ABSTRACT

It is the position of the Academy of Nutrition and Dietetics that individuals have the right to request or refuse nutrition and hydration as medical treatment. Registered dietitians should work collaboratively as part of an interprofessional team to make recommendations on providing, withdrawing, or withholding nutrition and hydration in individual cases and serve as active members of institutional ethics committees. This practice paper provides a proactive, integrated, systematic process to implement the Academy’s position. The position and practice papers should be used together to address the history and supporting information of ethical and legal issues of feeding and hydration identified by the Academy. Elements of collaborative ethical deliberation are provided for pediatrics and adults and in different conditions. The process of ethical deliberation is presented with the roles and responsibilities of the registered dietitian and the dietetic technician, registered. Understanding the importance and applying concepts dealing with cultural values and religious diversity is necessary to integrate clinical ethics into nutrition care. Incorporating screening for quality of life goals is essential before implementing the Nutrition Care Process and improving health literacy with individual interactions. Developing institution-specific policies and procedures is necessary to accelerate the practice change with artificial nutrition, clinical ethics, and quality improvement projects to determine best practice. This paper supports the “Position of the Academy of Nutrition and Dietetics: Ethical and Legal Issues in Feeding and Hydration” published in the June 2013 issue of the Journal of the Academy of Nutrition and Dietetics.

BACKGROUND AND CODE OF ETHICS

For centuries society has viewed food/fluid as necessary to sustain life and promote healing and recovery from illness. Credentialed dietetics practitioners often encounter ethical issues regarding feeding and hydration at the end-of-life and recognize that personal desires, as well as strong cultural and religious traditions, distinguish feeding issues from medical complications.

Ethics are standards of conduct and are part of the philosophy dealing with morals or how we protect the values of society. Clinical dilemmas involving nutrition and hydration occur when ethical principles conflict. As members of the health care team, registered dietitians (RDs) and dietetic technicians, registered (DTRs) have the duty to protect life, while also recognizing the individual has the right to choose their treatment plan. American bioethics affirms the individual’s right to self-determination as the overriding principle. RDs and DTRs, as credentialed food and nutrition practitioners, agree to abide by the Academy of Nutrition and Dietetics Code of Ethics. Under responsibilities to the client, the Code of Ethics states: “the dietetics practitioner recognizes and exercises professional judgment within the limits of his or her qualifications and collaborate with others, seeks counsel, or makes referrals as appropriate. The dietetics practitioner provides sufficient information to enable clients and others to make their own informed decisions and respects the client’s right to make decisions regarding the recommended plan of care including consent, modification, or refusal.”1

INDIVIDUAL’S RIGHT IN SELF-DETERMINATION

The 1991 federal Patient Self-Determination Act requires that individuals be informed about their right to participate in health care decisions, including their right to have an advance directive.2 Individuals must not only be informed of nutrition options, but be deemed competent to make decisions. An individual is considered competent to make informed choices if they can think rationally and make voluntary decisions. The individual’s primary care physician or referral for a consult would determine competency. Advance directives such as living wills are legal documents that allow individuals to convey their decisions about end-of-life care to family, friends, and health care professionals. The living will stipulates the type of medical care the individual desires to sustain life, such as tube feedings. The durable power of attorney
for health care identifies the individual’s surrogate, who will make health care decisions when the individual is not capable. This is different from a power of attorney authorized to make financial transactions for a person. If they are considered competent, individuals may change or cancel advance directives, which reinforces the need for RDs/DTRs to develop trusting relationships with individuals under their nutritional care role. The RD/DTR team should also be cognizant of both the ethical positions of professional organizations and the institution’s policies on administering and withdrawing nutrition and hydration.

COLLABORATIVE ETHICAL DELIBERATION ELEMENTS
As a member of the interprofessional health care team, RDs and DTRs should have sufficient knowledge of clinical nutrition, moral reasoning, health care law, and institutional policy to assist the individual or surrogate in making informed decisions. Interprofessional health care teams provide comprehensive health services to patients/clients/consumers by working together collaboratively to deliver quality care. These teams are composed of members from different professions and occupations with varied and specialized knowledge and skills. The following ethical deliberation elements provide the framework for working in collaboration with the team to present recommendations to individuals.

Knowledge
- Clinical nutrition—the RD is expected to know the interface of nutrition and physiology/pathophysiology to provide informed nutritional recommendations. The DTR works under the supervision of the RD to provide support with nutrition screening and the Nutrition Care Process (NCP), as assigned by the RD.
- Cultural and religious values—the RD is expected to incorporate cultural and religious values of the individual into the decision-making process.
- Moral reasoning—all educated adults have a functional sense of morality. The use of ethical language and concepts increases the sensitivity and confidence of the RD.
- Health care law—the RD is expected to apply basic requirements, limitations, and standards established and codified in law regarding feeding.
- Institutional policy—all health care professionals are expected to know and abide by the policies of their institution as the standard of care. RDs/DTRs should be aware of policies related to nutrition, hydration, feeding, weight loss, and other relevant topics and should assist in the review and revision of pertinent policies.

Skills
- Situation analysis—evaluation of multiple sides of an issue and relevant factors that influence a situation is essential for ethical decision-making. The word discernment is often used for the process of deciding what factors are important and how each factor will be interpreted.
- Critical thinking—refers to the process of analyzing, synthesizing, and evaluating a problem in order to reach an outcome agreeable to everyone. Many viewpoints are brought into a discussion, but some reasons are more appropriate and significant than others. The RD should use the best reasons for reaching a decision in each case.
- Facilitation—the ability to enable the group to work cooperatively and effectively by keeping a discussion focused on hearing all perspectives with the goal of reaching a decision acceptable to all parties. When the discussion is not allowing all parties to participate, or when the individual’s best interests are not the focus of concern, the RD can support the ethical process by calling attention back to the goal.
- Negotiation—conflicting positions usually can be adjusted if the parties are interested in reaching a mutually satisfactory middle ground rather than “winning.” The RD can serve the process and interests of the individual by carefully watching for signs of an acceptable consensus. Stating the possible consensus is often the action that brings the conflicted parties to a shared decision.
- Communication—sharing one’s position and reasons for that position in clear, convincing, and concrete language is a skill for all health care professionals, as well as listening to the viewpoints of others.
- Ethical decision-making—the key component is focusing on the best interests of the individual while allowing every stakeholder to share in the decision. Ethics is not just about doing what the rules require, or making certain that every virtue has been acted out. Ethics involves balancing rules, goals, and virtues to achieve moral justification of decisions in the best interest of the individual. This is the task for all who participate in making choices.

Attitude
- Empathy—the ability and willingness to experience the situation from the perspective of another person.
- Patience—this attitude requires taking whatever time is necessary to be certain that the individual understands the situation and has been able to grapple with whatever
is most important from the perspective of the individual's value system.

- **Team approach**—ethics is a group effort and not the action of a single agent; all stakeholders are part of the team.

- **Comfort with uncertainty**—clinical situations are often unpredictable. The ability to function within such ambiguity is necessary in order to allow a decision to be made without certainty about its correctness or its consequences.

- **Comfort with expressed anger**—individuals and family members frequently express anger to those who represent the medical organization. Understanding the criticism without feeling defensive is an important strategy and demonstrates concern and care for the individual.

### Bioethical Principles

- **Autonomy**—respect for the autonomy of the individual is a very strong value in American culture. Competent adults with full knowledge and understanding of the information necessary to make a decision should be free to make their own choices without undue influence. There is a limit to freedom, but that limit has to be defined with each situation and ought to strongly favor the individual.

- **Non-maleficence**—this word means, “do no harm.” This is a guide to action in clinical medicine. It is the warning to take care that whatever is done to help does not also hurt the individual. Basically, the balance of help and hurt must favor helping the individual.

- **Beneficence**—taking action for the benefit of the individual is the goal of clinical decision-making; whatsoever action is taken should be the most beneficial for the individual.

- **Justice**—distributive justice is more difficult to apply in clinical medicine. Justice as “fairness” is the main formula used in clinical decision-making. The moral action is the fair action that treats each person as equal to all similar persons in similar circumstances.

### Decision-Makers

- **Competent individual**—informed and able to make his or her own health care decisions. This would be determined by the primary care physician or referral to another physician to determine competency for decision-making.

- **Surrogate**—authorized proxy to act in the person’s place when that individual loses the ability to make his or her own health care decisions.

- **Family member(s)**—implied decision-maker(s), if no formalized (documented durable power of attorney for health care) surrogate, when individual unable to make his or her own health care decisions.

Important concepts incorporating the elements of collaborative ethical deliberation are identified in Figure 1. These concepts can be applied as the RD uses the information dealing with knowledge, skills, attitude, and bioethical principles defined in the chapter in the ethical deliberation process.

### COLLABORATIVE ETHICAL DELIBERATION PROCESS

**Roles and Responsibilities of RDs and DTRs**

RDs and DTRs are the primary advocates for nutrition care. RDs are responsible for following the NCP, completing a nutrition assessment, developing interventions based on the nutrition diagnosis, and nutrition monitoring and evaluation. DTRs work under the supervision of RDs and perform the NCP steps as assigned and supervised by the RDs based on demonstrated and documented competence. RDs are ultimately responsible for the nutrition care and services of individuals in the health care setting. When conflicts and dilemmas in treatment decisions arise, there is a need for ethical deliberation. It is the responsibility of each health care professional to have sufficient experience with clinical ethics to participate in or to facilitate deliberation.

RDs food and nutrition expertise can be shared with other members of the interprofessional health care team who also address nutrition and hydration issues. RDs have a responsibility to provide education that can assist others on the interprofessional health care team become more effective in dealing with difficult and delicate issues of nutrition and hydration. The education/discussion would involve the family/surrogate if the individual is not able to be involved. A formal ethics committee, including an RD as a member is highly valuable.

RDs often have specific knowledge regarding the individual’s preference because they discuss feeding issues with the individual and family. RDs contribute the most accurate and complete interpretation of nutritional value judgments, based on understanding what individuals prefer and how they express preferences concerning feeding issues.

RDs should assume the responsibility of communicating that the individual understands options and outcomes at the center of the deliberation on nutrition therapy options. RDs should ensure that adequate information has been shared with the individual/surrogate/family so that they may make an informed decision.
1. The individual’s expressed desire for extent of medical care is a primary guide for determining the level of nutrition intervention.

2. The decision to forgo hydration or nutrition should be weighed carefully, because such a decision may result in nutrient deficits that are difficult or impossible to reverse.

3. The expected benefits, in contrast to the potential burdens, of non-oral feeding must be evaluated by the health care team and discussed with the person. The focus of care should include the individual’s physical and psychological comfort.

4. Artificial nutrition and hydration are considered medical interventions.

5. Consider whether or not nutrition, either oral or through a tube, will improve the individual’s preferred quality of life during the end-of-life period.

6. Consider whether or not nutrition, either oral or through a tube, can be expected to provide the person with emotional comfort, decreased anxiety about disease cachexia, improved self esteem with cosmetic benefits, improved interpersonal relationships, or relief of fear or abandonment.

7. If death is imminent and feeding will not alter the condition, consider whether or not artificial nutrition through tubes will be burdensome, creating discomfort for the individual.

8. When oral intake is appropriate:
   a. Oral feeding should be advocated whenever possible, based on an individual’s desire. Food and control of food intake may give comfort, pleasure and a sense of autonomy and dignity. The most important priority is to provide food according to the individual’s wishes.
   b. Efforts should be made to enhance the person’s physical and emotional enjoyment of food by encouraging staff and family assistance in feeding the individual, as needed.
   c. Nutrition supplements, including commercial products and other alternatives, may be used to encourage intake and ameliorate symptoms associated with hunger, thirst, or malnutrition, if these occur.
   d. Dietary restrictions should be individualized and/or liberalized. Coordination of medication or medication schedules with the diet should be discussed with the physician, with the objective of maximizing food choices and intake by the person.
   e. The person’s right to self-determination must be considered in determining whether to allow the individual to consume foods that are not generally permitted within the diet prescription.
   f. Suboptimal oral feedings may be more appropriate than burdensome enteral tube feedings or parenteral feedings.

9. When enteral tube feeding or parenteral feeding is being considered:
   a. The informed individual’s preference for the level of nutrition intervention is primary. The person or designated surrogate decision-maker should be advised on how to accomplish whatever feeding is desired.
   b. When palliative care is the agreed goal, consideration of use or discontinuation of artificial nutrition should be part of the discernment process, based on the informed person’s wishes, including benefit and risk burden.
   c. Feeding may not be desirable if death is expected within hours or a few days and the effects of partial dehydration or the withdrawal of nutrition support (enteral tube feeding or parenteral nutrition) will not adversely alter the individual’s comfort.
   d. Health care facilities and/or agencies should provide and distribute written protocols for the provision of and termination of enteral tube feedings and parenteral feedings. The protocols should be reviewed periodically, and revised if necessary, by the interprofessional health care team. Legal and ethical counsel, as needed, should be routinely sought during the development and interpretation of the guidelines. The health care facilities’ ethics committee, if available, should assist in establishing and implementing defined, written guidelines for a nutrition support policy. The registered dietitian should be a contributing member of the committee.
   e. Conflict within the family or among stakeholders can be resolved by referring to an ethics committee or consultant if available within the institution.
   f. The potential benefits versus burdens of enteral tube feeding or parenteral feeding should be weighed on the basis of specific facts concerning the individual’s medical and mental status, as well as on the facility’s options and limitations.

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It is the responsibility of RDs to be certain that feeding issues are deliberated in such a way that all appropriate options are considered, rather than assuming that any strategy of feeding or not feeding is obligatory. This may require opening up the subject even after the principal decision-makers have reached their conclusion. The conclusion may appear that an enteral feeding tube is the only option, when, in fact, careful oral feeding assistance may be an appropriate option for adequate nutrition.

Aspects of Withdrawal of Nutrition Support
Withdrawal of nutrition support does not mean the withdrawal of comfort measures, including pain medication, human touch, and contact. Comfort measures only, does not mean lack of care. Mettulous mouth care should be provided especially when hydration is withdrawn. If hydration is given, the least invasive route should be used.

**NUTRITION/HYDRATION DECISIONS AND GOALS THROUGHOUT THE LIFE SPAN**

**Pediatrics**
The goal of health care decisions for children is to act in their best interests. The American Academy of Pediatrics comments that institutional ethics committees should not simply be a mechanism for implementing federal regulations about treatment of disabled infants and children, but should help resolve conflicts about treatment decisions through case consultation, providing a forum for discussion of policies relating to institutional ethics, and educating their health care communities about ethical concepts.

The Committee on Bioethics of the American Academy of Pediatrics notes that there is general consensus that withholding or withdrawing medical interventions is morally permissible when requested by a competent individual or, in the case of individuals without decision-making capacity, when the interventions no longer benefit the individual or when the burdens associated with the interventions outweigh the benefits received. The report maintains that medically provided nutrition and hydration are not different from other medical interventions and they can be withheld for similar reasons. Physicians and parents are often reluctant to discontinue medically-provided nutrition, yet are willing to forgo other forms of life-sustaining treatment.
Three conditions are commonly recognized as justification for removal of nutrition and hydration: neurological devastation, proximate death from any pathology, and irreversible total intestinal failure. The aim is quality of life without rigid distinctions between curative and palliative care. The intent is not to hasten death, but to emphasize quality of life.6

Children are incapable of independent decision-making and usually have not expressed any wishes that their parents and health care providers can use when deciding about their medical treatment. Allowing parents to choose on a child’s behalf is more respectful of him or her as an individual than acting as if he or she has no interests.

The American Academy of Pediatrics’ position on the right of minors to participate in medical decisions about their care is that health care providers are ethically obligated to solicit the assent (not consent) of their minors who are capable of participating in treatment decision-making, but have not yet fully developed decisional capacity.5

Adolescents should be treated like young adults in their use of life-sustaining medical treatment. There is no ethical reason not to treat the persistently unconscious child in the same manner as an adult.

Adults

Many individuals with permanent swallowing problems or damage to the esophagus, stomach, or intestines may be able to receive long-term feeding indefinitely via the stomach or intestines. Nutrition support can prolong the lives of those with short bowel syndrome and may improve the survival of people in the acute phase of head injury or stroke and among those receiving short-term critical care.7 One evidence-based recommendation is that feeding tubes should be placed in the case of four conditions: head and neck cancer, acute stroke with dysphagia, neuromuscular dystrophy syndromes, and gastric decompression.8 Aggressive nutrition support for older adults may be appropriate when a return to prior functioning is anticipated, such as in individuals who have had surgery, trauma, a stroke, or burns, but are expected to recover.9

The Standards of Practice for Registered Dietitians in Nutrition Support and the Standards of Professional Performance for the Registered Dietitians in Nutrition Support are key resources for RD’s at all knowledge and practice levels. When RDs incorporate these standards into practice and strive to improve their competency, they are valued as effective providers of nutrition support therapy. Consequently RDs should participate in any discussion dealing with the risks and benefits of providing enteral and parenteral nutrition support.10

**HEALTH CARE GOALS IN CONDITIONS**

**Advanced Dementia**

Dementia (including Alzheimer’s) is a terminal illness similar to incurable cancer.11 Research indicates that terminal anorexia and cachexia usually accompany dementia and appear to be due largely to inflammatory cytokines.12,13 Individuals with end stage dementia normally lose interest in food/fluid, become too confused to focus on meals, may refuse to eat by turning their heads away from food or clamping their mouths shut. Numerous studies found no evidence that enteral tube feeding provides any benefit for individuals with dementia in terms of survival time, mortality risk, quality of life, nutritional parameters, physical function, or improvement or reduced incidence of pressure ulcers.8,14,15

Other studies indicate that feeding tube insertion in nursing facility residents with dementia was associated with poor survival and a significant increase in the use of health care services after insertion.16,17 Individuals with dementia and/or their families don’t always understand that dementia is a terminal illness and a tube feeding will not stop the disease progression. Rather than enteral tube feeding, the preferred intervention for providing nutrition for individuals with advanced dementia is usually total assistance with oral feedings.

**Persistent Vegetative State**

Persistent vegetative state (PVS) is a state of prolonged unresponsiveness with complete unawareness of self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of brainstem and hypothalamic autonomic functions.18 Since the individual lacks self-awareness, they do not have the capacity to suffer and would not experience distress in the dying process. PVS is considered permanent if the vegetative state persists beyond 3 months, such as an anoxic brain injury, and after 12 months if the cause is traumatic.

When PVS is declared permanent withholding and withdrawal of treatment can be discussed,19 but should be discussed throughout the hospitalization with family/surrogate decision-maker, when appropriate. Since artificially provided nutrition and hydration are considered medical treatments, they can be withheld or withdrawn if the surrogate withdraws consent, the treatment fails to deliver the intended benefit, or the treatment causes a disproportionate burden.20

**Terminally Ill Individuals**

Individuals with a terminal illness, often described as an illness with a prognosis of death in 6 months, may benefit from oral nutrition or hydration based
on their current condition. Declining food and fluid intake and unintended weight loss are a natural part of the disease progression. Individuals with a terminal illness who selected hospice services are not considered candidates for aggressive nutrition support. Potential problems associated with enteral tube feeding include aspiration, diarrhea, over hydration, discomfort, and interference with personal dignity. As the end-of-life approaches, individuals do not experience hunger or thirst. The absence of food and fluid results in ketosis and a release of opioids in the brain, which may produce a sense of euphoria. Current literature suggests that the benefits of providing artificial nutrition in cancer patient care in the last days of life are limited and do not clearly outweigh the burdens, although some effects on specific symptoms may be present in some patients. RDs should act as a primary advocates for all aspects of individuals’ nutrition care.

UNDERSTANDING CULTURAL VALUES AND RELIGIOUS DIVERSITY IN CLINICAL ETHICS

RD understanding of cultural and religious diversity in clinical ethics is important to best meet the needs of each individual. This diversity awareness provides the RD the ability to tailor information for individuals, families, and significant others that promote understanding of aggressive life-sustaining treatments, which includes artificial nutrition. There are numerous resources in the literature identifying cultural and religious diversity to help the RD understand the patient and family perspective on nutrition and hydration ethical decision-making. These perspectives are not meant to be inclusive for everyone in that religious or cultural group, but are presented to facilitate a better understanding of religious and cultural diversity in clinical ethics.

INTEGRATING QUALITY OF LIFE GOAL SCREENING INTO RD/DTR CLINICAL PRACTICE

Quality of Life Goal Screening and the NCP

Health-related quality of life (QOL) can be defined as the value assigned to the duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy. QOL is highly individual and there are high levels of variability between individuals. QOL goal screening needs to become an initial step for the RD/DTR team prior to the NCP as indicated in Figure 2. This is especially evident in practice settings where early nutrition intervention is recommended to optimize health care outcomes. Nutrition, whether provided orally or through tubes, can provide a sense of caring for the individual/surrogate/family and become more difficult to withdraw after being initiated, than to be withheld initially. The NCP is a systematic problem-solving method that RDs use to think critically and make decisions that address practice-related problems. Just as nutrition screening is done before the NCP, QOL goal screening before NCP is crucial.

This alternative health care outcome paradigm would enhance the RD/DTR’s focus to provide goal-oriented patient-centered care. The Institute of Medicine defines patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs, and values” and that ensures “that patient values guide all clinical decisions.” This definition emphasizes the importance of clinicians and individuals working together to produce the best outcomes possible, rather than a disease outcome-based paradigm.

Various sources can be used by the RD/DTR team to screen for the individual’s QOL goals to facilitate patient-centered decision-making for initiation and continued use of artificial nutrition. Figure 3 provides sources in the individual’s chart, communication with the individual/surrogate/family, and discussion with other health care professionals that could add to the screening process for QOL goals.

Acute Care Case Study

During the daily intensive care unit (ICU) interprofessional health care team rounds, the registered nurse presented the case of UO, a 65-year-old female admitted the evening before with septic shock. In addition, on admit UO exhibited the following: hypotension; severe bandemia; lactic acidosis; encephalopathy; anemia; acute renal failure on chronic renal disease; hypernatremia; intra-abdominal mass with metastases; gastric outlet obstruction, obstructive jaundice, status post biliary drain; coagulopathy; respiratory failure on ventilator; hyperglycemia; and infected dermal ulcer.

The RD indicated that the individual met criteria for severe protein calorie malnutrition and discussed with the pulmonologist, surgeon, and gastroenterologist to determine if nutrition intervention was appropriate. Post discussion with the physicians and recommendation for hospice, which was documented by the physician in the chart, the RD documented further nutrition assessment and intervention were not warranted based on the individual’s clinical status and grave prognosis. The RD documented in the electronic medical record the professionals contacted and the outcome of the discussions. Additional documentation by the RD included that the individual was to be followed on an as needed basis, as determined by the physician in conjunction with person/surrogate decision-maker wishes based on burdens versus benefits of nutrition therapy and quality of life goals. A palliative care consult was ordered by the primary care physician to provide support for the individual’s family.
In addition to the unit chaplain, a chaplain specific to the individual’s culture and faith was consulted to help meet the needs of the cultural and religious aspect of the family during this end-of-life period. The person expired the next morning with family members present.

Nursing Facility Case Study

An 85-year-old woman with a diagnosis of recent cerebral vascular accident, mild dementia, osteoporosis, hypertension, and dysphagia was admitted from an acute care to a long-term care facility. The residual from her cerebral vascular accident resulted in neuromuscular impairment and at the request of her children a gastrostomy tube was placed in the hospital, in the hope that she would be able to return to her previous condition. Prior to her stroke, the resident had stated that she didn’t want to be kept alive with a tube feeding if she couldn’t enjoy eating. As part of the NCP, the RD interviewed the resident and her husband, completed a nutrition assessment, nutrition diagnosis, and plan of care. The interprofessional health care team supported the resident and her husband’s goal to continue the tube feeding, while the RD worked with the speech language pathologist (SLP) to improve her swallowing ability. The resident’s ultimate goal was to consume an oral diet and discontinue the tube feeding. The SLP worked daily with the resident for a month using strategies to improve her swallowing function, but the resident was unable to tolerate food/fluid without aspirating.

The resident suffered a major stroke and was now unable to swallow. The SLP determined she should not consume an oral diet and the resident became depressed and stated she was ready to die. The interprofessional health care team held a conference with the resident, and her family to discuss discontinuing the tube feeding and initiating comfort care that supported her quality of life goal to die with dignity. The MD and RD comforted the family and educated them on the benefit of discontinuing the tube feeding at end-of-life. The resident died peacefully in a few weeks with her husband and family at her bedside.

Home Care/Hospice Case Study

A frail, cachectic 49-year-old man with end stage lung cancer who lived at home with a caregiver was admitted to hospice. He was on continuous oxygen, routine pain medications, and he slept most of the day. The individual continued to lose weight and was only drinking 8–10 oz of fluid daily. His caregiver expressed concern that he would die of dehydration and requested that hospice consider an intravenous fluid for hydration and an RD visit.

The hospice nurse described the detrimental effects of intravenous hydration, which could lead to vomiting and increased respiratory distress. The RD completed the NCP and collaborated with the hospice staff and caregiver to develop a routine for offering him sips of liquids or a bite.
of his favorite food, only when he was awake and willing to accept nourishment. The RD explained that when he continued refusing food/fluid or was lethargic, he might no longer be experiencing hunger or thirst, but would benefit from mouth care for his dry mouth. The caregiver understood that as his terminal illness advanced, he would not experience discomfort from the lack of hydration and nutrition, but would die comfortably.

**Pediatric Case Study**

A 4-year-old girl with a brain tumor has been treated with surgery plus several rounds of chemotherapy but her prognosis has not improved. She continues to be in severe pain and suffers from frequent seizures. Prior to her initial surgery, the RD completed the NCP and recommended enteral nutrition be implemented to supplement any oral nutrition she was able to tolerate. Following her surgery, a gastrostomy tube was placed and she received bolus feedings that the family gave her when she was able to tolerate them. The RD and the interprofessional oncology staff treating her monitored her weight and nutritional status.

When the child developed respiratory distress and was admitted to the hospital, the interprofessional oncology staff concluded that the child’s condition was terminal and the enteral feeding was not benefiting her. The RD agreed to discuss the pros and cons of artificial nutrition and hydration with the family at their meeting with the interprofessional oncology team. Following the team meeting, the family decided to discontinue the enteral feeding and requested a palliative care consult for their daughter.

**IMPROVING HEALTH LITERACY AND USING TEACH-BACK METHOD FOR ARTIFICIAL NUTRITION**

**Health Literacy**

The RD/DTR team, with nutrition therapy, represents a bridge that gives a sense of normalcy for individuals, dealing with the technology driven health care system. This journey, including artificial nutrition, may result in the individual/surrogate/family accepting therapies, such as mechanical ventilation, cardiopulmonary resuscitation, and other advanced treatments that may not be in congruency with the individual’s wishes. Use of evidence-based practice guidelines, such as from the Academy of Nutrition and Dietetics, is beneficial in providing appropriate information. RDs/DTRs need to be a part of the interprofessional health care team effort that can facilitate improved health literacy.

Health literacy is defined as the degree to which individuals obtain, process, and understand basic health information and services to make appropriate health decisions. Health literacy involves a range of social, cultural, and individual factors, and poor health literacy affects all levels of the health care experience, from individuals, to providers, to health care environments.

**Teach-Back Method**

The teach-back technique is an effective method for ensuring that individuals understand what they have been told. It involves asking the individual to explain or demonstrate what they were taught. If the individual does not explain correctly, the assumption is that the information was not presented in an understandable way. The information then would be re-taught using an alternative approach. In addition to verbal communication, readability is a significant factor affecting the potential impact of the message. A fifth-grade reading level or less is recommended for information material and has been identified as criterion for low literacy. Samples are presented in Figure 4 on how to modify common statements between health care providers to improve health literacy when presenting information to an individual/surrogate/family.

**RECOMMENDATIONS FOR DEVELOPING POLICIES AND PROCEDURES TO ACCELERATE PRACTICE CHANGE**

**Acute Care**

Development and implementation of a policy and procedure for ethical decision-making for artificial nutrition in health care facilities requires modifications indicative of the specific population, type of health care facility, cultural diversity, and religious affiliation, where applicable.
The regulations specify abnormalities, and nasal-pharyngeal ulcers and to restore pneumonia, diarrhea, vomiting, dehydration, metabolic appropriate treatment and services to prevent aspiration is fed by a naso-gastric or gastrostomy tube receives the naso-gastric tube was unavoidable; and (2) A resident who ensure that: (1) A resident who has been able to eat enough alone or with assistance is not fed by naso-gastric tube unless the resident's clinical condition demonstrates that use of a comprehensive assessment of a resident, the facility must ensure: (1) A resident who has been able to eat enough food unless the resident's condition demonstrates that use of a naso-gastric tube was unavoidable; and (2) A resident who is fed by a naso-gastric or gastrostomy tube receives the appropriate treatment and services to prevent aspiration pneumonia, diarrhea, vomiting, dehydration, metabolic abnormalities, and nasal-pharyngeal ulcers and to restore if possible, normal eating skills.” The regulations specify that residents of nursing facilities have the right to make informed decisions about feeding tube placement, the right to devise an advance directive in accordance with state law, and the right to refuse treatment. Facilities are required to inform residents and/or their health care representatives of the risks and benefits of tube feeding placement and provide the guidance needed to make an informed decision. Quality of life issues are also regulated and nursing facilities are required to follow current standards of practice to ensure the best quality of life for residents. Nursing facilities regulated by the Centers for Medicare and Medicaid Services are required to employ a qualified dietitian either full time, part time or on a consultant basis to assume the responsibility of the nutritional services. RDs should implement the Standards of Practice and Standards of Professional Practice for RDs in Extended Care Settings, which are a guide for self-evaluation and expanding practice, a means of identifying areas for professional development, and a tool for demonstrating competence in delivering nutrition care services.

Home health care agencies regulated by the Centers for Medicare and Medicaid Services are not required to employ a RD but many agencies contract RD services. Hospice delivers end-of-life care by professionals who provide medical and spiritual support. Hospice services can be provided in the individual's home, in acute or long-term care facilities and services of the RD vary with the setting.

Figure 6 provides a sample format for the RD/DTR team to develop a policy and procedure for long-term care facilities, and home care agencies to address the ethically appropriate use of artificial nutrition. The form should be modified reflective of the specific population served, type of facility, and specific regulations in addition to other parameters identified by the health care professionals.

**ROLE OF RDs AND DTRs IN DESIGNING AND IMPLEMENTING QUALITY IMPROVEMENT PROJECTS AND BENCHMARKING DATA**

A sample quality improvement project in clinical ethics and artificial nutrition would be to identify if there is adequate documentation to determine that the individual/surrogate/family have been involved in the decision-making process dealing with artificial nutrition for individuals in the ICU. Other units of the hospital or different types of health care facilities could design similar improvement projects, implement, benchmark, and share their best practice data with other health care professionals. Data would be collected to determine how...
1. Policy Statement: The interprofessional health care team provides ethically and medically appropriate artificial nutrition, based on published evidence-based guidelines and recommendations of recognized authorities. The focus of this policy is to translate these guidelines and recommendations into patient-centered clinical practice.

2. Important considerations (may include components from following the organizations and other organizations, as appropriate for the individual population)
   a. Academy Nutrition and Dietetics position paper on ethical and legal issues in feeding and hydration
   b. Academy practice paper on ethical and legal issues in feeding and hydration
   c. American Academy of Family Physicians Center
   d. American Academy of Neurology
   e. American Academy of Pediatrics Clinical Report
   f. American College of Physicians Ethics Manual
   g. American Medical Association Policy on Provision of Life-Sustaining Medical Treatment dealing with nutrition
   h. American Nurses Association
   i. American Society for Parenteral and Enteral Nutrition Ethics Position Paper

3. Procedure
   a. Collaborative effort by the interprofessional health care team to determine individual’s wishes as expressed directly and/or designated surrogate health care decision-maker when the individual is not able to express desires for health care treatments and may be used for ethically appropriate artificial nutrition.
   b. Written documentation (advance directive designating surrogate decision-maker and treatment preferences) in the individual’s medical record is encouraged throughout the health care system to help in the decision process for artificial nutrition. Within the first 24 hours clarification of surrogate decision-maker, determine if advance directive exists, copy should be placed on chart and reviewed by provider.
   c. Clinical judgment based on a collaborative effort by the health care team including the individual/surrogate/family, in conjunction with published guidelines, should be used in the process to withhold or withdrawal artificial nutrition, including registered dietitian involvement.
   d. Family care conference is recommended for individuals in the intensive care unit 5-7 days or less to address plan of care, quality of life goals and to determine decision-maker if advance directive not on chart to provide direction for treatment from individual or an appropriate surrogate decision-maker for artificial nutrition. Written documentation of family care conference discussion and decisions should be included in the medical record.
   e. Palliative care team consult is recommended early in the process to assist with clarification of quality of life goals and assist with family, including artificial nutrition. Individuals in the intensive care unit ≥3 days should be screened for support care needs by palliative care team members.
   f. Bioethics Committee consult is recommended when there is a conflict in the process to withhold or withdrawal of artificial nutrition.

4. References (sources used to develop policy and procedure)

5. Approval: Committee/Approval Date

Figure 5. Sample format for acute care artificial nutrition ethical decision-making policy and procedure. Adapted from reference 33.

many individuals receiving artificial nutrition in the ICU also have an advance directive (designating surrogate decision-maker and treatment preferences) on the chart. DTRs would be helpful in collecting the defined information, as assigned by the RD. Information could include the individual’s age, sex, religion, culture, language, presence of family, and surrogate decision-maker. Additional information might be collected on family care conferences, palliative care consults and bioethics consults during the hospitalization.

RDs could design and lead this project in collaboration with other health care team members, including physicians, nurses, pharmacists, social workers, chaplains, palliative care team members or other health care team members as appropriate. This information would serve as a baseline before implementing any processes, such as development and implementation of a policy and procedure to improve and standardize the procedures of communication between the individual/surrogate/family and health care providers on artificial nutrition. Analyzing the problems and determining the root causes of these issues would help define the improvement process and goals.

After implementing the improvement plan, re-measuring would determine if targeted goals are achieved. Indicators
would be measured periodically to assess sustainability. Incorporating a standardized process in clinical ethics and artificial nutrition could then be shared between health care facilities to benchmark best practice and translate ethical decision making for artificial nutrition into clinical practice.

ADVANCE PLANNING INITIATIVES, CAMPAIGNS, PROGRAMS, AND PROFESSIONAL TOOLS
Numerous initiatives have been developed to promote concepts that help individuals and their family better understand advance planning. Figure 7 provides resources for health care providers and the public to increase their knowledge in this important aspect of health care that would be useful when determining the appropriate use of artificial nutrition.

The American Society for Parenteral and Enteral Nutrition developed a position paper on ethics to provide a critical summary of the major ethical and legal issues related to the provision of artificial nutrition and hydration, to provide guidance for credentialed dietetics practitioners confronted with these dilemmas, and to direct readers to additional references for further study. Geppert and colleagues compiled a review of current literature to supply a framework of clinical practices, ethical principles, legal precedents, and professional guidelines that can assist decision-making regarding artificial nutrition and hydration. Schwartz identified the stakeholders and issues in changing the current health care clinical ethics model by developing a proactive, integrated, structured process for health care ethical decision-making with measurable outcomes and shared best practice.

CONCLUSIONS
This practice paper provides the application process of the position statement and position paper of the Academy of Nutrition and Dietetics for the RD/DTR for clinical practice when dealing with ethical and legal issues of feeding and hydration. Use of this practice paper is to provide the RD/DTR with a proactive, integrated, systematic process to
achieve sustainable clinical practice changes in ethical and legal issues of feeding and hydration.

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