Assisted-feeding in advanced dementia is artificial nutrition and hydration

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EOL nutrition is caught between philosophy and management of death

• Palliative and hospice care physiologically manages a “good” death: pain control, avoiding futile treatments and peace along the journey.
• Modern medicine buys days, months, years of chronic disease at a huge financial and emotional cost. (Callahan, 2011)
• We manage both births and deaths
  — with the acceptation of some accidents 😊 or 😢

Why is something so simple so complicated?

• Food/drink are a symbol of life
• Sources of food/drink vary between cultures
• Religious and spiritual - personal
• Utilization of food/drink is mythical
• Food/drink is social & psychological
• We delay our own death by eating/drinking

But food/drink is simply chemistry on the table and biology in the body.
Key words for research related to EOL nutrition

Autonomy, beneficence, non-malfeasance, justice
Sanctity of life, dignity, duty to sustain, cost
Ethical, legal, informed, assumed
Withdraw, withdraw, acts, omission
Intent, double effect, neglect
Killing, letting die, causing death, allowing death
Forced, encouraged, reflexive, administered
Consent
Natural, artificial
Comfort and pleasure

Futility of the discussion

• The cycle of bioethics: 1945 – 2016 (Orr and Mellander, 2004)
  – Is food/drink treatment or personal comfort care?
• The anorexia of aging – a system failure in the body
  – Quinlan, Brophy, Cruzan, Pouliot, Schiavo
  – Margo Bentley: Advanced directives are disregarded
    • 2016 MO legislation: Adult Consent Act
    • McMath: Lost in the Valley of Death
• Suicides should be prevented when a natural death can happen
  – Gillian Bennet: (deadatnoon.com)
• Dignified decisions should be respected
  – AD for SED (Menzel and Chandler-Cramer, 2014)
• Vs. Reflex eating (Hobo, et al, 2013)
  – Or breaking Grandma’s teeth to get a spoon in is not ok

Current state of dementia care

• Dementia is progressive, fatal and occurs in formally competent people
• Death by eating problems occur in 85% of advanced Alzheimer’s dementia people due to brain failure (Mitchell, et al., 2009)
• 67% of AZ DZ pts enter a LTC facility (NCHS 2016)
• 50% of resident’s in LTC have some dementia and most progress to assisted feeding
• Eating disturbances: appetite and hunger
  – Swallowing, fine dexterity, food preferences, habits, reflexes, other progressive eating behaviors (lack of initiation, continued eating until satisfied or nourished)
• Poor nutrition is worse than no nutrition
GI production of enzymes and neuropeptides

Advanced Nutrition and Human Metabolism

Reflex eating
Gropper, Smith, Groff 2016

Ability to say NO? (Treman, Caring Advocates)

Surprise feedings

Orexins also simulate arousal: sleepiness

Peptides that stimulate eating: NPY, Melanin, Orexin A&B, Galanin, AgRP, Ghrelin

Peptides that inhibit eating: α-melanocyte stimulating hormone, a-msh, Corticotropin releasing hormone (CRH), CCK, CART, GLP-1, Serotonin

Cytokines of disease

Strong influences: which, when forced, or artificially provided, Calories may overcome

Clinical course of advanced dementia

Death by stopping food/drink

• Can occur in a healthy person
• Metabolism $\rightarrow$ ketones $\rightarrow$ endorphins $\rightarrow$ uremia $\rightarrow$ unconsciousness $\rightarrow$ death
• Aggressive nutrition is required until hospice is elected, then food/drink is for comfort and pleasure
• If stopping food/drink is not done within hospice care, it will be done outside of hospice care
• Is it legally different if a physician does this or a DPOA or a paid care giver or a NH?
• Prolonging death vs timing of death
• Cause of death: Dementia not “starvation”

Nutrition is a treatment

• A diet order requires a physician order
  – Calories, macronutrients, micronutrients, non-nutrients, continuous vs. bolus in 3 meals/day
• Chemistry in a bottle or on the table:
  – PO ($7) vs tube ($30) vs TPN ($200)
  – NH care is >$5-6,000/month – assistants to feed
• The cruelty of the health-care professional is unnecessary
• Bodily integrity – freedom from assault
  (Wells, 2015)

Protocols for stopping food and water

Addenda to the AD for Dementia of M. Colete Chandler-Cramer
Hastings Center Report May-June 2014

• Stop food first, for 1-3 weeks depending on the initial strength and vigor of the individual. Then stop liquids and attend to mouth care and provide other relevant comfort care.
• Stop food and water simultaneously and the attend to mouth care and provide other relevant comfort care.

“Which protocol to use should be determined by discussion between my proxy decision-maker and my primary medical and nursing care providers.”
Death by Alzheimer’s Dz, PCM, and a continued life

Nutrition
Intake, digestion, absorption, transport, storage, excretion

Why every hospice program should use their dietitian

• The food and nutrition expert
• Chronic disease management does use Medical Nutrition Therapy as a treatment
  — Comfort care sometimes does require MNT
• Compassionate education of the hospice staff, the patient, and the family
  — Personal biases, patient control over intake, relief of the responsibility that appetite decline is not their fault