

Ethical Aspects of Artificially Administered Nutrition and Hydration: An ASPEN Position Paper

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Abstract

The American Society for Parenteral and Enteral Nutrition (ASPEN) Position Paper focus is on applying the 4 ethical principles for clinician's decision-making in the use of artificially administered nutrition and hydration (AANH) for adult and pediatric patients. These basic principles are (1) autonomy, respect the patient's healthcare preferences; (2) beneficence, provide healthcare in the best interest of the patient; (3) nonmaleficence, do no harm; and (4) justice, provide all individuals a fair and appropriate distribution of healthcare resources. Preventing and resolving ethical dilemmas is addressed, with an emphasis on a collaborative, interdisciplinary approach. Optimizing early communication and promoting advance care planning, involving completion of an advance directive, including designation of a surrogate decision-maker, are encouraged. Clinicians achieve respect for autonomy when they incorporate the patient, family, community, country, geographical, and presumed cultural values and religious belief considerations into ethical decision-making for adults and children with a shared decision-making process. These discussions should be guided by the 4 ethical principles. Hospital committees and teams, limited-time trials, clinician obligation with conflicts, and forgoing of AANH are addressed. Specific patient conditions are addressed because of the concern for potential ethical issues: coma, decreased consciousness, and dementia; advanced dementia; cancer; eating disorders; and end-stage disease/terminal illness. Incorporated in the Position Paper are ethical decisions during a pandemic and a legal summary involving ethical issues. International authors presented the similarities and differences within their own country or region and compared them with the US perspective. (*Nutr Clin Pract.* 2021;0:1–14)

Keywords

enteral nutrition; ethics; nutrition support; parenteral nutrition

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Introduction

Position Papers provide the opinions, guidance, and recommendations of a group or organization based on a consensus. The focus in developing a Position Paper is on the interest of the patient and best practice using evidence-based medicine (EBM), expert opinion, and clinical experience current at the time of development.

Purpose

The purpose of this Position Paper is to provide statements on the major ethical and legal issues related to the use of artificially administered nutrition and hydration (AANH) in adult and pediatric patients. This serves to provide guidance for clinicians to assist patients and families or surrogate decision-makers (SDMs) confronted with ethical dilemmas and to direct readers to additional references for further study. The paper is organized initially with the purpose, background, and intended readership preceding the American Society for Parenteral and Enteral Nutrition (ASPEN) Position Paper statements. The paper addresses specific patient conditions because of the concern for potential ethical issues: coma, decreased consciousness, and dementia; advanced dementia (AD); cancer; eating disorders; and end-stage disease/terminal illness. The Position Paper underscores the focus on providing care based on the patient's preferences, quality-of-life (QOL) goals, and best interests, using EBM. Emphasized is the importance of cultural values, religious beliefs, ethnic background, country, region, and geographical considerations for decisions of patients and families or SDMs regarding the provision of AANH. The Position Paper presents a summary of key legal cases and rulings and outlines major ethical principles and theories, which provide the framework within contemporary clinical decisions about AANH. Finally, 4 additional sections since the original 2010 ASPEN Ethics Position Paper¹ are included, dealing with cancer and AANH, eating disorders and AANH, ethics during a pandemic, and an international perspective on ethics.

Background

ASPEN is an organization comprising healthcare professionals who represent the disciplines of medicine, nursing, pharmacy, dietetics, and nutrition science. The mission of ASPEN is to improve patient care by advancing the science and practice of clinical nutrition and metabolism. ASPEN vigorously works to support quality patient care, education, and research in the fields of nutrition and metabolic support in all healthcare settings. Under the guidance of the ASPEN Board of Directors, the ASPEN Ethics Position Paper Task Force¹ in 2010 developed the

original recommendations based upon general conclusions of experienced healthcare professionals working in the field of nutrition support and ethicists and as an extension of previously published guidelines. The task force, in developing such a position, balanced potential benefits to be derived from a particular mode of nutrition support therapy against inherent burdens/risks associated with such therapy within an overall framework of ethical principles and values.

The original Position Paper¹ is being updated by the ASPEN International Clinical (IC) Ethics Position Paper Update Workgroup, with the approval of the ASPEN Board of Directors. The ASPEN IC Ethics Section was created in 2013. The Position Paper is intended to supplement, but not replace, professional training and judgment and will include information dealing with the ethical decisions during the coronavirus disease 2019 (COVID-19) pandemic and an international perspective on ethics.

These recommendations do not constitute medical or other professional advice and should not be taken as such. To the extent that the information published herein may be used to assist in the care of patients, this is the result of the sole professional judgment of the attending healthcare professional, whose judgment is the primary component of quality medical care. The information presented in these recommendations is not a substitute for the exercise of such judgment by the healthcare professional. Circumstances in clinical settings and patient indications may require actions different from those recommended in this document, and in those cases, the judgment of the treating professional should prevail.

Intended Readership and How to Use This Document

Although this document will be useful to a wide variety of stakeholders, the intended users of this Position Paper are clinicians caring for adult and pediatric patients and families or SDMs faced with ethical and legal concerns involving AANH. This Position Paper is intended to update and replace the previous ASPEN Ethics Position Paper.¹ The Position Paper is not intended to be a full review of the clinical or even ethical and legal aspects of AANH or the medical disorders for which it is commonly utilized. This paper contains the major ethical positions of ASPEN regarding a variety of clinical situations concerning AANH, considerations during a pandemic, and an international perspective. Extended discussions of particular areas and additional reference material are available on the ASPEN website at https://www.nutritioncare.org/Guidelines_and_Clinical_Resources/Nutrition_Support_and_Ethics_Resources/.

Table 1. Acronyms Used in Document.

Acronym	Definition
AANH	artificially administered nutrition and hydration
ACP	advance care planning
AD	advanced dementia
APP	American Academy of Pediatrics
ASPEN	American Society for Parenteral and Enteral Nutrition
CAPTA	Child Abuse Prevention and Treatment Act
COVID-19	coronavirus disease 2019 (SARS-CoV-2)
DoC	disorder of consciousness
EBM	evidence-based medicine
EN	enteral nutrition
EOL	end of life
ESPEN	European Society for Clinical Nutrition and Metabolism
IC	international clinical
MCS	minimally conscious state
PN	parenteral nutrition
PVS	persistent vegetative state
QOL	quality of life
SDM	surrogate decision-maker
VS	chronic vegetative state

Definitions and Acronyms

Definitions of ethical terms can be found in a glossary on the ethics position portion of our website (www.nutritioncare.org) and should be used in conjunction with the “2018 Definition of Terms, Style and Conventions Used in ASPEN Board of Directors-Approved Documents,” which can also be found on the website (www.nutritioncare.org/Guidelines_and_Clinical_Resources/Clinical_Practice_Library/Special_Reports/).

Acronyms used in the paper are listed in Table 1. In this Position Paper, the reason for the insertion of the word “administered” in AANH is that it is important to recognize the route is artificial, not the nutrition or hydration. Other organizations from 2014 to 2020 have used different terms before the words “nutrition and hydration” to clarify the concept, including “medically administered,” “medically assisted,” “medically provided,” or “clinically-assisted.”²⁻⁶ Also, it is important to note that combining EN and PN with 1 term for ethical and legal issues does not necessarily mean that the benefits vs burdens/risks are of equal value. These concepts are beyond the scope of this paper. The intent is to provide a term that differentiates the delivery of fluids/nutrients by mouth into the person’s body vs administration by a tube or a catheter.

ASPEN Position Statements

1. Artificial nutrition and hydration is a medical treatment. The word “administered” in artificially

- administered nutrition and hydration clarifies the route is artificial, not the nutrition or hydration.
2. The 4 ethical principles of autonomy, beneficence, nonmaleficence, and justice should be equally applied to patient care.
3. Advance care planning (ACP) with establishment of an advance directive, including designation of an SDM, is recommended.
4. The cultural values, religious beliefs, ethnic background, country, region, and geographical considerations of patients and families need to be respected to the extent that they are consistent with the ethical principles and duties and legal requirements.
5. The use of interdisciplinary committees and teams and meetings with the patient and family or SDM is recommended for AANH discussions.
6. A surrogate committee should be created from bioethics committee members to perform an advisory role upon request for an *unrepresented* patient, without an advance directive or clear preferences or a designated SDM.
7. Limited-time trials are an acceptable alternative when the benefits of AANH are questionable and when the trial nature of AANH is communicated and agreed upon by the patient and family or SDM prior to its initiation.
8. Clinicians should not be ethically obligated to offer AANH if, in their clinical judgment, there is not adequate evidence for the therapy or if the burden/risk of the intervention far outweighs its benefit.

9. From a scientific, ethical, and legal perspective, there should be no difference between withholding and withdrawing of AANH; the term for both is “forgoing.”
10. If unable to resolve conflicts, despite an ethics consult, consultation with another provider and/or institution should be considered. Thereafter, if necessary, an orderly transfer of care is recommended to a qualified and willing clinician and/or institution, and care includes ensuring that these persons do not feel abandoned.
11. Scientific evidence related to the physiology of patients with brain death, in a coma, or in a previously referred to persistent vegetative state (PVS) indicates these patients do not experience thirst or hunger and, therefore, may not suffer.
12. AANH neither stops dementia disease progression nor prevents imminent death, and the decision to forgo EN in end-stage illness is supported by current scientific evidence.
13. For individuals with cancer, use of a patient-centered communication style—if the patient, family, or SDM desires—incorporates a shared decision-making process. Conflicts between the clinician obligations and the patient’s preferences involving AANH use should be acknowledged and evaluated on a case-by-case basis.
14. There is a delicate balance in treating eating disorders when AANH becomes a nonnegotiable aspect of an individual’s treatment, and AANH may be required when nutrition rehabilitation involves reversing the effects of life-threatening malnutrition.
15. For persons at the end of life (EOL), their preferences/QOL goals with acceptance or refusal of modified-consistency food and fluids provided orally or AANH must be respected.
16. Institutions should establish triage committees and develop protocols based on an ethical framework for the management of limited resources during pandemics in order to avoid perceptions/charges of inconsistent decision-making.
17. Forgoing AANH in infants and children at the EOL may be ethically acceptable when competent parents and the medical team concur that the intervention no longer confers a benefit to the child or creates a burden that cannot be justified.
18. The particular laws of state and national governments have to be considered when addressing whether or how to use AANH at the EOL and the role of informed consent.
19. States may apply a “clear and convincing” evidentiary standard in looking for evidence that the patient would want to forgo AANH, if the patient did not expressly give instructions on EOL preferences.
20. In the majority of cases, international ethical guidelines and practices are similar. The same is not true when considering legal mandates.

Ethical Decision-Making Background

Bioethical Theory

The term bioethics was created nearly half a century ago and, at the time, encompassed medicine, all of healthcare, and the entire field of the human life sciences. Evolving with the new field of bioethics came the term *applied ethics*, which involved the development of theory, concepts, problem identification, and conceptual clarification.⁷ The focus of today’s bioethical theory is patient care, with caring as its central element, which integrates ethical principles with clinical and technical expertise.⁸

An understanding of bioethical theory is the foundation of applying the ethical principles by clinicians to clinical practice in the majority of the world. Essentially, clinical ethics is grounded in patient-centered care with a goal to achieve healthcare that focuses on patients’ preferences for their own healthcare. Included in the goal is to use EBM that provides the most benefit with the least harm and is provided to all individuals equally.⁹

The 4 basic ethical principles are identified with the terms autonomy, beneficence, nonmaleficence, and justice. It is important for clinicians to be aware of these ethical principles and apply them in clinical practice. This application is achieved by making decisions regarding AANH based on the patient’s preferences, QOL goals, best interest using EBM, and the ideals of doing no harm and providing fairly to all patients. Autonomy refers to the right of decisionally capable adults to make decisions regarding their healthcare. Autonomy is not meant to imply that individuals can have whatever medical therapies they request, when that therapy may not be appropriate based on the trajectory of the person’s illness and may actually do harm. The intent of this ethical principle is that there is respect for the person’s preferences, that the person is fully informed of the healthcare options, and that the individual is involved in decision-making. ACP and establishment of an advance directive for all individuals 18 years or older optimize application of respect for autonomy. The advance directive should be reviewed periodically and can be changed by the individual. ACP is especially important when patients may not be able to speak for themselves at a later time in their life^{10–14} and would require an SDM to be involved in the healthcare decision process. Clinicians should determine the presence of an advance directive and review the content before providing AANH. Beneficence involves beneficial care by clinicians based on the patient’s best interest and clinical status. Nonmaleficence is based on not doing harm

to individuals. This ethical principle could involve not providing a procedure or therapy for a patient, when the burdens/risks outweigh any benefits that the individual would have received from the treatment. Justice indicates that all individuals have the right to receive healthcare that is provided fairly with the appropriate distribution of healthcare resources.

SDM

Clinicians often rely on an SDM, a relative or an individual designated in an advance directive, to make important healthcare decisions on behalf of a critically ill patient when the patient is incapacitated. Distinction should be made as to the legal authorization of the SDM between states and countries. The SDM should make decisions based on the patient's best interest, values, and preferences and not their own, using a shared decision-making process between the SDM and clinicians. Unfortunately, many individuals do not discuss their values and goals of care with their families or surrogate and complete an advance directive.^{15,16} The benefit of ACP may even extend beyond respecting an individual's preferences to also lessening the burden on the SDM, by providing early information and emotional support.^{17,18}

Considerations for Preventing and Resolving Ethical Dilemmas

Ethical dilemmas involve conflicts between clinicians and between clinicians, patients, family members, or SDMs dealing with healthcare decisions. Ethical dilemmas may be prevented and/or resolved through early optimal communication. The communication should involve balancing all opinions of the stakeholders for the individual's healthcare based on the ethical principles of autonomy, beneficence, nonmaleficence, and justice.¹⁹

Cultural Values and Religious Belief Considerations

The ethical principle of autonomy requires the clinician to be mindful of the diversity of cultural values and religious beliefs all over the world. This is important for clinicians for incorporating patients' preferences in the decision-making process. Individuals' and families' healthcare decision-making may be impacted differently within the various religions and cultures.^{19,20}

Multiple viewpoints on the use of AANH may be impacted by diversity of cultural values and religious beliefs. Resources are available to assist clinicians in learning about different cultures and religions and to enhance awareness of how these can impact ethical decision-making.^{19,21-27} Consideration of cultural values and religious beliefs impacted with COVID-19 may have increased complications around

EOL decisions and AANH. The limited presence of family members and faith leaders in the hospital setting may lead to patients feeling isolated at EOL and can impact healthcare decision-making around AANH.^{19,21,28}

Cultural values and religious beliefs include a wide range of implications that may both be new to some clinicians/teams and are imperative to gain knowledge so as to incorporate and improve decisions regarding AANH and interventions during care.¹⁹ Patients and family members may expect that the individual should at all times receive food and fluids, even if by an artificial route, as standard of care for survival. This assumption can additionally bring conflict to treatment expectations due to patient, family, community, country, geographical, and presumed or real cultural values and religious belief considerations.^{19,21} These practices and beliefs can cause ethical conflict, and the clinician should be aware of the relevance and emotional needs in providing guidance for decisions and AANH in an empathetic manner.^{19,21}

Clinicians who gather information on an individual's needs and apply this information in their decision-making should show sensitivity and respect for the individual's preferences. In instances when medical decisions conflict with an individual's preferences, the clinician has a duty to follow ethical guidelines that may be institution or state specific. Consultation for cultural values and religious belief support, an interpreter, visual information, or institution-based bioethics committee consults may additionally be necessary/offered.^{19,21,22}

Hospital Committees/Teams Addressing Ethical Dilemmas

Several interdisciplinary teams and committees are involved in preventing and resolving ethical dilemmas, including unit rounds, care teams, palliative care teams, bioethics committees, and surrogate committees.^{21,29,30} Hospital bioethics committee members include a diverse group of healthcare professionals and a community member to deal with ethical issues within the institution. The bioethics committee is responsible for consults that occur during patient care.^{21,31} A surrogate committee should be created from bioethics committee members to perform an advisory role upon request for an *unrepresented* patient, without an advance directive or clear preferences or a designated SDM. Surrogate committee decision-making ideals focus on either substituted judgment or best interest.^{21,29-32} The surrogate committee should often involve ad hoc members from different, appropriate specialties and professions (for instance, on matters involving nutrition, including a nutrition support clinician). During the team and committee meetings, it is important for the clinicians to address the ethical principles as they apply in patient care to AANH.

Limited-Time Trials, Clinician Obligation With Conflicts, and Forgoing of AANH

Despite the clinical evidence, some patients and families believe that the forgoing of AANH may inevitably result in death by starvation. For clinicians, it is advisable to administer the therapy on a trial basis, when the feasibility or efficacy of AANH is uncertain.³³ Essentially, limited-time trials may be an acceptable alternative when the benefits vs burdens/risks of AANH are uncertain or when there is a lack of consensus among the involved clinicians. However, the trial nature of the intervention and the criteria and time frame for reevaluation of the intervention should be mutually agreed-upon therapy goals with the patient and family or SDM prior to initiation of the trial.¹⁹

It is important for clinicians to know that they are not required to provide AANH if, based on their clinical judgment, there is not sufficient evidence for the therapy or if the burden/risk of the intervention outweighs its benefit. If conflict occurs between the clinicians and the decision-makers, the clinicians should seek guidance from the bioethics committee about the appropriate course of action.¹⁹

Clinicians should be aware that from a scientific, ethical, and legal perspective, there should be no difference between withholding and withdrawing of AANH.¹⁹ Basically, the end result is that the patient is without the nutrition therapy. This paper uses the term “forgoing” for both, recognizing that withdrawing is more emotionally burdensome than withholding, especially within specific cultures and religions. The decision to forgo AANH should be based on the preferences and values of the patient or authorized SDM, EBM, illness trajectory, the anticipated impact of the intervention on the disease/condition, and expected clinical outcomes. Understanding this term may help clinicians in discussions with the patient/family or SDM.

Clinicians should be aware that they have options when ethical conflicts cannot be resolved through approaches to develop a consensus among all stakeholders. If clinicians feel that they cannot in good conscience remain involved in the patient’s care, a second opinion from another provider and/or facility should be considered. An orderly transfer, if necessary, to a competent and willing clinician or institution is ethically appropriate. At no point should patients feel abandoned by their healthcare provider.¹⁹ Clinicians should reassure the patient/family or SDM that treatments may be stopped, but the individual will always receive care.

The Ethics of AANH in Specific Patient Conditions

The use of AANH may involve ethical issues in many conditions and situations. These issues may be more complex in situations such as when the patient lacks decision-making

capacity that is not likely to improve, such as in previously identified PVS or AD. However, in clinical conditions for which prognosis for QOL appears dismal, defining QOL is quite subjective.^{19,34} Ethical issues can arise when it is unclear that a diagnosis is accurate or that prognosis can be determined with confidence, which can lead to confusion or lack of consensus regarding appropriate plans or treatment goals. Challenges arise when inappropriate hope is held onto or when a situation is believed to be dire when, in fact, with appropriate treatment it may not be.^{35,36}

Coma, Decreased Consciousness, and Dementia

Instead of PVS in this paper, the updated terms of minimally conscious state (MCS) and prolonged disorders of consciousness (DoCs) will be used.^{35,36} Diagnosis of coma, decreased consciousness, and dementia in patients is not an exact science, and prognostication can be challenging, though efforts are being made to clarify diagnostics and effective therapies.³⁵ Practice Guidelines of the Dissemination and Implementation Subcommittees of the American Academy of Neurology, the American Congress of Rehabilitation Medicine, and the National Institute on Disability, Independent Living, and Rehabilitation Research³⁶ use the terms MCS and DoC. These may be more inclusive terms than dementia or vegetative state. They suggest that the term chronic vegetative state (VS) or unresponsive wakefulness syndrome should replace permanent VS, with the duration specified. Dementias or DoCs may be primary neurodegenerative disorders, eg, Alzheimer disease, Parkinson disease, chronic alcohol abuse, or infectious causes. The dementias or DoCs may be due to other conditions such as vascular disease or factors such as traumatic injury or tumors. Neuroscientific evidence suggests that patients who are comatose or in a prior noted PVS do not experience suffering from thirst or hunger, whereas patients in minimally responsive states or in whom some degree of consciousness is preserved may suffer.¹⁹ These distinctions may have clinical ethics implications for the analysis of benefits vs burdens/risks and in discussions by the clinician with the SDM. However, it should be noted that the distinction between the comatose patient and the patient in the minimally responsive state may not be clear-cut and consistent over time. For instance, when the prognosis or cognitive state is uncertain, such as early in the course of brain injury, a time-limited trial of AANH may be both clinically and ethically warranted. The goals of such a trial would need to be clear and mutually agreed upon. The trial can serve as a bridge until either recovery occurs quickly or it becomes apparent that the individual’s clinical status will not improve.³⁷

Disagreement about forgoing AANH is often caused by failure to ask the appropriate questions. These are difficult decisions and involve multiple discussions as to whether

Table 2. Recommendations for Artificially Administered Nutrition and Hydration in Patients With AD or Near End of Life³⁴.

Item	Recommendations
1	The decision to forgo EN in end-stage illness is supported by current scientific evidence.
2	AD should be seen as a terminal illness, and healthcare team members should clearly communicate this perspective to the patient's family, significant others, caregivers, and/or SDM.
3	A thorough discussion should take place with the patient, family, significant others, caregivers, and/or SDM, and the conversation should cover the most updated EBM regarding short-term and long-term benefits vs burdens/risks.
4	Alternatives such as assisted oral feeding and other innovative oral interventions should be thoroughly explored and discussed with the patient, family, significant others, caregivers, and/or SDM.
5	Autonomy of the patient or SDM should be respected. Emphasis should be placed on functional status and QOL. An essential aspect of this process involves cultural, religious, social, and emotional sensitivity to the patient's value system. A time-limited trial of nasogastric feedings may be considered if a decision to proceed in the future with a gastrostomy tube is made.
6	The final informed decision should be reached via a patient-centered approach, including family, significant others, caregivers, and/or SDM.
7	Clinicians, in both hospitals and long-term care facilities, should develop a process that is interdisciplinary, collaborative, proactive, integrated, and systematic to facilitate decision-making that engages the patient, family, significant others, caregivers, and/or SDM. The process should promote advance directives and provide healthcare based on the patient's preferences and best interest.

AD, advanced dementia; EBM, evidence-based medicine; EN, enteral nutrition; QOL, quality of life; SDM, surrogate decision-maker.

continuation of treatment without consent requires justification or whether withdrawal requires consent.^{38,39} Goals of care in agreement with an individual's cultural values and religious beliefs and appointment of an SDM during ACP are helpful for navigating care of patients exhibiting MCS and DoC.

AD

AD is a state of chronic, global, usually irreversible deterioration of cognition, motility, and dysphagia affecting primarily elderly patients. ASPEN IC Ethics Section members addressed the issue of AANH in patients with AD or near EOL in a Special Report³⁴ in 2014. In the article, the recommendations concerning gastrostomy tube placement apply to any long-term enteral access device. The recommendations are presented in Table 2.

The process should promote advance directives that provide healthcare based on the patient's preferences and best interest. PN was not mentioned in the above article but might be considered if the gastrointestinal tract was not functioning and if the PN was consistent with the patient's preferences, dependent on goals of care. However, it should be acknowledged that there is a distinction between PN and EN in terms of complication risks and adverse outcomes. PN may, therefore, be regarded as a more aggressive form of therapy, requiring more justification for its use. This viewpoint has obvious ethical implications, in both initiating and withdrawing therapy.

Ijaopo and colleagues⁴⁰ reviewed the literature from 2000 to 2019 to evaluate the burdens and perceived benefits of

EN in individuals with AD, investigating oral- vs tube-feeding outcome in individuals with AD. The authors noted that about 90% of individuals with AD suffer from eating problems. The eating issues lead to general health decline and ultimately impact the individual's physical, psychological, and economic well-being; caregivers; and the wider society. Findings from the study are presented in Table 3.

Evidence for the best EOL care in dementia is scarce; however, the number of people dying with dementia is increasing.⁴¹ Unfortunately, the capacity to make abstract decisions about future healthcare choices may be lost early in dementia. The potential loss of respect for autonomy would support the need for completing an advance directive before the development of dementia and assist caregivers and decision-makers.⁴¹

Caregivers interviewed by Zain et al⁴² reported internal conflicts regarding not feeding persons with severe dementia. The concern of the caregivers was that not feeding was causing death from starvation vs prolonging suffering in addition to external conflicts, such as when family members have conflicting opinions. Discussing alternatives such as comfort (oral) feeding may help reduce guilt by the family over not using AANH. Having objective guidelines to guide approaches to shared decision-making involving clinicians and caregivers not only can assist in establishing goals and plans but may help reduce moral distress. The information on AD is useful for clinicians addressing concerns when AANH is requested by family members or SDMs.

Table 3. Suggested Findings From EN in Individuals With AD Literature Review 2000–2019⁴⁰.

Item	Conclusions
1	EN neither stops dementia disease progression nor prevents imminent death.
2	Each decision for feeding tube placement in individuals with AD should be made on a case-by-case basis and involve an interdisciplinary team, including physicians, nurses, family, SDM, and relevant allied health professionals.
3	Careful considerations of the benefits-harm ratio should be discussed and checked with family and/or surrogate to determine whether they would be consistent with the preferences of a person with dementia.
4	Further research is required to establish whether EN of individuals with AD provides more burdens than benefits or vice versa and evaluate the impacts on QOL and survival.

AD, advanced dementia; EN, enteral nutrition; QOL, quality of life; SDM, surrogate decision-maker.

Cancer

A clear definition of ethical cancer care has become a matter of great debate with the rapidly increasing complexity of cancer treatments.⁴³ The ethical use of AANH when cancer treatments are no longer of benefit to the individual should be part of the discussion.

Many patients with terminal cancer with no possibility of cure or disease are referred to palliative care physicians for alleviation of pain and psychological distress. This step necessitates the transfer of care from the primary physician and care team to the palliative care team.⁴³ At this point, the patient may have nutrition deficits. The nutrition dilemma for decision-making becomes, do the care teams treat the ensuing malnutrition or recognize that the nutrition deficits are a component of the disease process?

In cancer care, there is use of communication between the clinician and the patient, family, or SDM, using shared decision-making. Oncologists understand that a patient may refuse therapy or a component of therapy regardless of the clinician's recommendation.⁴⁴

Cancer communication researchers have reported that most patients prefer a patient-centered communication style, which would include shared decision-making, yet a significant number prefer a doctor-centered style. No one style of decision-making should be advocated; rather, preferences should be obtained from patients. Thus, if a patient prefers not to take an active role, the patient may recommend the physician as the decision-maker.⁴⁵

Patients with cancer can disagree with their physicians on the importance ascribed to balancing QOL and aggressiveness of treatment.⁴⁵ The oncologist's primary obligation is to the best interests and well-being of patients. This includes promotion of a patient's health but also an obligation to respect the patient's individual goals and preferences for care. In addition, the physician has an obligation to avoid actions that may harm the patient.⁴⁴

Conflicts between the clinician's obligations and patient's preferences should be acknowledged and evaluated on a case-by-case basis. These conflicts may include when a

patient's preferences differ from what the physician believes will cause the patient to forgo an opportunity for benefit, if the patient requests the physician to act in a way that may bring harm, and if the patient's preferences also require inappropriate use of resources. Successfully negotiating these conflicting views requires consideration of the rights of the patient and limits of autonomy. If an informed patient refuses care and declines further follow-up, the oncologist's role is limited.⁴⁴

Eating Disorders

Eating disorders are psychiatric disorders with psychological, behavioral, emotional, and physiological characteristics involving a genetic component, with possibly lethal medical complications.^{46–48} Ethical dilemmas can occur in the treatment with nutrition therapies of individuals with eating disorders. The treatment team may encounter a variety of ethical challenges related to use of openly or concealed forced tactics for implementation of AANH. Medically necessitated refeeding may occur when nutrition rehabilitation requires reversing the effects of malnutrition.

Refeeding is recognized by law, medicine, and psychology as a necessary part of treatment for eating disorders. There is a delicate balance to improve the individual's nutrition status with refeeding as a nonnegotiable aspect of their treatment but still provide the person some form of autonomy for negotiable choices. Treatment teams deal with ethical decisions either to respect an individual's stated preference to forgo treatment or to potentially save the individual's life through forced hospitalization and/or tube feeding.⁴⁹

Dilemmas can involve weighing the ethical principles of respect for autonomy vs beneficence. Clinicians have to carefully delineate between these two ethical principles, especially when the individual's life is at stake. The delineation would include the individual's mental and behavioral functioning, cultural and spiritual needs, and a nutrition assessment to determine when beneficence is the highest priority over respect for autonomy.^{50,51}

End-Stage Disease/Terminal Illness

End-stage disease/terminal illness often results in decreased appetite or inability to tolerate or enjoy food and fluids. Patients, family members, caregivers, or SDMs may then seek options to provide AANH because of fears of starvation, weight loss, malnutrition, and dehydration. Families may express concern about their loved one starving to death without nutrition, yet individuals in the terminal phase will often deny sensations of hunger. Frequent oral care for the patient may be beneficial in alleviating the thirst sensation, if the family is concerned about hydration and the patient's presumed sensation of thirst. Discussions should be guided by the preferences of the patient and family or SDM, incorporating ethical, cultural values, and religious belief considerations; illness trajectory; and the principle to do no harm.⁵² Ultimate decisions would be the result of a shared decision-making process and reflect patient-centered care.

The decision to provide or forgo AANH can be laden with emotion for patients, as well as for families, caregivers, and SDMs. Nutrition is symbolic and deemed integral to hope and survival, and the decision to forgo it can lead to moral distress. Beliefs and attitudes about nutrition and hydration at the EOL may be rooted in religion, ethnicity, and culture.⁵³

Various professional organizations have addressed EOL and use of AANH. Principles developed in the Academy of Nutrition and Dietetics Code of Ethics were applied to ethical decisions for forgoing AANH.⁵ AANH is a medical therapy and a life-sustaining treatment vs death-delaying intervention. Essential in the communication process for decision-making is an interdisciplinary team approach, integrating person-centered, family-oriented care into practice, which requires understanding basic concepts and engaging in sensitive, compassionate conversations. For clinicians, these basic skills include cue-based patient/family discussion, ethical principles, health literacy, preventive ethics, shared decision-making, and the teach-back method of education. All individuals with the capacity to do so should have the opportunity to participate actively in their healthcare decisions at the EOL. The individual should receive medical and related social services consistent with their values, goals, and preferences and evidence-based practice. Clinicians should initiate conversations about ACP and integrate the results of these conversations in the individual's care plan.⁵

The American Medical Association Code of Medical Ethics⁵⁴ addressed key issues at the EOL, including forgoing life-sustaining treatment, which would include AANH. The document states that patients with decision-making capacity have the right to decline life-saving care; an SDM can make this decision on their behalf. The preferences documented in an advance directive should govern care decisions.

The American Nurses Association, in their position statement for adults at the EOL,⁵⁵ designated that those individuals with decision-making capacity, in collaboration with the healthcare team, are able to assess the benefits vs burdens/risks of AANH. The statement would also apply to SDMs for patients who lack capacity and includes both clinically appropriate food provided orally and nutrition through a tube. Essentially, the person's preferences of acceptance or refusal must be respected. Despite the individual being at risk for aspiration and despite the use of positional changes, slow and assisted oral feedings would be encouraged. Patients with decision-making capacity but not an SDM can make the decision to voluntarily stop eating and drinking, with the intent of hastening death, and these decisions remain even if the patient loses capacity.^{55,56}

It is the position of the Hospice and Palliative Nurses Association² that it is medically, ethically, and legally acceptable for patients with serious illness or their SDMs to choose to initiate or forgo AANH. A patient's prognosis and perception of QOL may determine the use of AANH. In hospice, when a patient is expected to have a prognosis with a short survival period, AANH may not be appropriate. If there is uncertainty about whether a patient will benefit from AANH, a time-limited trial, with specific goals of therapy, may be useful. The caregiving team should support the patient and family in creating goals for treatment; AANH can be withdrawn if it is not achieving its desired purpose^{19,33} or if it is causing harm.

Ethical Decisions During a Pandemic or in Situations of Limited Resources

Since the last publication of ASPEN's Ethics Position Paper¹ in 2010, the world has been presented with a devastating pandemic often compared to the 1918 influenza pandemic. The worldwide COVID-19 pandemic has brought to reality the potential of allocating limited resources for an increasing number of those in need. Although the rationing of ventilators in some countries may lead to more disastrous results, AANH resources may, at some point, become scarce for the population in need.

Regardless of the resources needed, an ethical framework for their allocation should be adopted by healthcare institutions. The framework should be developed with input from clinicians, ethicists, administrators, clergy, bioethics committees, legal advisors, patient representatives, and other stakeholders as needed in the particular institutions. In the early acceleration of COVID-19 cases in the US, several criteria for the development of an ethical framework were reviewed and summarized.⁵⁶ The adoption of such criteria and framework will assure a fair and an appropriate distribution process to all involved, avoiding charges of favoritism and arbitrary and capricious decisions.

The implementation or execution of the institutionally established protocols should be carried out by a triage committee or team, usually led by a physician and composed of the appropriate stakeholders, as was the case for the development of the protocols. Although the treating team provides information regarding the patient's status, prognosis regarding survival, QOL, postdischarge morbidities, etc, none of the members of the treating team should participate in the implementation. This separation of function between the treating team and the allocating of limited resources would remove a significant burden from an already stressed group. Numerous articles have been published on allocation of scarce resources during the COVID-19 pandemic⁵⁷⁻⁶² or any other similar situation.

The treating team, the bioethics committee, and the triage committee, though interdisciplinary in structure and administration/organization, should work in a transdisciplinary fashion, placing function over form. The roles are defined, but who executes those functions depends on the available individual who may be the most knowledgeable and experienced despite functioning outside traditional roles. Thus, transdisciplinary teams should work in a cross-functioning fashion.

Special Considerations for Infants and Children

Medically provided nutrition and fluids are commonly used in pediatric practice for a wide variety of both acute and chronic conditions. The provision of nutrition and fluids via medical devices is distinguished from the provision of food and liquids by mouth. In an article by Diekema and Botkin,⁶ the term *medically provided* designates nutrition and fluids administered through intravenous catheters and nasogastric, nasojejunal, and gastrostomy tubes.

Decisions related to EOL in children, especially those decisions related to feeding and fluids, evoke a wide range of emotions.⁶ Feeding is considered a basic need in the care of children both medically and socially; and, in general, the basic goal of pediatric healthcare is to support the best interest of the child.⁴ In addition, it is more controversial, since children do not always have the appropriate emotional maturity and intellectual development to make these decisions.^{4,6,63}

In general, parents are considered the ones who can determine the best interests of the child when making medical decisions.⁴ Legal consent for procedures or forgoing of medical support is given by the parent or a legally appointed surrogate.⁶³ Laws do vary between different states in the US^{4,63} and different countries.

In the US, there is a history of legal controversy related to withholding AANH from newborn infants. In 1982, Baby Doe was born with Down syndrome and esophageal atresia. The parents chose to withhold medical treatment, including AANH, based on the obstetrician's recommendations, even

though a local pediatrician and their family physician felt that the infant had a better prognosis than the obstetrician led the parents to believe. The court ruled in favor of the parent's decision, and the baby died before the case could be appealed.⁶⁴ This and other cases prompted the Department of Health and Human Services to issue a federal ruling, "Nondiscrimination on the Basis of Handicap," in 1984.⁶⁵ Congress amended the Child Abuse Prevention and Treatment Act (CAPTA) to protect the disabled infant from medical neglect based on the handicap alone. Under CAPTA, medical neglect includes "the withholding of medically indicated treatment"; nutrition and hydration are considered "medically indicated treatment." CAPTA does allow an exception for physician judgment that the treatment would "prolong dying," be "futile," or be "inhumane." Nutrition and hydration are not included in this exception.⁶

The American Academy of Pediatrics⁶⁶ (AAP) defines nutrition or hydration given through a tube or catheter as "medically provided nutrition," and it is considered a "life-sustaining medical intervention."⁴ AAP states that it is ethically justifiable to forgo medical interventions when "expected burden/risk of the intervention to the patient exceeds the potential benefit to the patient."^{6,4}

When appropriate, based on developmental capacity and level of consciousness, the child should participate in the discussions.⁶⁶ Discussions should provide the most recent medical treatments available, and prognosis needs to be clear. In the case of newborn infants when the prognosis is not clear, it may be in the best interest to start nutrition therapy until prognosis can be determined.⁴ Palliative care services can facilitate communication with the parents and caregivers and coordinate care with all the clinicians involved.⁶⁶ Ultimately, the parents will need to make an informed decision using current information and clear prognosis and considering the best interest of the child, with the support of the medical team.

Legal Summary

The particular laws of state and national governments have to be considered when addressing whether to use AANH at the EOL. Laws may change over time as governments consider the current state of science and medicine and enact legislation. Within court systems, legal precedent also evolves as particular cases with ethical issues come up for decision. In the US, one of the principles the courts rely on is the common law doctrine of informed consent, which includes the right of a competent person to refuse medical treatment.⁶⁷ This legal principle helps effectuate the ethical principle of autonomy. Courts will also look to state legislative and constitutional authority for guidance. For example, in the 1976 Quinlan case in New Jersey, the New Jersey Supreme Court evoked the US Constitution and named the right to privacy as a basis to allow cessation

of medical treatment. In this case, artificial ventilation was stopped.⁶⁸

The Cruzan case in the US is a seminal case in which the US Supreme Court squarely addressed the issue of stopping tube feeding in a patient in a PVS. Evoking the 14th Amendment Due Process Clause, the court stated that a competent person has a constitutionally protected right to refuse artificial nutrition. An individual's liberty interest must be balanced against the state's interest in preserving life. The court held that states may apply a "clear and convincing" evidentiary standard (a high legal standard) in looking for evidence that the patient would want to forgo nutrition. This was done if the patient did not expressly give instructions on EOL preferences.⁶⁷ If a patient has executed advanced instructions in the event of incapacity, some states require that directives to forgo AANH be addressed specifically.⁶⁹ So it is important for patients, caregivers, and clinicians to understand the requirements for creating and effectuating valid advance directives within a particular jurisdiction.

Taking these basic principles into consideration, clinicians must educate patients and families about the benefits vs burdens/risks of AANH so that the patient can make an informed decision about whether and under what circumstances AANH is desired. If a person becomes incapacitated because of a medical condition and cannot make healthcare decisions, clinicians would look to advance directives for previously communicated instructions. This would provide guidance as to whether life-sustaining treatments like AANH are acceptable to the patient. Likewise, if a patient has appointed an SDM, that person is entitled to a sufficient explanation of the benefits vs burdens/risks so that an informed decision may be made on the patient's behalf. Clinicians are legally bound to review and attempt to implement valid advance directives executed by patients or directives from legally appointed SDMs prior to initiating AANH. Failure to do so has resulted in lawsuits alleging battery (unlawful touching).⁷⁰ Although legislation and cases establishing legal precedents guide the courts, each case has unique facts, and laws vary in how they protect patients' rights.

International Perspective on Ethics

The international perspective regarding ethics and AANH, although slightly varied according to geography, parallels that of the US. The European Society for Clinical Nutrition and Metabolism (ESPEN)³³ in 2016 published guidelines on ethical aspects of AANH indicating the prerequisites of AANH: (1) an indication for a medical treatment; (2) the definition of a therapeutic goal to be achieved; and (3) the will of the patient and his or her informed consent. Respect for autonomy is an important focus of the guideline and, along with sensitive wording, is to be used in the

communication with patients and families. In 2020, ESPEN published guidelines on home PN that address issues around informed consent and QOL.

According to recent ESPEN guidance, nutrition therapy needs to form an integral part of the treatment of SARS-CoV-2 infection in the intensive care unit, ward, and general healthcare settings, especially for individuals who are older adults, frail, and/or comorbid.⁷² A comprehensive nutrition care plan that defines the rationale, explains the therapy, and provides suggestions for monitoring the efficacy of the plan should be developed. Involved in the process would be the interdisciplinary team together with the patient and caregiver, in order to achieve patient-centered treatment goals. The patient and/or the patient's legal representative must give fully informed consent to the treatment proposed. For palliative nutrition in late or end stages of the disease, the patient should be clearly informed about the benefits vs burdens/risks. Contraindications include patients who are not adequately informed about the aims of the nutrition therapy, its limited benefits, and potential complications. Also included in the contraindications are patients who are not informed of their predicted prognosis or of the possibility of changing/withdrawing the treatment when it becomes futile.

The Australian and New Zealand Intensive Care Society has responded to the COVID-19 pandemic by recommending an "open, transparent, reasonable decision-making process inclusive of patients, families, and staff."⁷³ Other recommendations parallel those of the US. The Australian Society for Parenteral and Enteral Nutrition has developed guidelines regarding the nutrition management for COVID-19 patients, providing evidence-based advice.⁷⁴

The Federation of Latin American Societies of Nutritional Therapy, Clinical Nutrition and Metabolism (FELANPE) published the Cartagena Declaration in 2019.⁷⁵ In this document, the 4 basic principles of bioethics are embraced. Additionally, the Cartagena Declaration stresses the recognition that nutrition care is a human right. Extrapolating from this document, it appears to support resource allocation in a fair, transparent, and consistent fashion.⁷⁶

In the United Kingdom, the British Medical Association provided Guidance Notes in April 2020,⁷⁷ recognizing the potential difficulty in providing care to existing standards during a pandemic. In addition, the document acknowledges that if resource allocation becomes necessary, prioritization and triage decisions will present challenges to healthcare professionals. The criteria for developing an ethical framework are like those of the US and other countries, eg, reasonable and based on best evidence and collaboration.

The British Association for Parenteral and Enteral Nutrition, in their *Ethical and Legal Aspects of Clinical Hydration and Nutritional Support*⁷⁸ in 2012, embraced the

concept that “health professionals have an ethical duty to recognize and treat malnutrition.” Two elements of the document differ from US laws/practices: (1) for “an incompetent adult patient the doctor undertaking care is responsible in law for any decision to withhold or withdraw treatment”; and (2) “under English law, a relative or nominated proxy cannot decide on behalf of an adult patient or override the clinician’s decision.”

In May 2020, the Joint Guidance for Decision Making in England and Wales regarding the *Clinically-Assisted Nutrition and Hydration (CANH) and Adults Who Lack the Capacity to Consent* was updated and published.³ It was endorsed by the British Medical Association, Royal College of Physicians, and the General Medical Council. Again, this updated version parallels the ethical principles and practices of other countries, including the US. Where major differences exist is in the realm of legal aspects of decision-making, particularly in the setting of a decisionally incapable individual.

The Italian National Society of Parenteral and Enteral Nutrition (Società Italiana di Nutrizione Parenterale ed Enterale [SINPE])⁷⁹ supports similar ethical principles and practices with different legal practices, as previously discussed.

In 2018, the Japan Medical Association in their *Basic Knowledge on Medical Ethics* supported the concept of respect for the will of the patients in constructing a framework among patients, their family members, and medical professionals. No statements are included that deal with the decisionally incapable individual.^{80,81}

Conclusion

Technological advances often present us with questions and challenges in the realm of ethics and law; such is the case for AANH over the past 40 years. There is a lack of parallel progress in the 3 arenas of technology (what can be done?), ethics (what should be done?), and law (what must be done?), which has been dubbed “The Troubling Trichotomy” by Barrocas.⁸² In consideration of not discounting the importance of the other 2 areas, this Position Paper deals primarily with the ethical aspects of AANH and the role of ASPEN in providing guidance and resources.

The Ethical Aspects of AANH

The ASPEN Position Paper focus is on applying the 4 ethical principles—autonomy, beneficence, nonmaleficence, and justice—for clinicians’ decision-making in the use of AANH for adult and pediatric patients. Preventing and resolving ethical dilemmas is addressed, with an emphasis on a collaborative, interdisciplinary approach. To support the process, optimizing early communication and promoting the use of advance directives and designating an SDM are encouraged.

The 20 ASPEN Ethics Position Statements are the foundation of the building blocks to apply the ethical principles with the supporting information sequentially following in the paper. Specific patient conditions are addressed because of the concern for potential ethical issues: coma, decreased consciousness, and dementia; AD; cancer; eating disorders; and end-stage disease/terminal illness. Incorporated in the Position Paper are ethical decisions during a pandemic and a legal summary involving ethical issues. International authors presented the similarities and differences within their own country or region and compared them with the US perspective.

Statement of Authorship

D. B. Schwartz, A. Barrocas, and M. P. Turon-Findley contributed to conception/design of the research; D. B. Schwartz, A. Barrocas, M. G. Annetta, K. Stratton, C. McGinnis, G. Hardy, T. Wong, D. Arenas, M. P. Turon-Findley, R. G. Kliger, K. G. Corkins, J. Mirtallo, T. Amagai, and P. Guenter contributed to acquisition, analysis, or interpretation of the data; D. B. Schwartz and A. Barrocas drafted the manuscript; D. B. Schwartz, A. Barrocas, M. G. Annetta, K. Stratton, C. McGinnis, G. Hardy, T. Wong, D. Arenas, M. P. Turon-Findley, R. G. Kliger, K. G. Corkins, J. Mirtallo, T. Amagai, and P. Guenter critically revised the manuscript; and all authors agree to be fully accountable for ensuring the integrity and accuracy of the work. All authors read and approved the final manuscript.

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