither consider the provision of palliative care for AN outside of the EOL context nor medical assistance in dying.

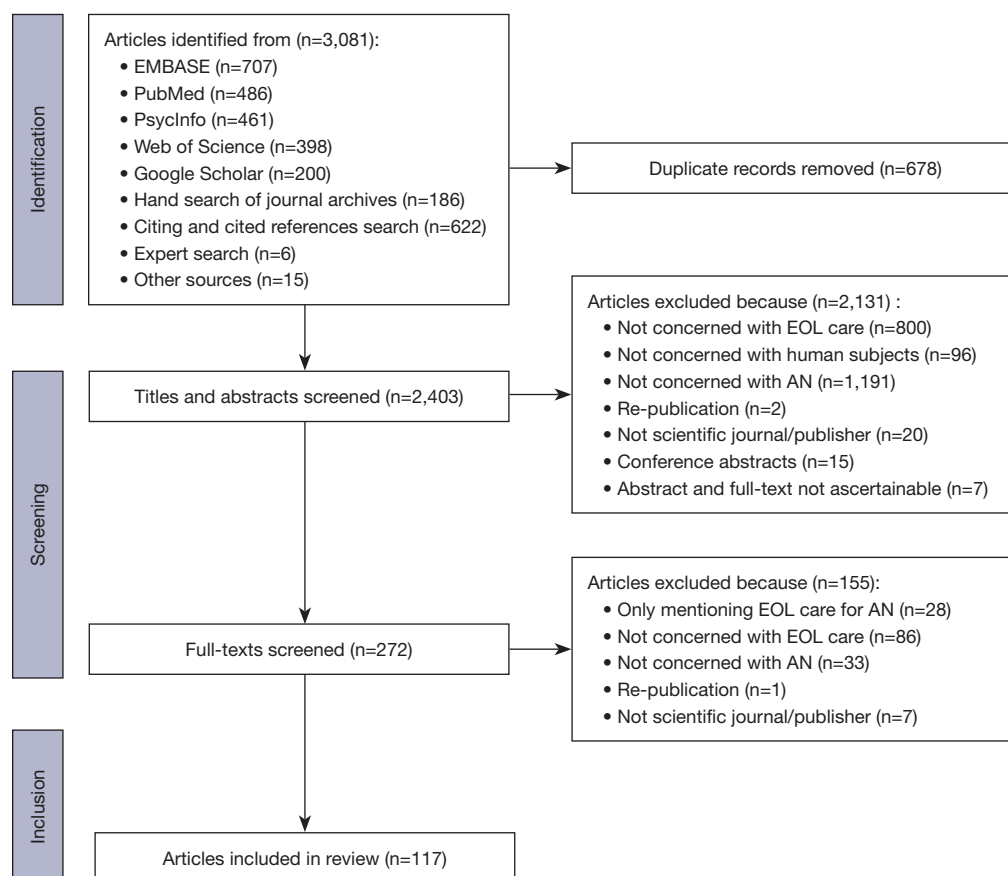
### Methods

Our aim was to portray the current body of knowledge on EOL care for AN, clarify key concepts, and identify

knowledge gaps (rather than provide a definitive, quantitative answer to a narrow question such as the effect of EOL care on standardized measures of quality of life). Therefore, scoping review methodology was most appropriate (28). As first step, a detailed protocol was developed according to Peters *et al.* (29) with input from all authors. As standard registries such as PROSPERO currently do not accept scoping reviews (29), we did not pre-register the review. A systematic search of the existing literature was conducted guided by the Cochrane Handbook for Systematic Reviews (30) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement (see the PRISMA flow diagram in *Figure 1*) (31). Four electronic literature databases with the appropriate thematic focus were searched (EMBASE, PubMed, PsycInfo, and Web of Science®). The search strategy was developed according to Bramer *et al.* (32) using controlled and natural language to search for the key concepts AN and EOL care and related concepts such as palliation, end-stage, terminality, and futility (see *Table S1* for the full search strategies). The search strategy was optimized based on sensitivity assessments using pre-determined highly relevant publications, both supportive and critical of EOL care for AN (16,21,22,33-41). The database search closed on April 15th, 2023. To compensate for eventual shortcomings, the database search was complemented with:

- ❖ A search on Google Scholar® for “anorexia nervosa palliative care” and “anorexia nervosa end-of-life care”, including the first 100 results each in the screening;
- ❖ A hand search of the archives of the three journals with the highest impact factor in the field of palliative care (*Palliative Medicine*, *Journal of Pain and Symptom Management*, *BMJ Supportive & Palliative Care*) for “eating disorders” and “anorexia nervosa” and in the field of eating disorders (*International Journal of Eating Disorders*, *European Eating Disorders Review*, *Journal of Eating Disorders*) for “palliative”, “hospice”, “end of life”, “terminal”, and “end-stage”;
- ❖ An expert search conducted by P.W., P.S.M., M.T., and F.E.

<sup>1</sup> Following the DSM 5 (2), we define (full) clinical remission as absence of symptoms that are diagnostic criteria for AN, i.e., as return to normal body weight and absence of behavioral symptoms (such as restricted eating) and psychological symptoms (such as intense fear of gaining weight) over a sustained period of time. We define partial clinical remission as return to normal body weight with some remaining behavioral and/or psychological symptoms.



**Figure 1** PRISMA flowchart. EOL, end-of-life; AN, anorexia nervosa; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

And for all publications included in the review:

- ❖ A search for citing publications on Web of Science<sup>®</sup> (Google Scholar<sup>®</sup> for publications not listed on Web of Science<sup>®</sup>), and
- ❖ A hand search of the reference lists.

Citavi<sup>®</sup> version 6.15 was used for managing the records. After deduplication, publications were selected in a two-step process guided by inclusion and exclusion criteria (see *Figure 2*). The criteria were pre-determined based on the purpose of the review, piloted on the first 100 records, and then refined for clarity and consistency. To broaden the scope of our review, we did not restrict our search by publication date or language and included a variety of article types such as case reports, ethical analyses, and legal opinions. However, conference abstracts were excluded because of their inherent lack of detail and grey literature such as guidelines was excluded for pragmatic reasons. In the first screening step, titles and abstracts were screened. When publications did not have an abstract and could not be

excluded unambiguously based on the title alone, they were included in the second screening step. Here, records' full-texts were screened. Nineteen publications included in full-text screening were not written in English (7%) of which 12 were written in another language the screeners are fluent in (German or French). The full-texts of the remaining seven publications were translated to English using DeepL<sup>®</sup>. If they could not be excluded unambiguously based on this translation, the corresponding authors were asked to verify the accuracy of the translation (n=3 with a 67% response rate) prior to the final decision on inclusion or exclusion. Ultimately, seven non-English language publications were included (6% of the included publications).

All individual exclusion decisions after full-text screening are explained in the online table (available at <https://cdn.amegroups.com/static/public/apm-23-522-1.pdf>). Screening was done independently by A.L.W. and S.W. with disagreements being resolved by discussion. In case of irreconcilable disagreement, M.T. and F.E. would have

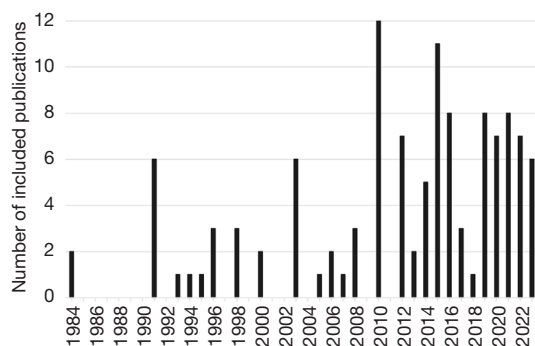
Included in this review were publications	Excluded from this review were publications
1. <b>discussing</b> aspects such as a) ethical reasoning about, b) legal opinions on, c) stakeholders' attitudes and opinions towards, d) practical aspects of, e) stakeholder needs when, or f) <i>outcome of</i>	1. <b>mentioning, but not discussing EOL care for AN</b> , e.g., a) <i>publications merely stating that EOL care for AN is discussed such as (42) or</i> b) <i>publications that do not contain more content on EOL care for AN than is cited from other publications such as (43).</i>
2. <b>forgoing coerced life-sustaining measures and/or providing EOL care</b> such as a) forgoing artificial refeeding despite acute danger to life, b) changing a patient's status to "Do Not Resuscitate", or c) transferring a patient to hospice care <b>in</b>	2. <b>not concerned with coerced life-sustaining measures or EOL care</b> , but rather with a) <i>any form of voluntary treatment such as (44),</i> b) <i>involuntary hospitalization alone such as (45),</i> c) practical aspects of life-sustaining measures for AN such as (46), d) palliative approaches to care outside of acute danger to life such as (40), or e) medical assistance in dying such as (47).
3. <b>persons with</b>	3. <b>not concerned with human subjects</b> such as (48)
4. <b>AN</b>	4. <b>not (primarily) concerned with AN</b> , but rather with a) anorexia as symptom of a somatic condition (e.g., anorexia-cachexia syndrome in cancer patients) such as (49), b) persons with a terminal somatic illness and comorbid AN, c) other mental disorders (e.g., bulimia nervosa or major depression) such as (50), or d) mental disorders in general such as (18,51).
5. with any study design (experimental, conceptual, theoretical, etc.), including article types such as reviews, opinion articles, and editorials,	5. that are a) conference abstracts such as (52).
6. <i>published for the first time</i> and	6. <i>that are not published for the first time such as</i> a) <i>re-publications such as (53,54) or</i> b) <i>previous versions of reviews for which an updated version has been published.</i>
7. published a) in a peer-reviewed scientific journal (defined as being listed in either the National Library of Medicine Catalog of journals referenced in the NCBI databases or Clarivate's® Journal Citation Reports) or b) in a book from a scientific publisher, regardless of date of publication and language.	7. <i>that are</i> a) dissertations such as (55).
	8. whose full-text version was not ascertainable.

**Figure 2** Inclusion and exclusion criteria (18,40,42-55). Stakeholder refers to all persons with a vested interest in a given case such as patients, significant others, and healthcare professionals. Criteria in italics were changed or added during pilot screening. EOL, end-of-life; AN, anorexia nervosa; NCBI, National Center for Biotechnology Information.

decided on inclusion or exclusion of the respective record. However, this did not become necessary.

Data extraction and analysis was aligned with the purpose of the review and the nature of the records included. As very little quantitative studies could be included in the review, only qualitative findings were extracted in a simplified qualitative

content analysis (56). Using Citavi®, relevant text segments were coded with broad pre-determined main categories based on the aspects reflected in the inclusion criteria—that is, ethical reasoning, legal opinions, stakeholders' attitudes, practical aspects, stakeholder needs—and additional aspects whose relevance became apparent during screening and extraction—



**Figure 3** Publication year of included publications (n=117).

that is, case reports, conceptual questions, eligibility criteria, outcome. Coding was done separately by A.L.W. and S.W. with disagreements being resolved by discussion. The main categories were then structured by creating lower-level categories reflecting the content of groups of text segments. For example, the text segment “It is argued that treatment refusals can sometimes be overridden when there is a reasonable chance of recovery, even when those decisions are competent and accepted standards for DMC are satisfied” (57) was identified as relevant, coded with the main category “ethical reasoning”, and subsequently sorted into the lower-level category “calls for hard paternalism”.

We chose the term “life-sustaining measures” to refer to intensive care for persons with life-threatening AN which usually centers on artificial nutrition. While this term is not value-free (discussed further in the section on conceptual questions), it has the advantages of being concrete as it describes interventions (which the term “treatment” does not) and implying the context of life-threatening AN (which is the scope of this review). Similar reasoning applies to our choice of “EOL care”.

In the results, publications are cited when mentioning a specific concept or argument—regardless of whether they opposed or endorsed it. To improve readability, concepts and arguments were sorted into the dichotomy of providing either coerced life-sustaining measures or EOL care. Thus, we did not consider the options of providing voluntary life-sustaining

measures (as this is outside the scope of our review), forgoing both coerced life-sustaining measures and EOL care (as this does not seem defensible) (58) or providing both at the same time (as they seem mutually exclusive)<sup>2</sup>. Neither of these options was discussed in the publications included in the review. The section on ethical reasoning was structured using the framework of principlism<sup>3</sup> as the majority of publications explicitly referred to it. However, the terminology of arguments from normative theories such as virtue ethics or rights-based ethics was preserved to portray the diversity of ethical reasoning.

## Results

Through two-step screening, we identified 117 publications eligible for inclusion (*Figure 1*), of which 104 were articles in scientific journals and 13 chapters in books from scientific publishers. The publications were published between 1984 and 2023 and almost exclusively from high-income countries [*Figure 3*; see the online table for further description of included studies (available at <https://cdn.amegroups.cn/static/public/apm-23-522-2.pdf>)]. They reported on 26 different cases of EOL care for AN patients (11,21,22,33,38,41,60-78) [see the online table (available at <https://cdn.amegroups.cn/static/public/apm-23-522-3.pdf>)]. These patients were between 18 and 56 years old and almost exclusively female.

In the included publications, we identified 965 relevant text segments and developed a system with 428 codes and categories [see the online table (available at <https://cdn.amegroups.cn/static/public/apm-23-522-4.pdf>)]. The main categories were conceptual questions, ethical reasoning, legal aspects, stakeholder attitudes, practical aspects, outcome, and stakeholder needs. We synthesize the pertaining literature in what follows.

### Conceptual questions

Key concepts in the debate around EOL care for persons with AN lack established, neutral definitions. These open conceptual questions pertain to terminality including the ethico-legal significance of treatment refusals, futility including the ethico-legal significance of artificial nutrition, and DMC.

<sup>2</sup> This is not to say that coercion cannot be a justifiable part of EOL care. For example, in case of other-endangering behavior, coercion may be a necessary precondition for providing EOL care. However, this is hardly ever the case in AN, and coerced life-sustaining measures seem mutually exclusive with EOL care.

<sup>3</sup> Principlism is a normative framework developed by Beauchamp and Childress (59) that is based on the ethical principles of respect for autonomy, beneficence, non-maleficence, and justice. Normative means relating to value judgements (rather than facts alone).

**Table 1** The concept of terminal AN

Conceptualizations of terminality	Arguments	
	AN cannot be terminal ...	AN can be terminal ...
Progressive (psycho)pathologic progress inevitably leading to irreversible organ damage (80-82)	... because starvation and most of its sequelae are reversible – (80,83-88)	
	... because irreversible organ damage is only possible, not inevitable in AN (80,81)	
Advanced stage with no known cure, inevitably leading to death (16,63,86,89)	... because there is no established staging system (85)	–
	... because AN is treatable/clinical remission is always possible (16,23,24,63,83,84,86,89-93)	
Short life expectancy + futility of further treatment (61,88,94)	... because AN is not a lethal disease (83), danger to life stems instead from treatment refusal (16,76,86,87)	... because a short life expectancy can be reliably established in the absence of nutrition (61,87,94)
	... because patients do not have DMC to judge futility (87)	... because (competent) patients can declare further treatment (qualitatively) futile even when (medically) viable options remain (94)
	... because individual prognoses can (currently) not be made with sufficient reliability to declare futility (84,85,88,93)	
Clinical remission highly unlikely + futility of further treatment (95) <sup>a</sup>	–	... when patients remain chronically, severely ill despite repeated high-quality treatment (95)
		... when healthcare professionals and patients declare further treatment futile (95)

<sup>a</sup>, as such a conceptualization of terminality is outside the issue at hand (namely, EOL care), it is not discussed further. AN, anorexia nervosa; DMC, decision-making capacity; EOL, end-of-life.

## Terminality

Recently, it was debated whether AN can become terminal<sup>4</sup> (*Table 1*). Authors opposing the concept tend to (implicitly) view a lack of therapeutic options to prevent death as definitional characteristic of terminal conditions. They then argue that this is never the case in AN as the effects of starvation are almost always reversible and clinical remission is always possible (16,23,24,63,80,83-86) and stress that danger to life stems not from lack of treatment options but from treatment refusal (16,76,86,87). Authors supporting the concept frame terminal AN as a short life expectancy combined with futility of further treatment. They argue that in the absence of nutrition, a short life expectancy can reliably be established and that some patients have DMC

to declare further treatment futile (61,94). Whether AN can be terminal thus hinges on the ethico-legal significance ascribed to treatment refusals: should they be disregarded when judging the prospects of life-sustaining measures? Or is treatment refusal an inherent feature of AN that sometimes amounts to an inability to show the minimum cooperation necessary for treatment to take effect, thus justifying futility judgements (41)? Or do some AN patients have DMC to declare futility and refuse life-sustaining measures, and should this then be respected? These questions are discussed further below.

## Futility

Except for actively dying patients<sup>5</sup>, considerable

<sup>4</sup> The current debate around terminal AN has many structural and material parallels to the earlier debate around end-stage AN. Also, the terms are often used interchangeably, e.g., by Geppert (79). Therefore, the concept of end-stage AN is not discussed here; relating categories can be found in the online table (available at <https://cdn.amegroups.cn/static/public/apm-23-522-4.pdf>).

<sup>5</sup> The term actively dying refers to the last days or hours of life, characterized by a breakdown of physiologic functions (96). In persons dying from starvation, a point of no return is reached when the molecular structures necessary for metabolizing nutrients have themselves been metabolized.

**Table 2** The concept of futility of coerced life-sustaining measures for AN

Conceptualizations of futility (judgements)	Arguments	
	Coerced life-sustaining measures cannot be futile in AN ...	Coerced life-sustaining measures can be futile in AN ...
<b>Impossibility</b>		
Irremediably shortened life expectancy (physiological futility) (79,97)	... because instances of physiological futility are not AN anymore, but a medical illness (79) ... because AN cannot be end-stage/terminal (11,16,79)	... when patients are actively dying <sup>a</sup> /when coerced LSM cannot reduce their mortality risk (68,79,97)
Impossibility of (at least partial) clinical remission (36,79,90,91,98,99)	... because clinical remission is always possible (74,79,81,90,91)	–
<b>Quantitative futility</b>		
Unacceptably low chance of survival (16,79)	... because the lives of AN patients can be sustained (11,68,79,86)	... because—contrary to a common misunderstanding—one can die from a mental disorder (16,64)
Unacceptably low chance of (at least partial) clinical remission (39,64,68,70,79,81,83,95,100,101)	... because a major impediment to treatment is patient refusal, an AN symptom that can and must be treated (11,16,79,90)	... when subsequent psychotherapy has a very low chance of success because no viable options remain or all options have been consistently refused by the patient when competent (68,83,101)
	... because prognosis for AN in general is good (39,102)	... when subsequent psychotherapy is cost-prohibitive (economic futility) (79,103)
	... because individual prognoses can (currently) not be made with sufficient reliability (89,90,102) ... because patients have not had access to high-quality treatment (104)	
<b>Qualitative futility</b>		
Unacceptable benefit/burden-ratio for the patient (11,68,70,83,95,100,103,105)	... because AN patients do not have DMC for qualitative futility judgements (16,39,79,100)	... when patients declare further treatment futile and die without healthcare (practical futility) (103)
		... because some patients have DMC for qualitative futility judgements (79,90,94)
		... because treatment can (also) be futile in incapacitated patients (83,106) and coerced LSM sometimes only prolong suffering (11,70,83,105)
Patient not worth resources for LSM/treatment (81)		–
<b>Pretext futility</b>		
Justification for healthcare professionals to unilaterally forgo an intervention the patient requests (35)	... because AN patients typically refuse, not request LSM (35)	... because futility also applies to providing treatment the patient deems inappropriate (reverse futility) (90)
<b>Pseudo-futility</b>		
Rationalization of negative feelings towards the patient (60,79,81,90,104)	... because futility does not exist <sup>b</sup>	... because not all instances are pseudo-futility <sup>b</sup>
Sign of incompetence of the treatment team (39)	–	–

Reported are both conceptualizations of futility (presupposing that futility exists) and conceptualizations of futility judgements (presupposing that futility does not exist). <sup>a</sup>, the term actively dying refers to the last days or hours of life; <sup>b</sup>, these arguments were not explicitly found in the included publications, but seemed implicit. AN, anorexia nervosa; LSM, life-sustaining measures; DMC, decision-making capacity.



controversy surrounds the conceptualization of futility and its applicability to coerced life-sustaining measures in AN (*Table 2*). Authors opposing the concept may frame futility judgements as rationalizations of negative feelings towards the patient (79,81,90,104). Or they (implicitly) conceptualize futility as impossibility of achieving at least a partial clinical remission and argue that this is never the case in AN (36,79,90,91,98). Authors supporting the concept tend to conceptualize futility as unacceptable benefit/burden ratio (11,68,83,95,100,103,105) and argue that this can apply to AN as coerced life-sustaining measures sometimes only prolong patients' suffering (11,83,105). A conceptualization of futility as unacceptably low chance of achieving at least a partial remission is endorsed by proponents from both sides. Some argue that this applies to coerced life-sustaining measures in AN when subsequent treatment of AN (e.g., psychotherapy) has a very low chance of success because no viable options remain or all options have been consistently refused by the patient when competent (68,83,101). Others counter that individual prognoses cannot be made with sufficient reliability (88,90,102) and that low chances of clinical remission stem from treatment refusal which is a symptom of AN that can and must be treated (11,16,79,90). Whether coerced life-sustaining measures can be futile in AN thus hinges on the ethico-legal significance ascribed to treatment refusals (discussed above) and on the ethico-legal significance of artificial nutrition. Making the futility or utility of artificial nutrition (and associated intensive care) contingent on chances of clinical remission, that is, on the anticipated effectiveness of subsequent AN treatment, is grounded in a view of artificial nutrition as a mere life-sustaining measure. Endorsed by several authors (63,68,70,77,105,107-112), this view increases the need for ethical justification in the form of either a patient request or an acceptable chance of improving health (77). Others, however, hold that artificial nutrition is not only a life-sustaining measure but itself treatment for AN (63,68,107,109). Here, additional ethical justification in the form of effectiveness of subsequent treatment is not needed, and the question of futility of artificial nutrition is reduced to the likelihood of sustaining life and achieving weight gain.

Another open question about both futility and terminality in AN seems to be with whom the authority lies to declare it. Because of the normativity of futility, it has been argued that such judgements should not be made by healthcare

professionals alone, but based on a societal consensus and/or together with patients (61,79,90,94,104,113). The ethico-legal significance of patient-declared futility, in turn, is intertwined with the question whether patients are ascribed DMC.

### DMC

While there is consensus that DMC can be impaired in AN, it is debated whether AN patients can have DMC for refusing life-sustaining measures. At the heart of this debate is the open conceptual question of how DMC should be assessed in this context (*Table 3*). Some contend that particularities of AN justify deviations from the functional approach to DMC assessment (23,79,80,109,132,133), such as presuming incapacity (36,109,114,115), reversing the burden of proof (98), or adding criteria for DMC such as the authenticity of the refusal's value base (35,57,104,109,125). These calls for ethico-legal exceptionalism are complemented by calls for hard paternalism<sup>6</sup> (discussed further in the section on ethical reasoning).

Others defend the functional approach, arguing that it can (and frequently does) find AN patients incapacitated (78,116) and that diagnosis-based deviation from this standard would discriminate against AN patients (38,78,120) and violate their right to self-determination (68,72,102,110,129). They further contend that incapacity regarding nutrition does not equate incapacity regarding medical intervention (11,63,68,72,75,78,113,117,130), and that the ability to appreciate the quality of one's life and the benefits and burdens of sustaining it can suffice for refusing life-sustaining measures (63,68,72,73,78,93,112,113,117,130). Thus, whether AN patients are deemed to have DMC hinges not only on how, but also for which question this is assessed (72,78).

### Ethical reasoning

Whether providing EOL care in AN instead of coercing life-sustaining measures can be justified and thus appropriate is controversial. This ethical debate is detailed in *Table 4*.

### Beneficence

Opponents of EOL care argue that the lives of most patients can be sustained (36,68,79,83,89,92,106,109,117,122,125,128), thus preserving their chance at clinical remission (22,36,86,92,98,108,121,140). Proponents of

<sup>6</sup> Applying the definition of Dworkin (134), hard paternalism refers to coercing patients that have DMC, whereas soft paternalism refers to coercing patients that lack DMC.

**Table 3** Assessment of DMC for LSM

Assessment of DMC	Arguments	
	AN patients lack DMC for life-sustaining measures ...	AN patients can have DMC for life-sustaining measures ...
Presumption of incapacity... because they have AN (79,98,104,114,116), a low (36,109,114,115)	BMI (68,109,115), or because they refuse LSM (36,98)	... because some patients have DMC (38,61,64,73,75,78,83,88,103,109,111,112,117-119)  ... because incapacity should not be presumed based solely on a psychiatric diagnosis (38,78,102,109,112,113,116,117,120-122) or the content of the decision (75,77,83,88,110,113,122,123)
Different procedure		
DMC, not lack thereof, has to be proven (98)	... until proven otherwise (98)	... because reversing the burden of proof would be discriminatory, expose patients to clinical overreach (120), and create legal uncertainty (36)
Higher threshold (38,80,122)	... because the stakes are too high (122)	... because the threshold should not exclude all refusals of LSM (38)
Additional criteria		
Rational capacity	... because they refuse for irrational reasons/goals (23,68,118)	... because they have the right to make irrational decisions (68,75,83,112,122)  ... because their refusals can be rational (38,68,75,77,124)
Value base of the decision (109,116)	... because their refusal is based on pathological, not authentic values (35,57,79,80,104,114,125,126)	... because "pathological values" cannot be differentiated from authentic ones objectively (36)
Volitional capacity (127,128)	... because they are internally coerced by AN to refuse treatment (57,80,127,128)	–
Emotional capacity (38,100)		... when they can appreciate the consequences of their refusal not only cognitively, but also emotionally (75,80)
Standard functional test of cognitive DMC <sup>a</sup> (68,88,116,123)		... because more stringent criteria would be discriminatory (38) and undermine patients' right to self-determination (68,72,102,110,129)  ... because only capacity for decision-making is necessary for DMC, not actual understanding, appreciation, and reasoning (72,118)
Understanding	... when basing their refusal on false assumptions (35,116,130,131)	–
Appreciation	... when they cannot apply information to themselves (74,78,104,116), e.g., due to lack of insight (74,78-80,124)	... because some patients can appreciate their quality of life and the benefits and burdens of LSM and reach a reasoned refusal (63,68,73,78,93,112,113,117,130)
Reasoning	... when their refusal conflicts with their own goals (16,74,78,87,104,116)	

Shown are both arguments for and against specific aspects of DMC assessment and arguments why AN patients can(not) have DMC if assessed in a specific way. Collapsing these two lines of argumentation seemed appropriate as they are intertwined: whether or not patients are ascribed DMC depends on how DMC is assessed, and DMC should take patients' decision-making deficits into account.

<sup>a</sup>, the fourth component of DMC in the functional approach, expressing a choice, was not discussed in the relevant literature. DMC, decision-making capacity; LSM, life-sustaining measures; AN, anorexia nervosa.

**Table 4** Ethical reasoning about end-of-life care for persons with AN

Arguments	Against EOL care	For EOL care
Based on beneficence	AN is never terminal, starvation is reversible, and patients will most likely survive with LSM (36,68,79,83,89,92, 106,109,117,122,125,128). As their life is worth living, it is in their best interest and their right to be kept alive (35,75,98,107,133,135)	Coerced LSM can be ineffective (94,136) and may even shorten lives (78,107) as they can increase dysfunctional behavior (78,94,105,109,121,122,137) and expose the patient to risks of somatic complications (36,60,78,98,105,110,120,124,129,138)
	Due to the sanctity of life (79,98,107,126,135), society and healthcare professionals have a duty to preserve it (35,79)	Life is not an absolute value (34,36,68,98). It can be in patients' best interest not to prolong their suffering (57,74,83,87,93,94, 103,110,118,121,139)
	Coerced LSM preserve patients' chance at clinical remission (22,36,86,92,98,108,121,140), which always remains possible (23,25,36,79,88,92,106,109,141,142)	It cannot be reliably predicted that a given patient will experience clinical remission (70,87). In some patients, clinical remission and a quality of life they deem acceptable are highly unlikely (16,36,61,63,71,78,83,98,99,103,106,110,112,117), which makes coerced LSM unjustifiable (68,103,105,121-123)
	Healthcare professionals have a duty to maintain hope and keep providing treatment (81,91,121,144)	Forgoing coercion can lead to more functional behavior (67,99,129,132,137,143), EOL care may be used/needed only intermittently (33,39,67,80,85,99)
	Coerced LSM express concern and "tough love" for the patient (82)	EOL care exemplifies the virtues of compassion (68,80,109) and humility (80)
		EOL care improves quality of life and relieves suffering (61,77,80,83,99,104,109,119,145). It preserves dignity and honors the life lived (36,61,68,98,116,145)
Based on non-maleficence	Coerced LSM are not objectively unbearable (35,82)	Coerced LSM are invasive and burdensome and violate patients' dignity (35,68,87,105,108-110,116,121,122,129,133,146). The burdens of coerced LSM can outweigh the benefits (36,60,94,100,112,120,130)
	Discussing EOL care can cause patients to lose hope, undermine their motivation for clinical remission, and induce a death wish (102,119,141)	Outright rejection of EOL care condemns some patients to endless cycles of coerced LSM and re-decompensation (68,93,103,105)
Based on respect for autonomy	Patient refusals of LSM and requests for EOL care are not competent <sup>a</sup> and thus need not be respected (35,79,91,98,114)	Some patients competently <sup>a</sup> refuse LSM, this should be respected (33,57,91,93,109,113,121,122,135,137,147). Rejecting the possibility of competent LSM refusals makes patient dependent on healthcare professionals' assessment of their best interest (112,117)
	As AN patients do not have a consistent death wish, we need to presume they wish for their lives to be saved (68,104,115,128). This is corroborated by patients later being thankful for having been coerced (23,39,57,68,82,83,100,104,106,109,115,131,133,136,142)	Patients have a right to decide about LSM, a right to die, and a right to choice in dying (36,61,75,77,86,103,109,148). Reports of retrospective gratitude are anecdotal and tainted by selection bias and positive outcome bias (94,109,121)
	Coerced LSM (= artificial nutrition) can restore capacity impaired by starvation (73-75,79,80,86,91,102,108,121,122,149). This enables patients to change their mind (36,75,83,86,98,142) or effect an advance directive against further LSM (101,122)	The possibility of EOL care encourages honest discussions about options and prognosis, enabling patients to make autonomous decisions and promoting patient-centered care (94,105)
	As refusal of LSM profoundly affects significant others, it does not constitute a responsible exercise of autonomy that should be respected (83,123,128)	The responsibility to consider the consequences for their significant others lies with the patient, not with their healthcare professionals (117)

**Table 4** (continued)

Table 4 (continued)

Arguments	Against EOL care	For EOL care
Based on justice	–	Providing EOL care acknowledges that psychological suffering can be as real and painful as physical suffering, thus countering stigma (11,16,38,71,80)
	As treatment failures stem from lack of resources and/or expertise, society has an obligation to provide those instead of EOL care (37,150-153)	Restricting EOL care to patients with extensive previous AN treatment would be unfair to patients who could not afford this (94)
	Patients have a right to be treated regardless of compliance and costs (108,141). EOL care is an excuse for professionals to get rid of cumbersome patients (68,91,141)	AN patients should have the same access to EOL care as persons with somatic illnesses (36,38,76,93,112,116), palliative care should be provided based on needs rather than diagnosis (38,73,154)
	EOL care suggests that AN treatment is futile in general, endangering access to care (82,141)	Rejecting EOL care to protect the majority of AN patients is unfair to the minority who would profit (63,117)
	EOL care would be profoundly distressing for significant others and healthcare professionals (91,93,106,132)	The purpose of medicine is not to serve the interests of the survivors (83)

Arguments against/for EOL care include arguments for/against always coercing life-sustaining measures. <sup>a</sup>, for an overview over whether AN patients can have decision-making capacity for life-sustaining measures, see Table 3. AN, anorexia nervosa; EOL, end-of-life; LSM, life-sustaining measures.

EOL care counter that some patients are highly unlikely to experience clinical remission and a quality of life they deem acceptable (16,36,61,63,78,83,98,99,103,106,110,112,117), which makes coerced life-sustaining measures unjustifiable (68,103,105,121-123). They further contend that EOL care improves patients' quality of life and relieves suffering (61,77,80,83,99,104,109,119,145).

### Non-maleficence

Proponents of EOL care argue that the burdens of coerced life-sustaining measures are high (35,68,87,105,108-110,116,121,122,129,146) and can outweigh the benefits (36,60,94,100,112,120,130). Opponents counter that life-sustaining measures are not objectively unbearable (35,82) and that discussing EOL care can undermine patients' motivation for clinical remission (102,119,141).

### Respect for autonomy

Opponents of EOL care hold that patients lack DMC for life-sustaining measures and that their presumed wish is to be kept alive (35,68,79,98,104,114,115,128). In addition, they contend that as DMC is impaired by starvation, life-sustaining measures in the form of artificial nutrition can restore it, thus respecting patients' future autonomy (73-75,79,80,86,91,102,108,121,122,149). Some even argue

that the reversibility of starvation and/or the inappropriateness of standard DMC assessment in AN (see above) justify coercing patients who meet DMC criteria, that is, hard paternalism (57,68,79,83,93,106,132,133,155). Proponents of EOL care counter that hard paternalism perpetuates stigmatization of persons with mental illness (57) and that treatability is not a sufficient reason for overriding patients' right to have their competent refusal respected (33,57,91,93,109,113,121,122,135,137,147). Also, they argue that the possibility of EOL care encourages honest discussions about options and prognosis, enabling patients to make autonomous decisions (94,105).

### Justice

Opponents of EOL care argue that it endangers patients' access to care aiming at clinical remission (82,141) and violates their right to be treated regardless of compliance and costs (108,141) which is already infringed on by lack of affordable high-quality care (37,150-153). Proponents of EOL care counter that AN patients should have the same access to EOL care as persons with somatic illnesses (36,38,76,93,112,116). In addition, they contend that providing EOL care acknowledges that psychological suffering can be as real and painful as physical suffering, thus countering stigma (11,16,38,71,80).

### Legal aspects<sup>7</sup>

It has been recognized that it may be more difficult to civilly commit a patient with AN than for other psychiatric illnesses. Compared to mental disorders such as schizophrenia or bipolar disorder (whose deficits are more likely global) individuals with AN tend to lack DMC in one circumscribed area (food and eating) with preservation of DMC in other areas. In addition, society's tendency to revere thinness (underestimating the dangers associated with thinness in its most extreme form) may impede judicial findings in favor of civil commitment (12).

Legal cases involving patients with AN have addressed the role of the court in ensuring that appropriate criteria are used for coerced treatment, e.g., clarifying that medications may be warranted in treating patients with severe AN (12). We identified six legal cases, mostly from the United Kingdom, in which the courts declared it lawful to forgo coerced life-sustaining measures and/or provide EOL care for a patient with AN [see the online table (available at <https://cdn.amegroups.com/static/public/apm-23-522-3.pdf>), column 10] (11,36,68,72-74,76-78,98,107,129). In another case, the court ordered EOL care to be discontinued in favor of coerced life-sustaining measures (11,36,68,77,98,129). Of note, in none of these cases was the patient found to have retained DMC by the court, and rulings were based instead on best interest considerations (see above for the debate on DMC assessment in AN).

To promote patients' autonomy, advance directives are proposed in the literature (71,73,99). However, there is legal uncertainty as to how persons with AN can ensure that their advance directive is not declared invalid on grounds of incapacity (36,77,91,98,107,122).

The lawfulness of forgoing coercive life-sustaining measures and/or providing EOL care in AN is also discussed under human rights law. Regarding the European Convention on Human Rights, coerced life-sustaining measures interfere with patients' rights under Article 3 (prohibition of inhuman and degrading treatment) and 8 (right to respect for private and family life). This can, but need not, be necessary and proportionate to defend their right under Article 2 (right to life) (36,77,78,98,107,121). In the United Nations Convention on the Rights of Persons with Disabilities

(UNCRPD), persons with psychosocial disabilities such as AN are explicitly included. The UNCRPD monitoring committee has interpreted Article 12 (right to equality before the law) as ruling out incapacity judgements as legal grounds for coercion, rendering any coerced life-sustaining measures in AN unlawful (116,129,136). This has been contested by authors interpreting Article 12 as (I) only ruling out coercion of persons who have DMC while (II) calling for respecting the preferences of persons who do not have DMC to the greatest extent possible (111,135).

### Stakeholder attitudes

We identified six empirical studies on attitudes towards forgoing life-sustaining measures and EOL care for AN. Two studies interviewed patients (n=10 and 29, respectively) and significant others from the United Kingdom (115,133). Participants in both studies mostly believed that persons with life-threatening AN lack DMC and supported coerced life-sustaining measures. The patients were 13 to 26 years old, only few had been subjected to formal coercion, and whether any had been subjected to coerced life-sustaining measures was not reported.

Four studies surveyed mental healthcare professionals. In a survey among senior psychiatrists in the United Kingdom (37), O'Neill *et al.*'s case report on hospice care for a 24-year-old AN patient (62) received little support (median score of 23 on a visual analogue scale from 0 to 100; n=43). Three studies (146,156,157) of mental healthcare professionals in Switzerland used the fictional case vignette of a 37-year-old patient with a 26-year history of AN, multiple failed high-quality treatment attempts, and a current body mass index of 9.5 kg/m<sup>2</sup>, who was deemed to have DMC for her refusal of further treatment. Most respondents believed further curative treatment to most likely be futile (73% of n=453 psychiatrists) and would not be surprised if the patient died within 6 months (87% of n=454 psychiatrists) (157). Consequently, the majority would prioritize quality of life over life expectancy (82% of n=452 psychiatrists and 91% of n=30 mental health nurses) (156,157) and agreed that palliative sedation could be appropriate (73% of n=24 mental health nurses) (156).

<sup>7</sup> Legal opinions regarding the conceptualization of terminality, futility, and DMC in AN patients are incorporated into the section on conceptual questions (see above). Legal analyses on whether coerced life-sustaining measures or EOL care is in patients' best interest are similar to ethical reasoning based on the principles of beneficence and non-maleficence (see above) and thus not detailed here.

While the majority would forgo coerced treatment in such a case (62% of n=454 psychiatrists and 73% of n=24 mental health nurses), a substantial minority reported they would coerce treatment (21% of n=454 psychiatrists) (146,156), indicating either disbelief in the stated DMC of the patient or hard paternalism (discussed further in the section on ethical reasoning).

### *Practical aspects of EOL care*

Practical aspects pertain to deliberating about EOL care including eligibility criteria and to providing EOL care. The overarching recommendation from the literature is to make voluntary treatment aiming at sustaining life and (at least partial) clinical remission available at all times (22,33,61,68,79,91,99,119,137). Procedural recommendations for deliberating about and recommendations for providing EOL care were highly consistent and are depicted in *Table 5*. In contrast, diverse eligibility criteria have been proposed, reflecting controversy even among authors who agree that EOL care for AN can be justifiable. Contested questions include: Can and should quantitative eligibility criteria be developed (such as number of previous treatment attempts) or only procedural criteria that describe which aspects need to be considered in a case-by-case evaluation (11,38,71,80,88,93,100)? Which moral weight should be given to the patient's preferences, healthcare professionals' assessment, and societal values (11,34,45,75,83,93,100,106,112,113,145)?

The proposed eligibility criteria pertain to confirmed DMC, unlikelihood of benefit from coerced life-sustaining measures, quality of life, and expiration of a waiting period. Proponents of DMC as eligibility criterion usually refer to DMC not for eating but for life-sustaining measures and call for very careful assessment (11,16,61,74,100,112). The criterion of unlikelihood of benefit can refer to somatic health and survival, meaning patients are deemed eligible for EOL care when actively dying and/or coerced life-sustaining measures cannot improve their prognosis *quoad vitam* (68,79,80,97,108). Unlikelihood of benefit can also refer to mental health and clinical remission and several proposed eligibility criteria attempt to operationalize it. These include higher age, long duration of AN, several high-quality treatment attempts including coerced treatment, lack of benefit from previous treatment attempts, and lack of motivation for clinical remission or harm

reduction (11,12,16,22,38,61,69,75,83,85,93,97,100,102,105-107,110,112,119,158-160). Unacceptable quality of life is usually proposed as eligibility criterion in conjunction with unlikelihood of benefit, thus amounting to irremediable suffering (11,22,75,83,106,110,158). Additionally, many authors propose expiration of a certain waiting period as due-diligence criterion for eligibility for EOL care. This is deemed necessary to (I) treat the patient to competence for an advance directive (101,121); (II) allow for a thorough assessment of eligibility, e.g., verifying that the treatment refusal is consistent over time (11,16,61,74,75,100,110,121); or (III) give the family time to process the impending death (83,106).

### *Needs of stakeholders*

We identified only one empirical study on stakeholder needs regarding forgoing life-sustaining measures and/or EOL care for AN, a qualitative interview study with Dutch mental healthcare professionals (119). These professionals struggled with diagnostic uncertainty in AN, proper timing for initiating discussions about EOL care, assessment of psychological and spiritual suffering, differentiation of capricious from competent treatment refusals, and with EOL care conflicting with their professional identity as healer. They identified the need for a clear concept of EOL care for AN and for support from other specialties.

### *Outcome of EOL care*

We did not identify any empirical study on outcome of forgoing life-sustaining measures and/or EOL care for AN. In case reports [see the online table (available at <https://cdn.amegroups.com/static/public/apm-23-522-3.pdf>)], quality of life during EOL care is described as good with subjective well-being and improved interpersonal relationships (22,41,61,62,64,75). The majority of patients died days to months after initiation of EOL care. Some patients, however, came to accept life-sustaining measures and even AN treatment and improved both regarding somatic and mental health, at least for some time (21,22,33,64,67).

## **Discussion**

In this scoping review of EOL care in AN, we identified 117 publications eligible for inclusion. Controversy surrounded

**Table 5** Recommendations for deliberating about and providing EOL care for AN

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Make voluntary treatment aiming at sustaining life and (partial) clinical remission available at all times (22,33,61,68,79,91,99,119,137)
Deliberating about EOL care
Allow for enough time for thorough decision-making (121)
Do a detailed work-up of the case (24,34,38,62) and get a second opinion from an independent expert (22,79,119)
Give best possible estimate of prognoses with and without coerced LSM (83)
Conduct two independent formal DMC assessments, providing assistance for the patient to meet DMC criteria (61,74,83,100,102,106)
Involve all stakeholders [patient (regardless of DMC), significant others, mental healthcare team, palliative care team, etc.] and clinical ethicists (21,22,62,74,87,116,129,138)
Submit the matter to the court for external review (79)
Expect and care for emotional and moral distress (38,60,64,71,75,100,109,158)
Reflect own biases, interests, beliefs, and values (21,74,125)
Consider caregiver burden and healthcare resources (21,71,74)
Providing EOL care
Get to know the patient (and surrogate decision-maker) before admission for informed consent and advance care planning (22,62,99)
Expect and care for emotional and moral distress (22,64,99)
Assemble a multidisciplinary team including mental healthcare and palliative care (62,71,99,119,124) and conduct frequent case discussions (64,99)
Stop weigh-ins, calorie/exercise monitoring, and any coercive measures (22,62,71,145)
Support and encourage eating for pleasure (62,99)
(De)prescribe psychotropic medication according to subjective benefit (11,64,73)
Provide relief for somatic symptoms such as pain (11,71)
Offer supportive therapy such as art therapy and massage therapy (22,99)

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EOL, end-of-life; AN, anorexia nervosa; LSM, life-sustaining measures; DMC, decision-making capacity.

the question whether providing EOL care in AN instead of coercing life-sustaining measures can be justified and thus appropriate. Ethical reasoning centered on weighing the preservation of life versus quality of life in the context of uncertainty about DMC and likelihood of clinical remission. Studies on stakeholder attitudes reflected this challenge. While patients with life-threatening AN often meet legal criteria for coerced treatment, this should not be pursued automatically. In some cases, courts have ruled against coerced life-sustaining measures and/or in favor of EOL care for AN patients. While eligibility criteria were contested, procedural recommendations for deliberating about and recommendations for providing EOL care for persons with AN were consistent. We identified only one study on stakeholder needs and none on outcome. Case reports described quality of life under EOL care as good and death as the most frequent outcome but treatment

acceptance and improvement in a minority.

Thus, our scoping review portrayed the complexity of the topic and associated debate and revealed two reasons for this, namely that several conceptual questions remain open and that it touches on fundamental normative questions. Regarding open conceptual questions, key terms such as terminality, futility, and DMC in AN are used by different authors in very different ways, often without making this explicit. Authors tend to use conceptualizations of key terms that promote their own stance towards forgoing coerced life-sustaining measures and/or providing EOL care in AN. For example, opponents of EOL care for AN tend to conceptualize futility as impossibility whereas proponents tend to view it as unacceptable benefit/burden-ratio. The conceptualizations are thus value-laden and intertwined with the arguments based on them instead of providing neutral terminological ground for the debate. In

addition, some conceptualizations and pertaining arguments are circular. For example, it is argued that futility is not applicable to AN as AN cannot be end-stage or terminal (11,16,79) and that AN cannot be terminal or end-stage as treatment in AN is never futile (11,73,79,88,91). Thus, the debate around EOL care in AN would be furthered by consented, coherent terminology whose value base is reduced to a minimum and is transparent.

Another factor complicating the debate is uncertainty, especially regarding patients' DMC and the likelihood of clinical remission after coerced life-sustaining measures. This uncertainty stems in part from the scarcity and usually observational design of outcome studies, which leaves much room for interpretation and thus subjectivity. For example, increased mortality after coerced treatment for AN has been reported in observational studies (161). For opponents of EOL care, this exemplifies the heightened need for intervention, if necessary against the patient's stated wishes (109), while for proponents of EOL care, the same result indicates the ineffectiveness or even harmfulness of coercion (121,122,124). Therefore, many authors, regardless of their stance towards EOL care for AN, call for further research on these topics (80,88,105,136). And of course, reducing uncertainty would likely allow care to be better tailored to the individual and reduce moral distress in healthcare professionals. However, data will never tell us the exact prognosis of a given patient or whether she has DMC. How data is interpreted and applied to a specific case is a normative and thus subjective question. For example, opponents of EOL care tend to refer to aggregated data such as the proportion of AN patients experiencing at least partial remission to substantiate their claim that life-sustaining measures are always appropriate (24,70,79,86,88,91,109). Proponents counter by presenting cases to which they believe the aggregated data are not generalizable (38,61,75,103).

Therefore, the underlying normative questions need to be addressed: what is the appropriate balance between evidence-based and case-/experience-based prognostication? How do we factor uncertainty into decision-making in clinical ethics? How high do we set the bar for AN patients to be deemed competent to refuse life-sustaining measures? Are we prepared to make diagnosis-based exceptions to ethico-legal standards such as the presumption of DMC or the inappropriateness of overriding competent refusals? Which ethico-legal significance do we ascribe to treatment refusals? Should they be disregarded when judging the prospects of life-sustaining measures? Or are they an inherent

feature of AN that sometimes amounts to an inability to show the minimum cooperation necessary for treatment to take effect, thus justifying futility judgements? Is it appropriate to weigh quantity versus quality of life and how do we do that? And regarding all these questions, which moral weight should be given to the patient's preferences, healthcare professionals' assessment, and societal values?

To help answer these questions, descriptive and normative ethics research is needed, prioritizing the voices of stakeholders. Important steps in this direction are recent publications co-authored by persons with lived experience of AN (61,100,104,141) and a qualitative study of persons with lived experience of coerced life-sustaining measures for AN (13). The attitudes of various stakeholder groups need to be measured and compared in representative studies, including possible determinants such as personality traits and religious beliefs. The needs of AN patients and their significant others during deliberation about and provision of EOL care need to be systematically assessed, especially as EOL care—like palliative care in general—should be provided based on needs (17). The outcomes of EOL care in AN need to be studied to allow for a better assessment of the benefits and burdens associated with this option, e.g., by comparing the accounts of significant others of patients that died from AN with versus without EOL care. Also, the meaning of concepts such as “suffering”, “unacceptable quality of life”, and “good death” in the context of AN needs to be clarified, operationalized, and made reliably measurable (38,119).

### *Strengths and limitations*

Strengths of this study are its wide thematic and methodological scope, the systematic literature search including four databases and complementary search strategies, the lack of restrictions regarding language or year of publication, and the in-depth analysis of included publications. However, the search's sensitivity for legal analyses might be low as neither archives of legal journals nor databases of legal rulings were searched. Also, we excluded grey literature for pragmatic reasons and might thus have missed important information, e.g., contained in eating disorder guidelines. Due to the number of text segments analyzed and characteristics of the qualitative approach, especially the complexity of the category system, it was not feasible to tabulate all text segments coded with each category. However, we tabulated all cases of EOL care [see the online table (available at <https://cdn.amegroups.cn/static/public/apm-23-522-3.pdf>)] and provided the



category system [see the online table (available at <https://cdn.amegroups.cn/static/public/apm-23-522-4.pdf>)]. In addition, all authors believe that providing EOL care (understood as not including medical assistance in dying) in AN can be justifiable in rare and extreme circumstances, which might have biased analysis and interpretation. Lastly, as a scoping review instead of a meta-analysis, our results do not allow for firm policy or clinical recommendations.

## Conclusions

The debate around EOL care in AN needs consented, coherent terminology whose value base is reduced to a minimum and made transparent. While more empirical research into decision making in AN and (predictors of) outcome might help reduce uncertainty, it is vital to address fundamental normative questions, for example regarding the ethico-legal significance of treatment refusals, the weighing of quantity versus quality of life and the appropriateness of diagnosis-based ethico-legal exceptionalism such as hard paternalism. More research is needed on stakeholder needs regarding, outcome of, and concepts relevant for EOL care for persons with AN.

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Table S1 Search strategies

Database	Search strategy	Results
EMBASE	('eating disorder'/exp OR ((eating NEAR/5 disorder*):ti,ab,kw) OR 'anorexia nervosa':ti,ab,kw) AND ('palliative therapy'/exp OR 'terminal care'/exp OR palliat*:ti,ab,kw OR terminal:ti,ab,kw OR 'end-of-life care':ti,ab,kw OR 'end of life care':ti,ab,kw OR 'comfort care':ti,ab,kw OR 'best supportive care':ti,ab,kw OR 'treatment withdrawal'/de OR (((withhold* OR withdraw*) NEAR/5 (treat* OR therap*)):ti,ab,kw) OR 'right to die'/exp OR euthanasia:ti,ab,kw OR 'end stage' OR 'end-stage' OR futil*) OR (((('end stage' OR 'end-stage' OR terminal OR futil*) NEAR/5 anorexia):ti,ab,kw)	707
PubMed	((("Feeding and Eating Disorders"[MeSH Terms] OR "eating disorder"[Title/Abstract:~5] OR "anorexia nervosa"[Title/Abstract]) AND ("Terminal Care"[MeSH Terms] OR "Palliative Care"[MeSH Terms] OR "Palliative Medicine"[MeSH Terms] OR "Terminally Ill"[MeSH Terms] OR "terminal care"[Title/Abstract] OR "palliat*" [Title/Abstract] OR "end-of-life care"[Title/Abstract] OR "end-of-life care"[Title/Abstract] OR "comfort care"[Title/Abstract] OR "best supportive care"[Title/Abstract] OR "Withholding Treatment"[MeSH Terms] OR "withdraw*" [Title/Abstract] OR "withhold*" [Title/Abstract] OR "Right to Die"[MeSH Terms] OR "euthanasia"[Title/Abstract] OR "end-stage"[Title/Abstract] OR "end stage"[Title/Abstract] OR "Medical Futility"[MeSH Terms] OR "futil*" [Title/Abstract])) OR ("end-stage anorexia"[Title/Abstract:~5] OR "end stage anorexia"[Title/Abstract:~5] OR "terminal anorexia"[Title/Abstract:~5] OR "futile anorexia"[Title/Abstract:~5] OR "futility anorexia"[Title/Abstract:~5])	486
PsycInfo	(DE "Anorexia Nervosa" OR DE "Eating Disorders" OR TI "Anorexia nervosa" OR AB "Anorexia nervosa" OR TI "anorexia" OR AB "anorexia") AND (DE "Palliative Care" OR DE "Hospice" OR DE "Terminally Ill Patients" OR TI "palliat*" OR AB "palliat*" OR TI "hospice" OR AB "hospice" OR TI "end-of-life care" OR AB "end-of-life care" OR TI "end of life care" OR AB "end of life care" OR TI "comfort care" OR AB "comfort care" OR TI "best supportive care" OR AB "best supportive care" OR TI "terminal" OR AB "terminal" OR TI "end-stage" OR AB "end-stage" OR TI "end stage" OR AB "end stage" OR DE "Euthanasia" OR TI "euthanasia" OR AB "euthanasia" OR TI "right to die" OR AB "right to die" OR DE "Treatment Withholding" OR TI "withhold*" OR AB "withhold*" OR TI "withdraw*" OR AB "withdraw*" OR TI "futil*" OR AB "futil*")	461
Web of Science	((TS=("eating disorder" OR "anorexia nervosa")) AND (TS=("Hospice" OR "palliat*" OR "end-of-life care" OR "end of life care" OR "comfort care" OR "best supportive care" OR "Euthanasia" OR "right to die" OR "withhold*" OR "withdraw*"))) OR (TS=((anorexia) NEAR/5 ("terminal" OR "end-stage" OR "end stage" OR "futil*")))	398