Nutrition at End of Life: How Dietitians Can Be Educated and Involved

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Objectives

1. To learn the changes in nutrition as people age and near end of life: Learning codes 4190, 5100

2. For dietitians to understand the ethics when dealing with patients and families questions and concerns with end of life nutrition: Learning Code 1050

3. For dietitians to become better educated in end of life care nutrition and how to better help their patients and families at this time in their lives: Learning Code 5430
“It is the position of the The American Dietetic Association that the development of clinical and ethical criteria for the nutrition and hydration of persons through the life span should be established by members of the health care team. Registered dietitians should work collaboratively to make nutrition, hydration and feeding recommendations in individual cases”

Journal of the ADA, May 2002, Volume 102 Number 5
Changes in Elderly Nutrition

- Metabolism slows down so less calories are needed
- Senses of taste and smell decrease
- They often take lots of Medications
- Dental problems
Changes in Elderly Nutrition

- Dysphagia can happen
- Decrease in saliva production
- Depression
- Peristalsis is slower and therefore people can get constipation
- Having trouble with fixing food for themselves
- Trouble with feeding themselves
“Meals on Wheels”

- Mnemonic for some common treatable cause of weight loss in elderly
  - M – Medication effects
  - E – Emotional problems, especially depression
  - A – Alcoholism
  - L – Late life paranoia
  - S – Swallowing Disorders
  - O – Oral factors
  - N – No money
“Meals on Wheels”

- W–Wandering/dementia
- H–Hyper/hypo thyrodism
- E–Enteric Problems
- E–Eating problems (unable to feed himself well)
- L–Low salt diet
- S–Social problems (Isolation, etc)

Physiologic Anorexia of Aging

- As we age, the body produces more Cholecystokinin, which causes increased fullness

- Also, it is thought that the elderly produce more cytokines (especially when ill), causing increased fullness and weight loss

- With aging, we also have more loss of lean body mass
Principles of Ethics

- **Autonomy** – respect self-determination of each person
- **Beneficence** – Do good for each person
- **Nonmaleficence** – Do no harm to any person
- **Justice** – treat each person with fairness
Bioethics

- Taking ethics and applying it to the fields of medicine and healthcare
- Bioethics blends together philosophy, theology, history and law with medicine
- Interdisciplinary

- Good website for more info
  Center for Practical Bioethics
  www.practicalbioethics.org
Dilemmas and Challenges at End of Life


Go to the above website and click on Bioethics videos and the title above is good.
Great articles on Ethics for Dietitians


Advance Directives

- Written documents that help families know what a patient’s wishes are if they become incapacitated

- These are very important for everyone to fill out (no matter their age)

- Two types: Living Will and a Durable Power of Attorney (DPOA)
Living Will

- States what the patient’s wishes are should they not be able to communicate them anymore

- Often can be unclear on nutrition issues

- Each state has different living will laws

- Need to encourage patients to be as specific as possible when writing down their wishes regarding nutrition
Durable Power of Attorney (DPOA) for Healthcare

- Designates someone to make decisions on the patients behalf if they are not able to (regarding healthcare and not finances)

- Need to make sure you designate someone that you trust to follow your wishes and then talk to this person about your wishes
Oklahoma Laws


- http://www.okbar.org/public/brochures
Anorexia

- “Lack or loss of appetite, resulting in the inability to eat”
- Very common in patients at the end of life
- Caused by the disease process (nothing that the patients or caregivers are doing wrong)
Common Causes of Anorexia in End Stage Diseases

- Pain
- Dysguesia—change in taste
- Aguesia—loss of taste
- Hyersomia—sensitivity to smells
- Dysphagia—trouble with swallowing
- Constipation
- Multiple medication use
- Dyspnea
- Nausea/vomiting
- Psychological or spiritual distress
Anorexia–Cytokine Production

- Happens in inflammatory or neoplastic conditions
- Often seen in elderly, AIDS, cardiac cachexia, COPD and cancer
- Affect the hypothalamus (hunger sensation center)
- Decrease gastric motility and emptying
Substrate changes

- Body uses up glucose first
- Next changes to using protein
- Body tries to spare protein so it changes to ketone production
Ketones at end of life are good! (not like with diabetes)
- Cause mild euphoria
- Cause decreased appetite
- Produce natural endorphins which help with pain
- Something to remember: Even just a small amount of carbohydrates prevents ketone formation (ex: D5W)
Physiologic Adaptations to Fasting

- Decrease in use of protein substrates reduces urea load to the kidneys which causes a decrease in need for large urine volumes.

- With a reduction in intake there is less respiratory secretions, coughing, nausea, vomiting and diarrhea.

- All of these adaptations lead to a decrease in the metabolic rate and energy needed.
Does Dehydration and Lack of Intake of Food Cause Suffering??

NO
Possible Mechanisms to Explain the Absence of Suffering

- Endogenous opioid production
- Ketone production
- Electrolytes remain stable until later stages
- Sparing of greater muscle breakdown
- Reduced gastric stimulation leads to absence of hunger
- Cytokine production
- No hunger sensation from the hypothalamus
- Decreased urea load means decreased water needs
Dehydration and Lack of Suffering

- Studies and personal accounts show dehydration is not painful and does not cause suffering
- Main complaint is dry mouth. This can be relieved with ice chips, sips of liquids, lip moisteners and good mouth care
- Patients with decreased fluid intake experience less CHF, edema, incontinence, coughing, nausea and vomiting
- Less mucus production (less death rattle)
Patient’s are not “starving to death”. They are dying from their disease progression.

Lack of intake is a natural progression and has happened to patients all the time. It is the bodies way of helping itself stay comfortable ("letting nature take it’s course")

Patients are not suffering and actually have an increased comfort with dehydration and lack of intake.

Dehydration and “Starvation”
Starvation

Defined as: Depriving food to cause suffering
Desiring or craving food: famished, hungry, ravenous, voracious

End of life patients have none of the above symptoms
Megace (megestrol acetate)

- Synthetic version of the hormone progesterone
- Used in the treatment of breast cancer
- Dosage: 400 mg bid
- Elixir is preferred due to only needing 20 ml per day instead of 20 pills
- Also, elixir is much cheaper
Megace ES (5 ml/day) equals 625 ml—Very expensive and not really proven to work that much better

No studies have been done with the elderly

Studies show weight gain is mainly adipose tissue and not lean muscle

No study has shown survival benefit

Only 20–30% of cancer patients have shown a significant response

Takes at least a month to 8 weeks to work
Megace

- Side effects of thromboembolic events (use in caution with patients with a history of this)
- If I use, I only give a 1–2 month trial and if no response, then we discontinue it.
- Sometimes, families need to try something, even if it does not work
- But need to be very clear on outcomes as sometimes it gives families false hope
Avoidable vs. Unavoidable Weight Loss in Nursing Homes

- **Avoidable**– the resident does not have an identified reason to lose weight and the facility did not address this.

- **Unavoidable**– The patient has an identified reason for weight loss (end of life, etc.) that causes weight loss even with the facility addressing the weight loss.
This is important for the state for us to show that the weight loss is addressed

Multiple team members documenting help

Good terms to use:

1. In this end stage patient on hospice, weight loss is occurring in spite of ________________
2. Weight loss is inevitable due to ________________
3. Pt’s severe anorexia from _____ end stage disease is contributing to weight loss.
4. Mrs. G is given multiple supplements, fortified foods and other high calorie foods, but she is not eating very much of them and therefore is going to lose weight.
Education on End of Life Nutrition

- Needed by many people and the Dietitian needs to be able to do this education

- Educate
  1. Facility staff
  2. Family members
  3. Doctors

- State surveyors need education also and this is something that is important to me
Good Articles

- Nutritional Deficiencies in Long Term Care. Annals of Long Term Care. 1998;6(10), 325-332

“If a resident is at an end of life stage and has and advance directive, according to the state law, or the resident has reached an end of life stage in which minimal amounts of nutrients and fluid are being consumed, and all appropriate efforts have been made to encourage and provide intake, then weight loss may be an expected outcome and does not constitute non compliance with the requirement for nutrition parameters.”

MO state operations manual, Appendix P
Food intake to the family often serves as a main indicator of the patient is doing

Many times patients feel like caregivers are forcing them to eat. They feel they will let the caregivers down if they don’t eat.

When a person has a terminal illness their priorities change and they don’t want to spend all time and energy on eating
Many times the caregivers are concerned with lack of intake but the patient is not at all.

The patients wish they would not focus on it as much and focus on other things they can do together.

Hard thing for all as we can’t “fix” this with medicine and make it better.
Helping Families Cope Emotionally with Loss of Appetite

- Educate on how anorexia at end of life is a normal process

- Hardest on caregivers who were food preparers. Encourage them to cook for others

- Help families to understand the patient is dying from the disease process and not from lack of food and water
Helping Families Cope Emotionally with Loss of Appetite

- Encourage caregivers to find non-food ways of care giving
- Help caregivers to talk to others about their frustrations
- Help caregivers understand the patient is not purposefully rejecting the food they prepared
- Dietitians need to be aware when this is a problem and be able to listen and provide education as needed
Dying Wish: A dying doctor’s decision to stop eating and drinking and die with grace

“Retired surgeon, Michael Miller is dying of end stage cancer and is determined to avoid the hospital at all costs. He’s researched the dying process and believes that stopping eating and drinking will ease his suffering and result in a peaceful, more natural death. During his fast, Micheael suffers neither thirst nor hunger. Buoyed by the legacy of this film, he enjoys a last meal, surrounds himself with art and music, and takes leave of his family. Medical ethicists speak about patients’ rights, and hospice staff share their own, similar experiences of others who have made this choice.”

www.dyingwishmedia.com
PEG Placement: Medical and Ethical Issues

- PEG developed in 1980 (used for infants that could not eat)
- Use has sky rocketed and they have become “common practice”
- PEG feeding tube are indicated for long term nutrition (>30 days)
- PEG placement is not without risks or consequences
- Studies and experience has shown that life expectancy after some placements does not improve quantity of life but does affect quality of life
PEG Placement

- When should PEG’s be placed?
- Pt’s with a long term diagnosis with expectance of some improvement
- Quality of life will be improved not just quantity
- Pt’s with dysphagia and with no other complicating factors
- Need for medications for comfort
PEG Placement

When should PEG’s not be placed
- Advanced anorexia–cachexia syndrome
- If not expected to live >30 days
- Dysphagia with other medical complications that are not improving
- When quantity of life improved but not quality
- When the benefit is less than the burden
- For a person refusing to eat if there is not an underlying condition causing this
Health Care Professional Responsibilities

- Inform pt and family of benefits/consequences of placement and determine if pt wants a PEG (if pt is able to express wishes)
- Discuss with family what patients wishes would have been if they were able to express them (look at advanced directives and living wills)
- Do no encourage PEG if it is not indicated or the patients quality of life would not be improved
- Do not let your own personal, moral or religious convictions affect recommendations on a feeding tube
Contact Info

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