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Ethical concerns in caring for persons with anorexia nervosa: content analysis of a series of documentations from ethics consultations

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Abstract

Background Caring for patients with anorexia nervosa (AN) is associated with high levels of moral distress among healthcare professionals. The main moral conflict has been posited to be between applying coercion to prevent serious complications such as premature death and accepting treatment refusals. However, empirical evidence on this topic is scarce.

Methods We identified all 19 documentations of ethics consultations (ECs) in the context of AN from one clinical ethics support service in Switzerland. These documentations were coded with a sequential deductive-inductive approach and the code system was interpreted in a case-based manner. Here, we present findings on patient characteristics and ethical concerns.

Findings The ECs typically concerned an intensely pretreated, extremely underweight AN patient endangering herself by refusing the proposed treatment. In addition to the justifiability of coercion, frequent ethical concerns were whether further coerced treatment aimed at weight gain would be ineffective or even harmful, evidencing uncertainty about beneficence and non-maleficence and a conflict between these principles. Discussed options included harm reduction (e.g. psychotherapy without weight gain requirements) and palliation (e.g. initiating end-of-life care), the appropriateness of which were ethical concerns in themselves. Overall, nine different types of conflicts between or uncertainties regarding ethical principles were identified with a median of eight per case.

Conclusions Ethical concerns in caring for persons with AN are diverse and complex. To deal with uncertainty about and conflict between respect for autonomy, beneficence and non-maleficence, healthcare professionals consider non-curative approaches. However, currently, uncertainty around general justifiability, eligibility criteria, and concrete protocols hinders their adoption.

Keywords Anorexia nervosa, Eating disorders, Clinical ethics, Ethical concerns, Harm reduction, Palliative psychiatry

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Introduction

Between one and four percent of females in high income countries suffer from anorexia nervosa (AN) at some point in their life [1, 2]. The main behavioral symptom of AN is a restriction of energy intake leading to significant underweight [3] which can entail a variety of medical complications [4]. Evidence-based treatment options have been shown to be effective at the group level [5], and 80% of patients experience at least partial remission over the course of their AN [6]. However, a significant proportion of AN patients do not access treatment, prematurely end it or do not respond to it, or relapse shortly afterwards [7–9], resulting in 20% of patients suffering from chronic AN. The mortality rate in AN is estimated at 5% [6], corresponding to a five-fold increase in mortality risk compared to a healthy same-age sample [10]. To prevent death or other serious medical complications, formal coercion such as enforced hospitalization or tube feeding is employed in 13 to 44% of inpatients [11]. In addition, AN patients report high levels of informal coercion and procedural injustice in the context of inpatient treatment [12–14].

In healthcare professionals caring for AN patients, the risk of poor outcome, the unsatisfactory efficacy and effectiveness of available treatment options, and the use of coercion often lead to aversive emotions, negative judgment of self and patients, and moral distress [15]. Matusek and Wright [16] posit that the main moral conflict in this context is between the use of coercion to prevent severe complications and death from AN (following the principle of beneficence as defined by Beauchamp and Childress [17]) vs. accepting a treatment refusal and the associated risks for the patient (following the principle of respect for autonomy). This issue has been the subject of intense debate in the clinical ethics literature. Geppert [18] argued that AN treatment could never be foregone on futility grounds as clinical recovery occasionally occurs even after decades [19–21]. She also dismissed refusal by the patient as grounds for forgoing treatment, arguing that the value basis of this decision is heavily influenced by the disorder and that neurocognitive functions are impaired by starvation, rendering patients incompetent to make autonomous decisions in this regard. Charland [22] and Giordano [23] argued that even when standard criteria for decision-making capacity are met, coercive life-sustaining measures may be justified in AN (hard paternalism as defined by Dworkin [24]). The reasons given for this paternalism are the reversibility of the symptoms and the absence of an unambiguous death wish in most AN patients. Other authors have argued that in the most severely ill patients, the chances of symptom remission and subjectively acceptable quality of life can become so small that they may be outweighed by the burdens of repeated, invasive, coerced life-sustaining measures [25–27]. In addition, it has been argued that some treatment refusals by AN patients are competent and should therefore be respected [28–30]. This could be especially the case in patients with long-standing AN because, based on their long-term experience with AN, they tend to have more insight into their quality of life with the disorder as well as the burdens of treatment [23, 31]. Palliative approaches[1] have been proposed as alternative models of care for those patients [27, 29, 36–39], and a failure to take this option into consideration has been argued to reinforce the mind/body dualism and thus perpetuate the stigmatization of severe mental disorders [31].

Thus far, this ethical debate has been largely based on theoretical reasoning and single case studies of exceptional cases, leaving its relevance to care for patients with AN in general unclear. To start filling this knowledge gap, the present study aims at a thick yet structured description of ethical concerns in routine care for patients with AN and the clinical situations giving rise to them. The findings inform both mental health professionals caring for AN patients and clinical ethicists supporting them, and thus contribute to ethical decision making in mental healthcare.

Methods

Approach, context, and reflexivity

We took a constructivist approach [40] to explore how individuals and teams caring for AN patients 'make' ethical concerns: Which clinical situations are constructed as both problematic and morally relevant and why? Accepting that there is not one objectively true view of the moral dimension(s) of a particular clinical situation, we aimed to systematically describe the diversity of possible ethical concerns in this context. For this descriptive research aim, the theoretical framework of content analysis was deemed appropriate [41]. Qualitative content analysis of documents [42] has previously been applied to ethics consultations (ECs) in somatic medicine [43–45].

Building on a previous case series on ECs in psychiatry [46], we analyzed documentations of Ethics Consultations

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[1] Palliative care aims at improving the patient's quality of life by preventing and/or relieving suffering [32]. When directed at persons nearing death, palliative care is called end-of-life care [33] which can take on the form of hospice care. There is international consensus that palliative care does not intend to hasten death [32] (implying that medical assistance in dying is not a form of palliative care), but this is not undisputed. While palliative care evolved in somatic healthcare, it is not limited to certain diagnoses [32]. Accordingly, the concept of palliation is increasingly being adapted to mental healthcare where it is called palliative psychiatry [34]. It has been argued that palliative psychiatry encompasses approaches ranging from harm reduction to end-of-life care as they all prioritize maximizing quality of life over other goals of care such as achieving clinical remission or improving psychosocial functioning [34]. However, this terminology is not consolidated yet. For an ethical justification of palliative psychiatry, see Westermair and Trachsel [35].

(EC) carried out in various clinical contexts by the Clinical Ethics Support Service (CESS) in Basel, Switzerland. This service was formally implemented in 2012 and currently serves four tertiary care hospitals. It takes a principle-oriented approach [17] combined with a systematic change of perspective [47, 48]. The content and results of ECs are summarized in a protocol that is proofread by the EC requester and then archived in both the patient's medical record and the service's EC database.

Importantly, in each of the ECs analyzed, one or more of the clinical ethicists among the authors (ALW, SRT, and MT) participated as part of their clinical duties and thus brought their personal experience and attitudes to both the deliberation process and documentation of the ECs, and the interpretation of the coded documentations. All of them have been trained in mental health care and believe that in severe and persistent AN, switching from the standard goal of care (e.g. weight increase) to non-curative goals of care can be in the patient's best interest [27, 34].

Selection strategy

For this study, the service's EC database was searched for the terms "anorexia" and "eating disorder", covering the period from its inception in July 2012 until end of June 2022. Included were all documented ECs that focused on an individual patient with a diagnosis of anorexia nervosa (ICD-10 F50.x; [3]). The exclusion criteria were (a) EC not focused on individual patients such as ethics support in guideline development, and (b) EC focused on patients with anorexia occurring in contexts other than AN, such as restricted eating due to dysphagia in pharyngeal carcinoma. No restrictions were made on the exhaustiveness of the EC (e.g. full or brief ECs as differentiated by [49]) or other characteristics. See supplementary material S1 for an overview of the included documentations and supplementary material S1 for details on data management and processing.

Coding and analysis

The EC documentations were coded by ALW following a sequential deductive-inductive approach as described by Kuckartz [50] (see supplementary material S2 for examples). As the CESS's standard for documenting ECs changed during the study period and EC documentations did not strictly adhere to them, the material was first sorted into pre-determined deductive categories based on the key elements of EC documentations identified by Pearlman et al. [51]. Reported here are findings on the categories (a) consultation-specific information such as medical facts and patient preferences, (b) ethical concern(s), and (c) analysis of ethical concern(s). We used a broad definition of "ethical concern" that included (a) problems relating to normatively justifiable patient care as well as practical implementation of normative positions and (b) the perspective of EC participants as well as clinical ethicists [52]. Then, inductive codes were formed to reflect the content of text segments, such as sociodemographic information on the patient (factual codes) and doubts about the patient's decision-making capacity (thematic codes). These lower-level inductive codes were bundled into more abstract codes, creating a hierarchical code system. Inductive codes were characterized and delineated from similar codes in memos. MAXQDA 2022® was used to apply deductive categories, develop and apply lower-level inductive codes, extract coded passages for identification of higher-level inductive codes, characterize inductive codes in memos, and extract code frequencies.

While the number of available EC documentation was limited, the documentations pertaining to the last five patients did not contribute new aspects. Thus, data saturation seems to have been achieved as defined by Saunders et al. [53]. The quality of the code system was ensured by consensual coding [50]. Five documentations (EC11_1 to EC15_1) were coded independently by SRT. Ambiguities, inconsistencies, and discrepancies were detected and resolved through discussion between the coders [ALW and SRT] and the method consultant [SW] and incorporated into the code memos.

As units of analysis, cases instead of documents were used since, in the cases with several ECs, these were close together in time (intervals ranged from eight days to under eight months) and referenced each other, reflecting an ongoing deliberation process. Coding and analysis were conducted in the original language (German), with the findings being translated into English by ALW and the quality of the translations being checked by MT. To improve readability, everything is reported in the simple past, regardless of the temporal context of the respective EC (that is, regardless of whether the EC was pro- or retrospective). Reporting follows the standards for reporting qualitative research (SRQR; [54]) where applicable.

Findings

The search yielded 19 documentations concerning 14 different patients, corresponding to 5.7% of all ECs documented in the study period. Two of these documentations reported brief and 17 full ECs (as differentiated by Tapper et al. [49]) with at least one full EC reported per patient (see supplementary material S1). The brief ECs were telephone or email conversations between a healthcare professional and a clinical ethicist, and the full ECs were face-to-face or virtual meetings of several healthcare professionals and two or more clinical ethicists. Relatives participated in three of the full ECs, while patients participated in none. In total, the documented ECs had 130 participants (with several persons participating in

Table 1 Metadata on the full ECs included in the analysis

requester	count	13 different requesters from 7 different institutions
	profession	9 physicians 2 psychologists (1 relative)
	medical specialty	8 mental healthcare 2 pediatrics 1 internal medicine 1 oral and maxillofacial surgery
	work setting	9 university hospital 1 general hospital 2 private practice
participants	count	Median = 9 participants (range [3; 12])
	professions	Median = 3 different professions (range [1; 6])
	medical specialties	Median = 2 different medical specialties (range [1; 3])
	institutions	Median = 2 different institutions (range [1; 5])
EC	duration	Median = 85 min (range [30; 135])
protocol	Word count	Median = 2123 words (range [530; 3368])

Notes: The specialty "mental healthcare" comprises psychiatry including child and adolescent psychiatry, psychosomatic medicine, and clinical psychology. EC = ethics consultation

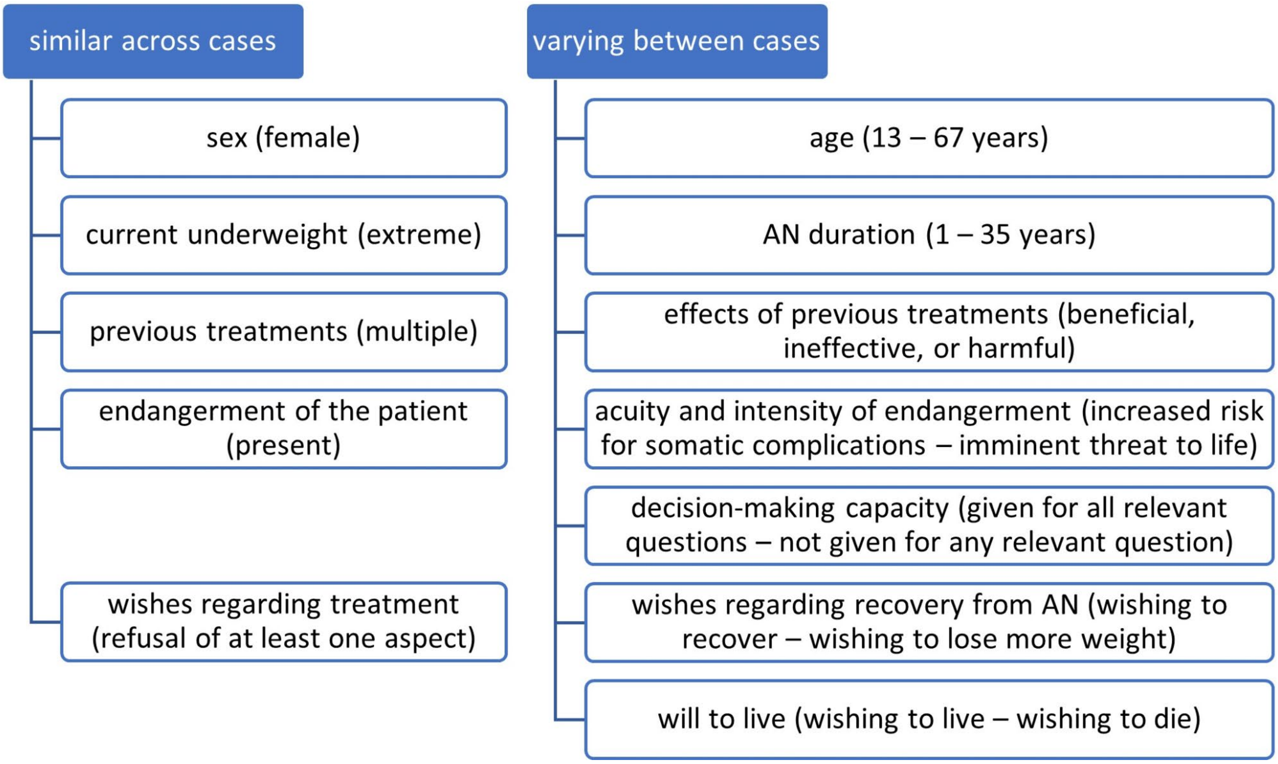

Fig. 1 Characteristics of patients and their history

Some characteristics of the patients and their histories were similar across cases (that is, the same or similar in at least 12 cases), while others varied widely. For the variable characteristics, the range of expressions is given in brackets. A detailed description of the characteristics of the patients and their history can be found in supplementary material S2

more than one EC). Fifteen documentations related to pro- and one to a retrospective EC, with three relating to ECs with both retro- and prospective ethical concerns. Metadata on the full ECs are given in Table 1.

The ECs typically concerned an intensely pretreated, currently extremely underweight anorexia nervosa (AN) patient who was seen as endangering herself by refusing the proposed treatment. Other characteristics of the patients and their histories varied widely between cases (see Fig. 1 for an overview and supplementary material S2 for a detailed description).

Ethical concerns

Ethical concerns were cited by the EC requesters as reasons for requesting CESS, voiced by other participants during the EC as morally problematic, and/or identified by the clinical ethicists. Per case, three to 13 different ethical concerns were identified with a median of eight. They related to suffering and endangerment of the patient, patient wishes, decision-making capacity, surrogate decision-makers, and current treatment (see Fig. 2).

In all cases, ethical concerns included **self-endangerment of the patient**. This was mainly due to her refusing treatment (11 cases) such as tube feeding (EC5_1) or hospitalization (EC9_1), and posed either an increased risk for somatic complications (e.g. an underweight patient refusing routine medical check-ups; EC3_2) or an acute danger to life (e.g. significantly elevated heart enzymes due to severe iron deficiency anemia combined with excessive exertion; EC9_1). **Unclear or contentious patient wishes** caused ethical concern in three cases (e.g. EC7_1) and **doubtful or contentious decision-making capacity** in five cases (e.g. EC6_3, EC9_1). Ethical concerns regarding **surrogate decision-makers** comprised lack of cooperation such as refusing consent to the proposed treatment and questionable suitability for the task (e.g. EC5_1).

In all cases, ethical concerns included doubts concerning current treatment. **Appropriate treatment seemed impossible** in five cases due to lack of resources (e.g.

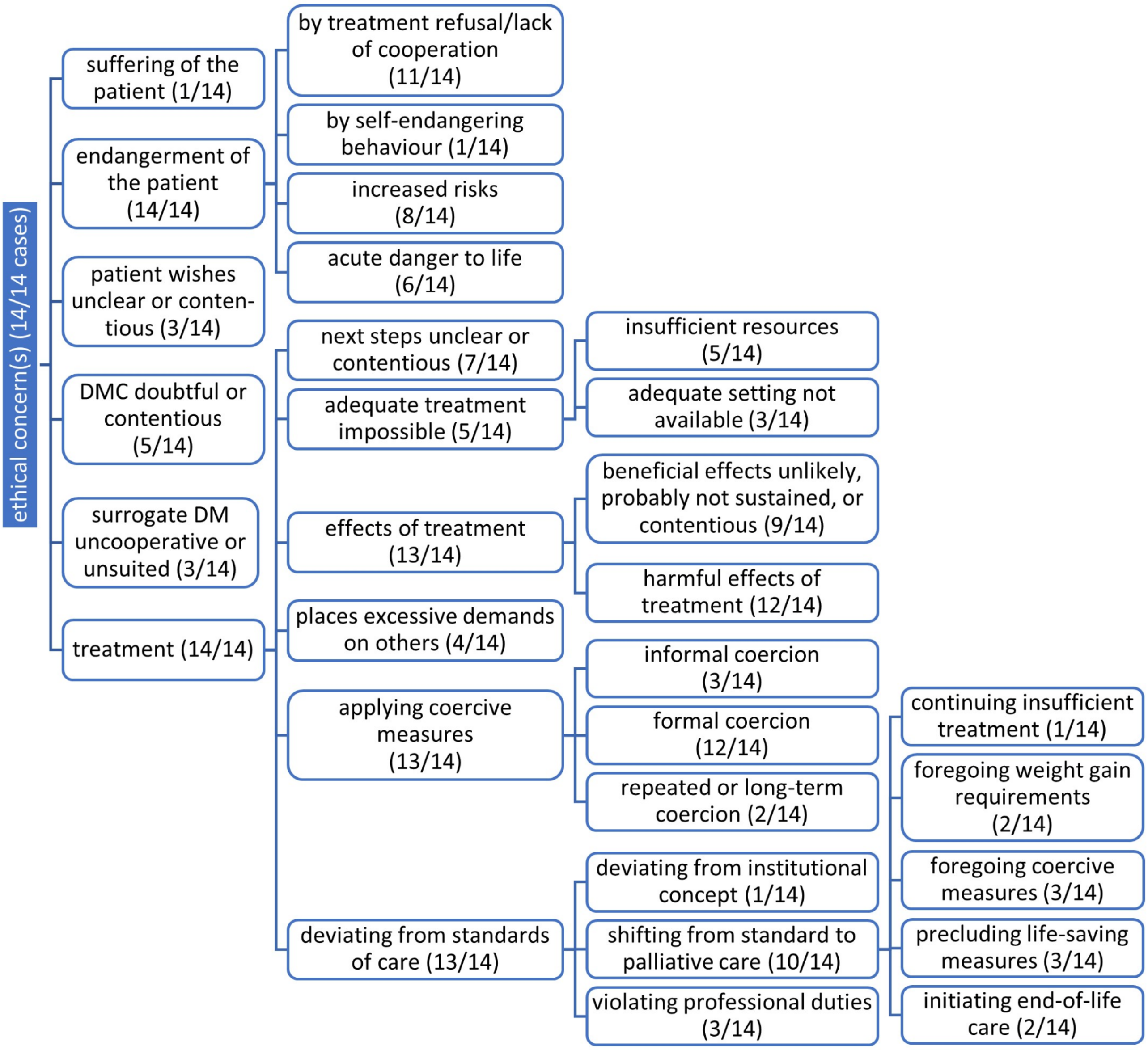

Fig. 2 Ethical concerns in caring for persons with AN

Frequencies of ethical concerns are presented as being present in x out of the 14 cases analyzed. DM = decision maker, DMC = decision-making capacity insufficient time for nursing; EC12_1) or the unavailability of a specialized setting (e.g. a closed ward offering both acute psychiatric and medical care; EC7_1). Treatment seemed to place **excessive demands on others** in four cases (e.g. nursing staff being repeatedly spat at; EC7_1). In nine cases, participants were **uncertain whether further treatment aiming at symptom reduction would be effective** (e.g. EC1_1), including whether potential treatment effects would be sustained after discharge. They wondered whether they should **use coercion**, either informal (e.g. pressuring a patient into coming to the emergency department; EC5_1), formal and/or repeated (e.g. repeatedly restraining a patient to tube feed her; EC7_1), but worried that **coerced treatment might be harmful** (e.g. by putting strain on the therapeutic relationship; EC8_1). In most cases, EC participants also pondered **deviating from standards of care** such as professional duties (e.g. violating the duty of veracity by withholding the information that a coercive measure was being planned; EC11_1) or shifting from standard care (aimed at increasing weight and normalizing eating behavior) to a more palliative approach. The latter included continuing outpatient psychotherapy although it was deemed insufficient for weight gain (e.g. EC8_1), not requiring a commitment to weight gain for the patient to access psychotherapy (e.g. EC3_2), foregoing coercion because of an unfavorable benefit/burden ratio (e.g. EC12_1), precluding life-saving measures (e.g. granting a patient request for do not attempt to resuscitate status; EC2_1), and initiating end-of-life care (e.g. referring the patient to hospice care; EC10_1).

Analysis of ethical concerns

Analyzing these ethical concerns through the normative framework of principlism [17] revealed a diverse set of nine conflicts between or uncertainties about ethical principles (three to seven per case; see supplementary material S3 for a complete description). These were centered around the principle of beneficence (see Fig. 3). A **conflict between beneficence and respect for autonomy** (13/14 cases) arose from the question of whether to accept a treatment refusal or use coercion to prevent serious harm. In nine of these cases, the conflict was further complicated by uncertainty. **Uncertainty about (respect for) autonomy** stemmed from doubts regarding patient wishes, decision-making capacity, or substitute decision-makers, or from a conflict between respecting current autonomy (and thus, the treatment refusal) and respecting future autonomy (and thus coercing treatment aimed at improving the capacity for autonomous decision-making). **Uncertainty about beneficence** (12/14 cases) was, for example, evidenced in concerns that appropriate treatment was not possible or lacked effectiveness and in deliberations regarding whether deviating from standards of care might be more beneficial to the patient. Equally frequent were concerns about harmful effects of treatment such as pain or traumatization (11/14 cases), representing **uncertainty about non-maleficence**. Taken together, these concerns led EC participants to worry that further treatment aiming at symptom reduction might result in more harm than benefit (11/14 cases), showing a conflict between **beneficence and non-maleficence**.

Discussion

The ethics consultations (ECs) analyzed here typically concerned an intensely pretreated, currently extremely underweight anorexia nervosa (AN) patient who was seen as endangering herself by refusing the proposed treatment. The clinical situations giving rise to the EC requests were further complicated by uncertainty about patients' wishes and decision-making capacity.

These challenging situations gave rise to several ethical concerns per case, the analysis of which revealed nine different types of conflicts between or uncertainties about ethical principles. In addition to the question of whether to use coercion to prevent serious complications from AN (representing a conflict between respect for autonomy and beneficence), EC participants frequently wondered whether further treatment aimed at symptom reduction had an acceptable chance of success, might engender harm, and/or might result in more harm than benefit (representing uncertainty about beneficence, non-maleficence, and a conflict between these principles, respectively; see also Fig. 3). This reflects the lack of empirical evidence on the long-term effects of treatment for AN, especially coerced treatment in persons with longstanding AN [55], as well as the lack of established staging models and validated prognostication tools for AN [56]. On the normative level, this begs the question of how to incorporate the uncertainty of prognoses into ethical reasoning.

Regarding the present study, the major finding is that ethical concerns in AN are too complex and diverse to be subsumed under "conflict between respect for autonomy and beneficence". Rather, the participants of the ECs analyzed here frequently pondered the question of whether to use coercion to prevent severe complications and death from AN *although this might result in more harm than benefit* or accept a treatment refusal and the associated risks for the patient. This displays a three-way conflict between beneficence, non-maleficence, and respect for autonomy, further complicated by uncertainty about these principles.

The importance of considering the principle of non-maleficence in caring for persons with AN has been underscored by recent ethical justifications of harm reduction approaches for adults [57] and adolescents with AN [58]. However, it has been argued that harm

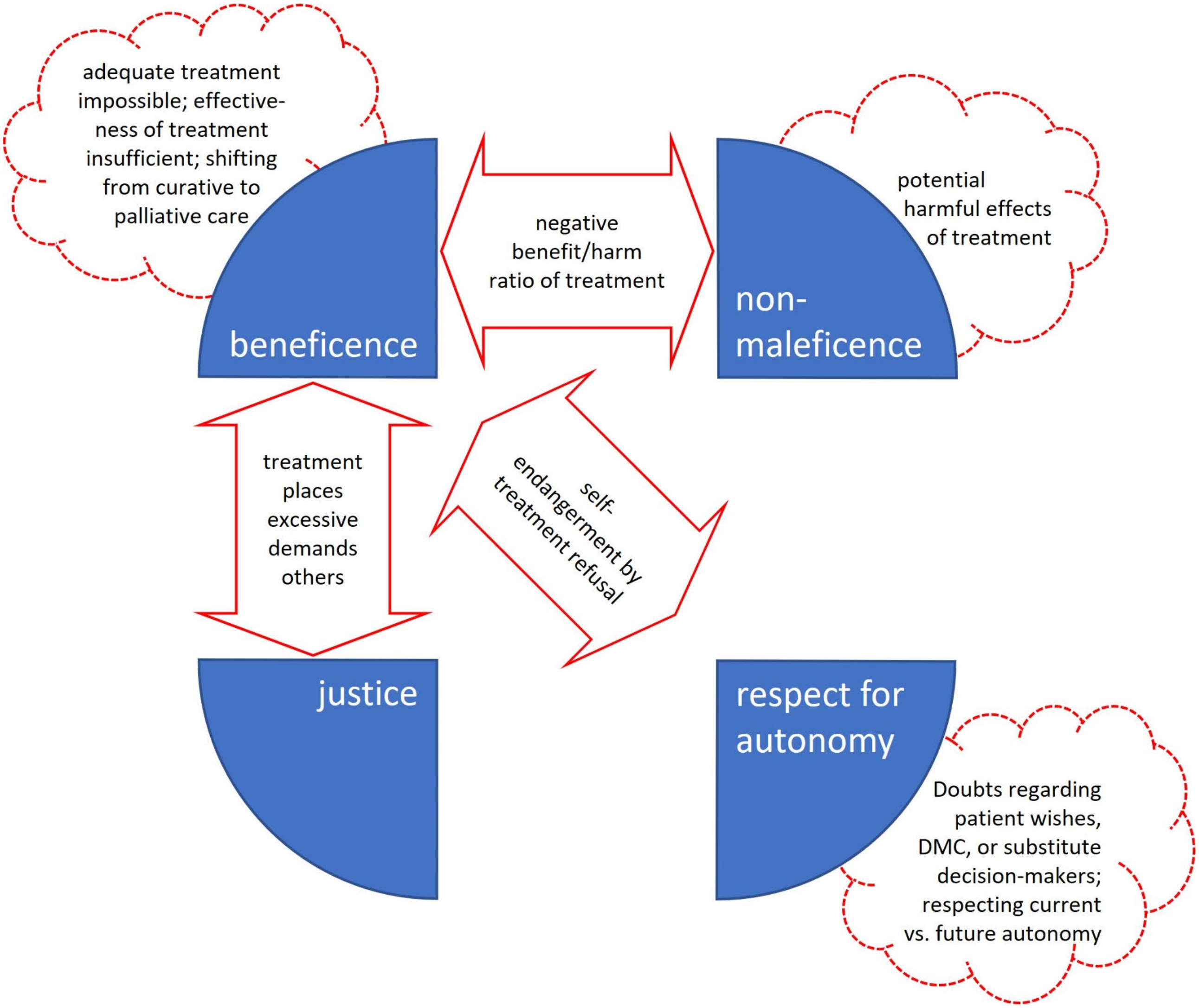

Fig. 3 Analysis of ethical concerns in caring for persons with AN
Conflicts between ethical principles are shown as two-headed arrows, and uncertainty regarding principles as clouds. The text in the arrows and clouds summarizes the main ethical concerns pertaining to this conflict or uncertainty about principles. For ease of reading, only conflicts/uncertainties conveyed in more than two cases are shown (see supplementary material S3 for a complete overview of the analysis of ethical concerns). DMC = decision-making capacity

reduction alone is insufficient to attend to the needs of all patients with AN, especially those with severe and longstanding forms [27]. In line with this, while some of the options discussed in the ECs analyzed here could be subsumed under harm reduction (e.g. forgoing weight gain requirements for psychotherapy, forgoing coercion despite endangerment), others went beyond what is generally considered harm reduction and constituted end-of-life care (e.g. precluding life-saving measures, initiating end-of-life care). End-of-life care for AN is a controversial and complex issue. A recent review revealed two reasons for this, namely that (a) conceptualizations of key terms such as futility are heterogenous, often value-laden and circular and that (b) fundamental normative questions remain open such as the appropriateness of diagnosis-based ethico-legal exceptionalism [59]. Reflecting this complexity, the appropriateness of any non-curative approach was itself an ethical concern in the ECs analyzed here, representing uncertainty about whether the principles of beneficence and non-maleficence could not be best served by deviating from standards of care. Currently, healthcare professionals are left with little guidance regarding this question, which likely adds to their moral distress and may negatively affect patient care. Preliminary guidance on how to reflect on instances of possible futility in mental healthcare has been published [60], but much work is left to be done.

In addition, more research is needed to establish reliable procedures for assessing decision-making capacity in AN, develop and establish staging models and prognostication tools, and characterize alternative options for caring for persons with AN. On this basis, healthcare professionals and clinical ethicists could be provided with improved recommendations and guidelines for ethical decision making in these highly complex clinical situations.

Strengths and biases

Although it constitutes the greatest number of clinical ethics cases in the context of AN published thus far, the number of cases included in the study is modest. This may be due to (a) the low prevalence of eating disorders, especially severe eating disorders and (b) a program for the treatment of severe eating disorders being established in one of the hospital serviced by the CESS only in the last years of the study period. However, as saturation was achieved during coding, we are confident that the findings show most ethical concerns of healthcare professionals caring for persons with AN in Switzerland.

It is possible that some ECs, especially brief ECs by telephone, were not documented, e.g. due to time constraints, and are thus lost for analysis (so-called biased selectivity of document analysis [42]). Additionally, EC participants were largely self-selected, which is why this study cannot capture the ethical concerns of persons not attending an EC, e.g. due to negative expectations of clinical ethics support. The self-selection of participants may be compensated for by the diversity of EC requesters and participants, contributing opinions and attitudes from different professions, specialties, and institutions. Also, the design of this study (retrospective document analysis) speaks to its **confirmability**, as the behavior of neither EC participants nor CESS members could have been influenced by knowledge about the study or its aims [42].

This study analyzes not ECs themselves, but heavily pre-structured and selective routine documentations from a single CESS. Therefore, the type and extent of information given on cases varied and some potentially relevant aspects could not be reconstructed (e.g. how decision-making capacity was assessed specifically in each case or who brought forward which ethical concern). In addition, the coding focused on ethical concerns, largely disregarding equally important psychosocial aspects (e.g. communication between patients and healthcare professionals) and legal aspects (e.g. Swiss guardianship jurisdiction).

The **transferability** of the findings is limited by the study analyzing only documentations from a single CESS operating with a single ethical framework (principlism) and servicing mainly healthcare professionals working at a single level of care (tertiary) in a single healthcare system (Switzerland). Clinical ethics support based on a different ethical framework is likely to bring forward different concerns, as is caring for persons with AN at other levels of care and in other systems, e.g. without universal healthcare coverage. This is evidenced by a study of predominantly US psychologists working with outpatients that found ethical concerns mainly relating to access to appropriate, affordable, evidence-based healthcare [61]. In addition, as only few informal caregivers and no patients took part in the ECs analyzed here, the findings are likely not transferable to these stakeholders. Lack of participation of patients and/or persons with lived experience of AN likely promoted a biomedical view of patients and their AN, reducing the appreciation of sociocultural determinants of incompetence judgements as well as treatment refusals [62].

For an even more detailed picture, ethnographic studies focusing not only on the EC but also on the interactions leading up to the request for (or a decision against) an EC would be needed. Such a study could also explore whether EC participants' profession or hierarchical position is associated with their position on ethical concerns.

Conclusions

Ethical concerns in caring for persons with AN are diverse and complex. To deal with uncertainty about and conflict between respect for autonomy, beneficence and non-maleficence, healthcare professionals consider non-curative approaches. However, currently, uncertainty around general justifiability, eligibility criteria, and concrete protocols hinders their adoption.

Abbreviations

AN	Anorexia nervosa
CESS	Clinical ethics support service
DMC	Decision-making capacity
EC	Ethics consultation

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

Supplementary Material 5

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Author contributions

SRT, MT, and ALW designed the study. ALW coded and analyzed the data unter methodological supervision from SW. ALW drafted the manuscript, and SW, SRT, and MT revised it for important intellectual content. All authors read and approved the final version.

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Data availability
The datasets supporting the conclusions of this article cannot be made available as they are part of patients' electronic health records.

Declarations

Ethics approval
Prior to the start of this study, its design was positively evaluated by the internal review board of the University of Zürich (CEBES 2021-04).

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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