FR26- Stopping Eating and Drinking by Advance Directives: Choose Your Injustice

Friday, March 23
3:30 PM- 5:00 PM

Session Description

This session will discuss the ethical dilemmas involved in an advance directive that asks the provider to withhold food and fluid in patients with dementia. The presentation will focus on the dilemma of autonomy and the injustice inherent in a decision to implement or to refuse to implement the advance directive. A panel discussion by members of the Society Ethics Committee will follow.

Learning Objectives

Discuss the concepts of Voluntarily Stopping Eating and Drinking (VSED) and Stopping Eating and Drinking by Advance Directives (SED by AD).

Describe the various ethical issues involved in implementing SED on a patient with advanced dementia.

Explain the difference between critical and experiential interests and how they contribute towards ethical decision making.

Appreciate the practical difficulties in implementing SED in the nursing home or assisted living setting.

Presenter(s): Fatima Naqvi, MD, CMD; James Wright, MD, PhD, CMD; M. Rosina Finley, MD, BSN, CMD; Peter Jaggard, MD, CMD; Timothy Holahan, DO, CMD

Presenter(s) Disclosures: All speakers have reported they have no relevant financial relationships to disclose.
Stopping Eating and Drinking by Advance Directives: Choose your Injustice

Speaker Disclosures

- Drs. Wright, Jaggard, Naqvi, Finley and Holahan have no financial relationships to declare.

Learning Objectives

By the end of the session, participants will be able to:

- Describe the concepts of Voluntarily Stopping Eating and Drinking (VSED) and Stopping Eating and Drinking by Advance Directives (SED/AD)
- Discuss the various ethical issues involved in implementing SED/AD on a patient with advanced dementia
- Appreciate how the Western emphasis on Autonomy can de-emphasize the personhood of those with dementia
- Appreciate the practical difficulties in implementing SED/AD in the nursing home or assisted living setting

Jerome Medalie, 88 years old

New York Times:

"Complexities of Choosing an End Game for Dementia" in The New Old Age, 1/20/2015

Voluntarily Stopping Eating and Drinking: VSED

- Used by competent adults
- Protected by law (Supreme Court 1997)

SED by Advance Directives (SED/AD)

- Used in advance directives for those with dementia (or those worried they may develop dementia)
Ethics in America

Medical Ethics in the US
- Before 1950s:
  - Doctor knows best
- 1960s-70s:
  - Syphilis studies in Tuskegee (exposed in 1972)
  - Advances in medical technology (dialysis 1960s, ICUs 1960s, mechanical ventilation late 1960s)
  - Karen Ann Quinlan (1976)
  - The Belmont Report 1979
- After 1970s:
  - Patient knows best

The 4 principles of Medical Ethics
- Patient Autonomy
- Non-Maleficence ("First do no harm")
- Beneficence
- Justice or Fairness

FROM BEAUCHAMP AND CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS

Patient Autonomy
- The owner of the body gets to decide what happens to that body
- Must have capacity:
  - Do they understand the disease and consequences of treatment/non-treatment?
  - If the person has lost capacity, their agent assumes their autonomy

Justice or Fairness
- What is fair to the individual?
  - The care of the person should be impacted as little as possible by prejudice regarding
  - Race
  - Gender
  - Sexual orientation
  - Religion
  - Wealth
  - Cognitive Abilities
  - Physical Abilities
  - Age
  - Burden of Care

The 2 principles of Medical Ethics
- Patient Autonomy
- Justice or Fairness
The 2 principles of Medical Ethics

- Justice or Fairness
- Patient Autonomy

FROM BEAUCHAMP AND CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS

Margo, Sheri and Walter

- “I wish my caregivers to initiate SED/AD if...”
- “I no longer enjoy simple activities”
- “I no longer recognize my children or spouse”
- “I no longer laugh”
- “I can no longer walk”
- “I no longer speak in coherent sentences”


3 Residents in Your Facility

- **Margo**: still obviously enjoys eating and drinking. Attends art class. Consistently happy. Does not recognize family, no longer reads. Speaks, but speech is fairly devoid of meaning.
- **Sheri**: significant dysphasia, eats by herself, but needs encouraging, enjoys chocolate ice cream, non-ambulatory. Enjoys taking care of her doll. In no obvious pain or distress.
- **Walter**: no social interaction, difficult to interest in food and fluids. Does not express interest or pleasure in anything. Flat affect, mainly non-focal.


Whose Advance Directives do you Honor?

Ethical decision making

- Pits two principles against each other
- Examples
  - Autonomy vs. beneficence
  - Person with Bipolar disease refuses to take her medicine
  - Autonomy vs. non-maleficence
  - 92 yo with history of falls wants lorazepam for insomnia
  - Beneficence vs. Non-maleficence
- *Every* decision in geriatrics!

SED/AD: Ethical principles at odds

- Autonomy vs. Autonomy (the “then-self” vs. the “now-self”)
  - Who gets to decide: pre-demented Margo or Margo, the nursing home resident?
- Justice vs. Justice
  - Honoring advance directives vs.
  - Honoring wishes of person with dementia
  - Which is the greater *Injustice*?
Autonomy vs. Autonomy: Whose Autonomy matters?

- The “then-self” vs. the “now-self”
  - Whose desires and wishes take precedence?
  - Do Margo, Sheri and Walter HAVE autonomy?

The problem with autonomy

Autonomy depends on Capacity

- If nursing home resident Margo, Sheri and Walter have lost capacity to understand their condition and consequences of treatment/non-treatment, are they still autonomous? (i.e., do they get to take part in the decision making?)

But...
Autonomy also depends on Informed Consent

- Decision making relies on "informed consent": the decision maker has as much of the facts necessary to make a decision that takes into account the ramifications of the proposed course of action.
  - Who is more fully informed: the pre-demented person or the person with dementia?

Who is truly “informed” about QOL in Dementia?

- Caregivers consistently underestimate QOL of those with Alzheimer’s disease
- QOL scores depend on other things than the condition of the person with dementia:
  - Caregiver stress
  - Low caregiver QOL
  - Health provider bias

If autonomous decision making depends on informed consent...

WERE (PREDEMENTED) MARGO, SHERI AND WALTER FULLY INFORMED?

Reframing the discussion
JUSTICE > AUTONOMY

Injustice #1: Violating Advance Directives
• The whole point of ADs (advance directives) is to maintain patient autonomy even when one becomes incompetent.
• If we honor the wishes of the person with dementia, we commit an injustice when we violate that person's previously stated ADs.

Injustice #2: Ignoring the Wishes of Your Patient
• If we honor the AD of the pre-demented person, we might violate the wishes of the person with dementia
• Ethical principle of Justice:
  • Your care should be influenced as little as possible by prejudice against
    • Age
    • Physical Debility
    • Cognitive Debility

Choose Your Injustice
#1 Do you violate Advance Directives?
#2 Do you violate the resident's current wishes (stated or presumed)?

SED by AD: The Role of the PALTC Provider
SED by AD = Stopping Eating and Drinking by Advance Directives

Understand the culture of your patient
Individualistic societies (USA, UK, Canada)

- Measures of life satisfaction
- Independence
- Health
- Control
- Economic freedom


Understand your own prejudices

Understand the discussion:

Autonomy > Justice
Advance Directives > Your Patient

Flip the discussion:

Justice > Autonomy
Your Patient > Advance Directives

Demented lives matter.
Stopping Eating and Drinking by Advance Directives

- Autonomy seems to be the main concern for most
- Try to reframe the discussion to one of Justice
- Understand that you will participate in an injustice of some sort (don’t pretend that the only ethical approach is to honor AD)
- Help families and proxies to “de-label” people with dementia
- Recognize the “now-self” is still a person
- Limit influences of dementism on your practice and your families perception of your patients. Demented lives matter.

Panel Discussion

PLEASE HOLD QUESTIONS UNTIL AFTER PANEL DISCUSSION, THANKS!

Practical Aspects of Implementing SED by AD in Facilities

TIMOTHY HOLAHAN, DO, CMD, UNIVERSITY OF ROCHESTER, ROCHESTER NY

Case Study

- 72 yo male with history of advanced Alzheimer's Dementia who has FTT and worsening behaviors
- Was living at an assisted living facility memory care unit and recently declining functionally
- He also developed further aggression and agitation requiring further titration of his antipsychotic regimen
- Non verbal and bed bound
- Hospice evaluation ordered and admitted to hospice
- Has had goodpo intake and eats/drinks when food offered but needs assistance with meals (hand feeding, etc.). Seems to enjoy eating without profound dysphagia or discomfort.

Case Study

- Wife is HCP and POA
- She is upset that we have been feeding him since this is not consistent with advance directives he has made in his living will
- “an incurable or irreversible condition from which there is no reasonable expectation to recover...nutrition and hydration shall be withheld or withdrawn unless necessary for comfort or to alleviate pain.”
- Ethics consult called to discuss this and wife is requesting food/drink be withheld

Case Study

- Nursing staff and Aides very uncomfortable with plan
- They feel that he is getting some enjoyment from eating and drinking
- However, providers feel that his previous advance directives are clear and should be honored
- Hospice refused to admit due to ethical concerns
- Staff feel that this is “too risky” from a legal perspective
- What Now?
Staff concerns

- Highlights challenges with staff
- Feeding in general is engrained in our culture and society
- To not provide it seems ethically wrong
- Brings into the fold religious and cultural beliefs/feelings as well
- The outcome of the ethics decision needs to include a plan about how to counsel staff and support them.

Family Disagreement or Concerns

- Be prepared for possible disagreement among family members
- Plan should be clearly communicated with all close family involved with the care
- Reassure them of symptom relief and comfort through process
- Likely will involve ongoing involvement of ethics committee as opposed to a one time consult.
- Ensure ongoing resources to help assist/comfort them (ex: chaplain, etc.)
- Always bring the focus back to their loved one

SED by AD and symptom management

- If decision is made to withhold or withdraw nutrition, need to be aware of symptoms
- Common things to keep in mind are delirium, abdominal pain, agitation, xerostomia, etc.
- Pain = opioids (morphine, hydromorphone, etc.)
- Delirium = haloperidol, lorazepam, etc.
- Xerostomia = appropriate oral care, artificial saliva, etc.
- Ethically obligated to ensure comfort regardless of the plan of care

Cross-Cultural Aspects of SED by AD

M. ROSINA FINLEY, MD, CMD UT HEALTH SAN ANTONIO, SAN ANTONIO, TX

Doorway Thoughts: Cross-Cultural Health Care for Older Adults*

- Cultural competence which combines attitudes, knowledge base, acquired skills, & behavior is an approach in understanding of the determining role that culture plays in all of our lives & of the impact culture has on every health care encounter.

Doorway Thoughts: Cross-Cultural Health Care for Older Adults*

- Cultural & historical facts & issues relating to the members of an entire minority group can be in play in any cross-cultural encounter.
- Attitudes & beliefs vary widely from one individual to another within a single cultural group.

*Doorway Thoughts: Cross-Cultural Health Care for Older Adults, Introduction to Cross-Cultural Health Care for Older Adults, AGS, 2004.
Maximization of the effectiveness of cross-cultural encounters includes an awareness & sensitivity of the following:

- Preferred Terms for Cultural Identity
- Formality – Addressing the Patient & Health Provider
- Language & Literacy
- Respectful Nonverbal Communication
- Elephants in the Room
- History of Traumatic Experiences
- Immigration Status
- History of Immigration or Migration
- Acculturation
- Tradition & Health Beliefs
- Use of North American Health Services
- Culture-Specific Health Risks
- Approaches to Decision Making
- Disclosure & Consent
- Gender Issues
- End-of-Life Decision Making & Care Intermediary
- Use of Advance Directives

Doorway Thoughts: Cross-Cultural Health Care for Older Adults, Introduction to Cross-Cultural Health Care for Older Adults, AGS, 2004.

ETHICS, CULTURE & COMMUNICATION

Fatima A Naqvi, MD, CMD

Ethics and Culture

**Balancing the Extremes**

1. Respect for Core Human Values
2. Respect for local tradition
3. Belief and practices- context matters when deciding right from wrong

On Managing Across Cultures: P Christopher Early

Ethics and Culture

Culturally Competent Physician

- Understand
- Empathy
- Patience
- Respect
- Ability
- Trust

Ethics and Culture- African American

<table>
<thead>
<tr>
<th>Address</th>
<th>Address by their formal name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye</td>
<td>Direct eye contact</td>
</tr>
<tr>
<td>Obtain</td>
<td>Obtain reason for obtaining information</td>
</tr>
<tr>
<td>Be</td>
<td>Be cognizant of basic distrust of health professionals</td>
</tr>
</tbody>
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Ethics and Culture- Chinese Patients

<table>
<thead>
<tr>
<th>More formal than American</th>
<th>Spouse may not have the same last name</th>
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<tbody>
<tr>
<td>Treatment decisions often made by family</td>
<td>Illness resolves with symptom resolution</td>
</tr>
<tr>
<td>Importance of &quot;saving face&quot; - Yes or No</td>
<td>Explain why blood draw is important - source of life</td>
</tr>
</tbody>
</table>
Ethics and Culture- Japanese Patients
- Doctors are seen as authority figures
- Family make treatment decisions
- Elderly not accustomed to verbalizing emotions
- Appreciate Empathy and kindness
- Eye contact is variable

Ethics and Culture- Latino Patients
- Involve entire family
- Inquire Folk Medicine
- Food choices- Hot and cold
- Traditions

Ethics and Culture- Islam
- May be Passive in front of authority Figure
- Explain the need to share information
- Effort to gain trust of the patient
- Family spokesperson
- Sub groups /Sunni / Shia/ Others
- Variation exist – total independence to interdependence

Ethics and Culture- Hindu
- Cast System- Four cast
- Intermarriages among the cast not approved by parents mostly
- Culture and Myths
- Concept of reincarnation

Ethics and Culture – Judaism
- Infinite value of human life
- Three subgroups – Orthodox, Non-traditional and Modern
- No sufferings
- Withhold treatments
- Assisted suicide, Euthanasia

Ethics and Culture- Christianity
- Faith
- Death is not the end
- Many Subgroups
- Life after Death
Ethnic and Culture - Russian

- Bad news is not given to the patients
- Russian patients want to know new treatments
- Distrustful of doctors
- Psychiatric disease is considered disgraceful
- Homeopathic remedy versus western therapy

Ethics and Culture - What's Common?

- Living and working together (Japanese)
- Individual liberty (Western)
- Fulfillment of inherited duty (Hinduism)
- Importance of limited desires (Buddhist)
- Egalitarianism (Western)
- The duty to give alms to poor (Muslims)
- Human Rights (Western)

What is “Good Death?”

- Patient wishes respected
- Symptom control
- Family and friends close by
- Leaving a legacy
- Opportunity to say good-bye
- Communication
- Goals of Care
- Spiritual well being
- Attention to the needs
- Closure for person, care givers and clinician

What is “Good Death?”

Unconditional Positive Regard towards the person & their family
Some Reflections on SED by AD

PETER JAGGARD, MD, CMD, FACP
CHAIR, AMDA-SPALC ETHICS SUBCOMMITTEE

Reflections on SED by AD: Objectives

1. Clarify Terminology related to SED
2. Support contention that SED by AD involves a potential conflict (“choose your injustice”) inherent to ADs
3. Examine the role of “best interests” approach on both sides of argument in SED by AD
4. Reveal inherent conflict of principles in mid-level principlism
5. Comfort Feeding Only – A Better Way?

Clarifying Terminology: Distinctions

1. Voluntary Stopping Eating and Drinking (VSED)
2. Stopping Eating and Drinking by AD (SED by AD)
3. Stopping Eating and Drinking by POAHC Request
4. Stopping Eating and Drinking by Natural Decline

Rationale for SED by AD: Includes “Best Interests”

“the authority of an advance directive to withhold life-sustaining food and water . . . Increases as the person’s capacities to generate new critical interests and enjoy life decrease. . . .”

“implementing an AD is morally justified when the diminished subjective value of survival is outweighed by critical interests and respect for autonomy.”


Is VSED by AD “voluntary”?

1. Given: Volitional expressions of “competent” persons in the moment override prior advance directives
2. A terminally ill person with dementia may no longer be deemed “competent” or having capacity – yet may be able to manifest (apparently) volitional acceptance or rejection of offered feeding by caregiver – “Behavioral capacity”
3. The choice to act upon an SED by AD is not a volitional act of the patient but rather a volitional act of the proxy.
4. When it comes to eating, which has priority – volitional capacity of agent, or behavioral capacity of the resident?

A Rejoinder to SED by AD: An Inherent Conflict in all Advance Directives

“Menzel and Chandler-Cramer want to empower competent persons to impose potential discomfort and distress on a later self who will be unable to understand the reasons for that choice. In this situation, the price of respecting autonomy is paid by a frail incapacitated patient who has no idea why food and water are no longer offered to her. . . .”

“A focus on comfort would seem to support offering food and water to all patients who are willing and able to eat and drink.”

Dresser R. “Toward a Humane Death with Dementia.” HCR 44(3);2014:38-40.
### 3. Challenging Substituted Judgment: Best Interests for Incapacitated Persons?


- "The orthodox approach to non-treatment decisions for incompetent patients is seriously flawed and should be scrapped. It mistakenly assumes that incompetent patients should be regarded as choice-makers when they are incapable of decision. By overlooking the conflict between past directives and current interests, it allows concerns with family stress and costs to override the real needs of incompetent patients, without an adequate evaluation of each."
- Dresser argues for a "best interests" standard for the care or incompetent persons; it focuses on the patient as she now is.

### 4. Conflict of Principles: Inherent Weakness of Mid-level Principilism

- Ethical principles (autonomy, beneficence, justice, non-maleficence) are prima facie, not absolute, constraints
- Conflicts between principles are inevitable
  - Autonomy vs. beneficence
  - Autonomy vs. justice
  - "Past-self " autonomy vs. present-self (in the moment) autonomy
- Is SED by AD are we not overriding the "substituted judgment" (SJ) of patient behavioral preference in favor of SJ of another?
- PJ: Why is it not possible to define a severely demented person’s capacity to assent to eating or not by behavioral preference?

### 5. Practical Alternative to SED by AD: Comfort Feeding Only (Palecek et.al. JAGS 2010;58:580-84)

- Offer feeding by hand at mealtimes
- Provide feeding as long as resident is not showing signs of distress
- If oral feeding causes sign of distress (or refusal), stop the feeding
- Over time the ability to eat declines further
- Premium is placed on comfort during feeding
- PJ: Work with families to understand comfort feeding, natural trajectory of decline; reassure them of commitment to Hospice or Comfort Care approach when consistent with goals of care

### Approach to Weight Loss and Declining Oral Intake in Advanced Dementia

**CASE 1: Abrupt Spontaneous Cessation of Intake**

- Advance Care Planning Discussion with POAHC
- Consider rule out simple reversible medical etiologies
- Offer Comfort Feeding Only
- Offer Hospice Referral

**CASE 2: Steady Decline in Intake and Weight over months**

- Offer feeding by hand at mealtimes
- Provide feeding as long as resident is not showing signs of distress
- If oral feeding causes sign of distress (or refusal), stop the feeding
- Over time the ability to eat declines further
- Premium is placed on comfort during feeding

- PJ: Work with families to understand comfort feeding, natural trajectory of decline; reassure them of commitment to Hospice or Comfort Care approach when consistent with goals of care

### Comfort Feeding Only: A Realistic Policy for SNF to Address Declining Intake in Advanced Dementia?

- Responds to behavioral preferences of “the person in front of you”
- When a resident receives spoonfeeding, feed her
- When a resident rejects spoonfeeding, stop feeding
- No “forced feeding” – No PEG tube
- No “forced non-feeding” – Do NOT make staff the “food police”

### Questions/Comments?
Thank you!