Bioethics, End of Life, and Nutrition Support Issues

Forging New Roles for Registered Dietitians

CRM 2017 SPRING SYMPOSIUM
CLEVELAND CLINIC
BONNIE JAVUREK, MEd, RDN, LD
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Learning Objectives
Upon completion of this session, participants will:

- Develop appreciation for nutritional issues impacting End of Life (EOL) care
- Explain the bioethical principles that affect EOL decision-making
- Describe the bioethical principles employed in deciding EOL legal cases
- Apply new approaches for managing nutrition support care and EOL issues

Why Should We Care?
- Nutrition support (NS) decisions may be made without full knowledge of patient wishes and may not be fully discussed with patients and families
- There is a lack of understanding of how NS will help the patient
  At times, there are misconceptions about NS
  - Is it curative?
  - Can it appreciably extend life?
  - Does it prevent suffering?
- RDs are trained to make clear recommendations re: EN or PN but may not be included in bedside discussions or bioethical discussions
What is “Quality” EOL Care?
• Seen by many as a critical component in medical care for patients at the EOL
• Cleveland Clinic’s President and CEO, Toby Cosgrove, MD, says his view on end-of-life care has evolved since he retired from his prolific cardiothoracic surgical practice
  ➢ “For a cardiac surgeon, death is failure. We are doers. We see our job as trying to preserve life at all costs… I am still haunted to this day by some of the deaths that happened on my operating table 20 to 30 years ago.” (Cosgrove, 2016)

• Medical schools often focus on curative care
• Physicians are unwilling and/or lack skills to have discussions on EOL.
• Physicians may not be willing to give up aggressive treatments
• Collaboration with medical team, including nurses, social workers and dietitians may be non-existent
• EOL discussions may be kept quiet
• Collectively, professionals have discomfort in discussing EOL issues

Academy’s Position Paper on Ethical and Legal Issues in Nutrition, Hydration and Feeding states RDS should:
➢ Work collaboratively as part of the interdisciplinary team
➢ Have an active role in determining the nutrition and hydration requirements for individuals throughout the life span

(Journal of the Academy of Nutrition and Dietetics, 113, 2013)
How has medical care affected life expectancies?

- Americans are living longer, but face chronic conditions
- Average life-expectancies
  - 1900: was about 50 years
  - 2014: estimated as 78.8 years

Life expectancy at birth, at age 65, and at age 75, by sex, race, and Hispanic origin: United States, selected years 1900–2014

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Consider these facts...

- For much of man’s history, death was an ever-present possibility. Medicine and public health have transformed the trajectory of our lives
- In 2014, if you reached the age of 65, you would be expected to live another 19.3 years, living to 84.3 years
- If you reached 75 years in 2014, you would be expected to live another 12.1 years, living to 87.1 years of age
Patterns of Decline

- Today, people still die suddenly, but the more common trajectories of death consist of patterns of steady decline from:
  - a progressive disease, such as cancer, with a predictable "terminal phase" or
  - a slow decline with periodic crises and "sudden" death in the case of advanced illness and disabilities, such as CHF and COPD

4 theoretic functional trajectories described in the literature

- Organ failure
- Terminal illness
- Frailty
- Sudden death

Functional Decline in Organ Failure

No clear point in decline; decline appears over time
Is there a cost to the “measure and patch” system of care?

“Resuscitative measures in hospitalized patients are associated with significant morbidity, mortality and cost. The incidence of withholding and withdrawing life support has shown a significant increase over the last two decades and there is marked variability in the practice of end of life care between centers.” (Anselm, 2005)
Communication Difficulties
- Common when discussing nutrition and end of life goals
- Perceived as suboptimal despite good intentions of care providers
- Many of their findings and discussion points in Anselm's study can be applied to situations experienced by today's dietitians

Barriers to Communication
 Patients
- Exclusion by family of patients of their wishes
- Difficulty in designating a decision maker or reaching consensus
- Family tensions
- Differences in culture or values
- Variable capacity to understand and appreciate discussions
- Appropriate timing
- Temporal lability of appropriateness of resuscitation

Health Care Providers
- Inadequate expertise in prognosticating and leading discussions
- Discomfort with emotions involved
- Role ambiguity
- Prognostic uncertainty
US Health System Impact on EOL Care
- Suboptimal coordination of information exchange
- Impersonality of large teaching hospitals
- Providers unskilled in discussions as a result of specializations in certain areas
- Scheduling difficulties
- Lack of external support
- Risk of abandonment for “DNR” patients

Common Concerns for Dietitians
- Nature of “DNR” that may be perceived as nonsensical or defeatist
- Societal values surrounding death
- Lack of trust in providers’ commitment or competence
- Dietitians have their personal beliefs and values that may conflict with patient care goals
- RDs have been trained similarly from the competencies outlined in didactic and experiential programs

The Fundamental Moral Principles of Bioethics
- **Autonomy**: refers to a person’s rational capacity for self-governance or self-determination
- **Beneficence**: means that we should do good for others and avoid doing them harm by using the right actions
- **Nonmaleficence**: We should produce the most favorable balance of good over bad (or benefit over harm) for all concerned
- **Justice**: refers to people getting what is fair or what is their due
Other Guiding Principles to Consider

- Paternalism: overriding a person’s actions or decision-making for her own good
- Veracity: Truth-telling
- Informed consent: Adequate consent must be based on accurate information, include benefits and harms and probabilities of their occurrence, and information about treatment alternatives

Legal Cases Involving Withholding or Terminating Life-Sustaining Treatment and Care

Landmark judicial decisions addressing the issue of withdrawal of life-sustaining treatments have been made over the last few decades

- Decision-making capability
- Advanced directives
- Competent patient who wish to refuse treatment
- Capacity
- When the patient or family requests futile treatment

When patients lose decision-making capability:

**Schindler v. Schiavo**

- In 1990, Schiavo suffered cardiac arrest, severe hypoxia, PVS
- Husband was appointed plenary (legal) guardian
- He asked the Fla court to assess the situation and decide on continuing or discontinuing her TF
- In 2000, the judge agreed there was clear and convincing evidence that Terri met the definition of permanent unconsciousness
- The parents appealed and the case went to the appellate court
- Feedings were stopped in 2001, but restarted two days later
- Feedings were stopped again in 2002 and 9 days later the Fla governor and Fla legislature passed Terri’s Law, which deemed tube feedings a form of “medical treatment”
- In 2004, the Fla Supreme Court issued a decision that Terri’s Law was unconstitutional and a third date to discontinue feedings was set
- President George W. Bush and the US Congress attempted to intervene but were unsuccessful; the TF was discontinued
- 8 days later in March of 2005; Terri died; autopsy results confirmed irreversible PVS
Key Findings

- The Schiavo case demonstrated that the principle of autonomy and liberty of the patient prevailed.
- As legal guardian, husband was allowed final decision to stop feeding despite protests from parents.

Considerations:

1. Were her views on terminal illness expressed prior to the event?
2. Was nutrition and hydration somehow special or so basic that they must be provided even if life sustaining treatment were discontinued?
3. Is artificial nutrition and hydration (ANH) useless?
4. Does it create a net burden for the patient?

Advanced Directives:

*Cruzan v. Director, Missouri Department of Health 1990*

- First right to die case
- 1983 After a car accident, Nancy Cruzan was resuscitated, but experienced severe anoxia
- Remained in a coma which progressed to persistent vegetative state; PEG was placed with husband’s consent
- Parents requested hospital employees terminate the TF “so that she could die in peace”
- Missouri sought to block the removal of the feeding tube; parents appealed to the Supreme Court (1990)
- Justice Rehnquist delivered the court’s opinion
- Justice O’Connor concluded that artificial feeding was a form of medical treatment and that it is within one’s liberty to refuse treatment
- A few months after the ruling, the state stopped opposing, and said if it had sufficient evidence Cruzan would have wanted the feedings stopped
- Almost 8 years post-event the feeding tube was removed and Cruzan expired
Key Findings

- The state has the right for “clear and convincing evidence” to continue or discontinue artificial nutrition hydration (ANH).
- ANH is medical treatment.
- For the first time, the Court acknowledged that if a person becomes incompetent, this right could be exercised through a living will or by a designated surrogate.
- States could still restrict this liberty interest if a person’s refusal was not stated clearly or strongly enough.

Competent Patient Who Wish to Refuse Treatment

**Bouvia v. California Superior Court (1986)**

- Pt in public hospital sought to have her NG tube removed, claiming she was being force fed.
- Severe cerebral palsy, quadriplegic, total care dependent.
- Mentally competent with college degree.
- Expressed desire to die on several occasions and tried to starve herself to death; eventually lost ability to swallow and feeding tube placed.
- At trial, the Court determined she could live another 15-20 years with TF and so the preservation of her life outweighed her right to decide.
- Her lawyers made the case that her condition was irreversible and painful and disagreed that “every life must be preserved against the will of the sufferer.”
- She had the fundamental right to remove feeding tube and that the hospital and staff had a duty to alleviate her pain/suffering.

Key Finding

- This was first legal case in which a court sided with a competent patient’s determination to die.
Capacity: is one's authority to engage in a particular undertaking or maintain a particular status

State v. Northern, 1978

Mary Northern, 72 yo female suffered thermal burns on her feet after self-treatment for frostbite, leading to gangrene and hospitalization.

Clinicians recommended bilateral amputations of the feet, but she refused.

Suite was filed by Tennessee Department of Human Services, alleging Mary lacked capacity.

A legal guardian was then appointed ad litem and reflected the patient's thoughts and wishes.

She never expressed the wish to die, but inferred she would rather die than lose her feet, but refused to make a decision.

Considerations

Did Mary have capacity to:

- make a rational decision by perceiving/appreciating relevant facts?
- reach a rational decision based on those facts?

Key Finding

Capacity is not necessarily synonymous with sanity. A person may have capacity to some matters and lack capacity for others. Court concluded she was unable or unwilling to even dimly comprehend very basic facts. Even so, she passed away without ever having the surgery that could have saved her life.
When the Patient or Family Requests Futile Treatment

Causey v. St Francis Medical Center (1998)

- Believing it medically appropriate, a physician and hospital withdrew life-sustaining care for a Sonya Causey, a 31-year-old, quadriplegic, comatose patient with ESRD; care was perceived as being futile and decision supported by the hospital's Moral and Ethics Board
- Strong family objections
- HD, Life-support procedures discontinued and "no code status" was entered. TFs also stopped
- Causey died the day she was extubated
- The case was filed as an intentionally battery-based tort. The trial court concluded that the defendants acted in accordance with professional opinions and professional judgment

Key Finding

Key finding: There was consensus by practicing physicians that the Standard of Care was met. The case was dismissed by the trial court.

When is discussion needed?

Types of conditions that may warrant discussion: advanced dementia, PVS, terminal illness (Barrocas, et al.)
Shared Decision-making and ANH—What should be considered?

- Consider ethical, legal, religious and cultural aspects. (Barrocas, et al.)

“Process should be interdisciplinary, collaborative, proactive, integrated and systematic in order to facilitate decision making that engages the patient, family, significant others, caregivers and/or surrogate decision makers. The process should promote advanced directives that provide healthcare based on the patient’s wishes and best interest.” (Schwartz)

How Can the Registered Dietitian Become Involved?

Understand the Decision-Making Process

- There are 5 steps to systematically resolve ethical problems
- Linear in fashion

1. Respond to the “sense” or feeling that something is wrong
2. Gather information and assess the situation: gather facts for informed decisions

3. Identify the ethical problem and moral diagnosis

- Use ethical principles as guidelines
  - Respect the patient and autonomy
  - Use beneficence (goodness/kindness)
  - Avoid malfeasance (doing harm)
  - Practice veracity (truth-telling)

  **The patient’s preferences or wishes always take priority and should be considered first.**

4. Seek a resolution: consider what courses of action are possible

- Actions must be morally justifiable
  - Eliminate or reject those that could result in harm or conflict with another basic ethical principle
5. Work with others to determine the course of action

- The best decisions are made when those that are involved have the opportunity to discuss their perceptions, values, and concerns openly
- Views and insights of caregivers should be shared

Foster Improved Awareness

- Consider if the risks and burdens outweigh the potential benefits
- Identify what “best care” means

- Per ASPEN and AND, for individuals receiving active treatment for underlying disease and underlying physiologic derangements, NS should be prescribed when the potential benefits outweigh the risk/burdens as evaluated by an evidence-based analysis
- Only interventions likely to benefit the patient should be undertaken

Define the Role of the Dietitian

- RDs should be involved in clinical ethics activities
- Supported by AND position/practice papers and ethics action paper
- Model the interdisciplinary team approach
**How can the RD facilitate culture change?**

- Participate on ethics committees
- Practice critical thinking skills
- Help individuals/families, surrogates differentiate the meaning and emotions attributed to food as opposed to medically administered nutrients through tubes, with burdens and risks
- Role play different ethical or EOL clinical situations with other health care professionals
- Understand that palliative care extends beyond EOL and is a broader focus than hospice
- Have quality of life discussions when difficult situations arise
- Be a resource for others
- Read, read, read and start Book Clubs
- Ask to join bioethics committees, participate in interdisciplinary meetings, huddles, etc.

**Why does it even matter?**

- Quality EOL care must allow for the unpredictable timing of death. Approach to change must be multidimensional.
- Promoting improved education and providing beneficial info to all those directly involved in patient-centered care:
  - will translate to an increased satisfaction for the individual/family/surrogate.
  - decrease medical costs for services that may not be wanted or warranted, based on the individual's quality of life goals.
- Always remember that the patient’s self-determination takes precedence over the beliefs of healthcare providers (Vaughn)

**The Gold Standard**

Ask yourself, "Do I really know what my patient’s goals of care are?"
"Death is a natural act. Societally and professionally we are uncomfortable with it, but we as professionals have to figure out how to get comfortable with it." (Cosgrove, 2016)

Summary

- RDs have a distinct and unique role
- RDs have a place on interdisciplinary teams dealing with EOL situations in hospitals, clinics, and in skilled and LTC facilities
- Informing patients about their right to render personal health care decisions will help them make educated choices, leading to positive experiences
- Patients should be encouraged to plan ahead by having meaningful discussions about goals of care and completing advance directive documents
- For patients without capacity, facilitating discussions about goals of care with surrogates will help the treatment team understand the patient's preferences and offer treatment options that are aligned to the patient's wishes

Suggested Readings


KALANTHI, PAUL. WHEN BREATH BECOMES AIR. NEW YORK: RANDOM HOUSE, 2016.

SACKS, OLIVER. GRATITUDE. TORONTO: ALFRED A. KNOPF AND ALFRED A. KNOPF CANADA, 2015
Bibliography


