Ethical Decisions for Withholding/Withdrawing Medically Assisted Nutrition and Hydration

For millions of Americans who work in health care, including RDNs, providing high-quality care for people who are nearing the end of life is a matter of professional commitment and responsibility. A substantial body of evidence shows that broad improvements by professional societies, health care delivery organizations, and health care professionals regarding end-of-life care are within reach. In Dying in America, a 2014 consensus report from the Institute of Medicine (IOM), there are key findings and recommendations that apply to RDN practice.

The following principles of the Code of Ethics are applicable to this discussion and should be considered when facing the withdrawal or withholding of nutrition and hydration:

Responsibilities to the Public
Principle #5: The nutrition and dietetics practitioner provides professional services with objectivity and with respect for the unique needs and values of individuals, in a manner that is sensitive to cultural differences.

Responsibilities to Clients
Principle #9: The nutrition and dietetics practitioner treats clients and patients with respect and consideration; 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.

Responsibilities to the Profession
Principle #12: The nutrition and dietetics practitioner practices dietetics based on evidence-based principles and current information.

Principle #13: The nutrition and dietetics practitioner presents reliable and substantiated information and interprets controversial information without personal bias, recognizing that legitimate differences of opinion exist.

Principle #14: The nutrition and dietetics practitioner assumes a lifelong responsibility and accountability for personal competence in practice, consistent with accepted professional standards, continually striving to increase professional knowledge and skills and to apply them in practice.

PERSON-CENTERED, FAMILY-ORIENTED CARE

Integrating person-centered, family-oriented care into RDN practice requires knowledge and application of basic skills in clinical ethics. It is crucial that the RDN understand the basic concepts and apply learned skills in order to engage in compassionate conversations regarding decisions for withholding/withdrawing medically assisted nutrition and hydration. These basic skills involve cue-based patient/family discussion, ethical principles, health literacy, preventive ethics, shared decision making, and the teach-back method of education.

The RDN understanding that these are personal topics and difficult for most people adds to the sensitivity of the conversation between the RDN and the patient, family, and/or surrogate decision maker. The Academy and A.S.P.E.N. have developed practice and position papers, ethics columns, and a special report dealing with ethical decision making for medically assisted nutrition.

Figure 1 depicts the process RDNs should use to apply the Academy/CDR Code of Ethics to ethical decisions for withholding/withdrawing medically assisted nutrition and hydration.

Development of a proactive, integrated systematic process in each
health care delivery organization to prevent ethical dilemmas should involve RDNS, including development of policies and procedures for ethical nutrition support practice and quality improvement projects in clinical ethics in nutrition support.\textsuperscript{10} RDN accountable nutrition support practice involves consideration of the therapy benefits vs burdens/risks, incorporating respect for autonomy, in an interprofessional, collaborative process.

**DYING IN AMERICA: KEY FINDINGS AND RECOMMENDATIONS**

**Delivery of Person-Centered, Family-Oriented Care**

People nearing the end of life often experience multiple transitions between health care settings and fragmented care; this can create burdens for patients and families. Palliative care is associated with a higher quality of life, including better understanding and communication, access to home care, emotional and spiritual support, well-being and dignity, decreased symptom burden, and care at time of death.

Comprehensive care should be seamless, high-quality, integrated, patient-centered, family-oriented, and consistently accessible. This care should be provided by professionals with appropriate expertise and training; and consistent with individuals’ values, goals, and informed preferences. Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed. The informed individual choices should be honored, including the right to decline medical or social services.

**Clinician—Patient Communication and Advance Care Planning**

Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about health care. Advance care planning is essential to ensure that patients receive health care reflecting their values, goals, and preferences. Frequent clinician—patient conversations are necessary to avoid unwanted
treatment. Clinicians need to initiate conversations about end-of-life care choices and strive to ensure that the patient and family decision-making is based on adequate information and understanding.

Professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning that are measurable, actionable, and evidence-based. All individuals with the capacity to do so should have the opportunity to participate actively in their health care decisions throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals, and informed preferences. Clinicians need to initiate conversations about advance care planning, integrate the results of these conversations into the ongoing care plans of patients, and communicate with other clinicians as requested by the patient.

**Professional Education and Development**

The establishment of specialty practice in hospice and palliative medicine is a major improvement in the education of health professionals. Three problems remain: 1) insufficient attention to palliative care in medical and nursing school curricula; 2) prevention of the development of interprofessional teams; and 3) deficits in equipping physicians with sufficient communication skills.

Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life. All clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management. Educational institutions and professional societies

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<tr>
<th>Code of Ethics Principles</th>
<th>RDN Basic Concepts and Skills for Person-Centered, Family-Oriented Care and Resources in Clinical Ethics</th>
<th>IOM Dying in America report Key Findings and Recommendations</th>
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<td>Provides professional services with objectives, respect for the unique needs and values of individuals.</td>
<td>Cue-based patient/family discussion, Ethical principles, Health literacy, Preventive ethics, Shared decision making, Teach-back method</td>
<td>Delivery of person-centered, family-oriented care.</td>
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**Figure 2.** Integrating Academy of Nutrition and Dietetics/Commission on Dietetic Registration Code of Ethics; registered dietitian nutritionist (RDN) basic concepts and skills of person-centered, family-oriented care and resources in clinical ethics; and Institute of Medicine (IOM) *Dying in America* report findings and recommendations.
should provide training in palliative care throughout the professional’s career.

Policies and Payment Systems
Polices and payment systems should require the use of interoperable electronic health records that incorporate advance care planning to improve communication of individuals’ wishes across time, settings, and providers, by documenting: 1) designation of a surrogate decision maker, 2) patient values and beliefs and goals for care, 3) presence of an advance directive, and 4) presence of medical orders for life-sustaining treatment for appropriate populations.

Public Education and Engagement
Public education and engagement about end-of-life care issues is needed at the societal, community/family, and individual levels. Most Americans lack knowledge about end-of-life care choices. Efforts are needed to normalize conversations about death and dying.

Professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to 1) encourage advance care planning and informed choice based on the needs and values of the individual, 2) provide evidence-based information about care options and informed decision making regarding treatment and care, and 3) dispel misinformation that may impede informed decision making and public support for the health system and policy reform regarding care near the end of life.

Health care delivery organizations should provide information and materials about care near the end of life as part of their practices to facilitate clinicians’ ongoing dialogue with patients, families, and caregivers. Health care professional societies should develop educational materials and encourage their members to engage patients and their caregivers and families in advance care planning, including end-of-life discussions and decisions. Professional societies, health care delivery organizations, and health care professionals should work collaboratively, sharing successful strategies and promising practices across organizations.

CONCLUSION
Based on the Code of Ethics for the Profession of Dietetics, the RDN should participate in ethical decisions for withholding/withdrawing medically assisted nutrition and hydration. This interprofessional process is supported by the findings and recommendations from the IOM Dying in America consensus report. Clinical practice concepts in ethics are available from the Academy of Nutrition and Dietetics and A.S.P.E.N. Figure 2 depicts the integration of the Code of Ethics, RDN concepts and resources in clinical ethics, and the IOM Dying in America report’s findings and recommendations. Decisions regarding withholding/withdrawing medically assisted nutrition and hydration should include the RDN with evidenced-based practices, involving an interprofessional health care team approach, and incorporating person-centered, family-oriented care.

References