Nutrition in Palliative Care

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Outline

- The Changing Landscape
- Importance of Food
- Patient’s Nutritional Experience
- Family Response
- Palliative Nutrition Support
- Does Setting Matter?
The Changing Landscape

- Evolving definition of palliative care.
- Managing nutritional changes as disease progresses.
- Encountering dilemmas - clinical, moral, ethical, individual, consent, benefits/discomfort.
- Responding to progressive nutritional deterioration.
The Importance of Food

- Physical
- Culture/Tradition
- Comfort/Nuture
- Socialization
- Psychological
The Importance of Food in Advanced Disease

- Hope
- Comfort
- Connectedness
- Pleasure
Food & Nutrition

Food
- Love
- Caring
- Nurturing ritual
- Symbolism
- Hospitality
- Pleasure
- Taste
- Smell
- Memory
- Colour
- Texture

Nutrition
- Life/Survival
- Health
- Fighting disease
- Requirements
- Metabolism
- Nutrients
- Medicine
- Intervention
- Technology
- Guidelines
- Rules

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009
Patients’ Nutritional Experiences

- Change in appetite
- Inadequate food intake
- Change in nutritional requirements
- Failure to achieve balance
  - ↓ oral intake
  - ↓ absorption
  - altered energy utilization
- Weaker & smaller
Factors Affecting Appetite

- Depression/distress
- Pain
- Nausea/Vomiting
- Ascites
- Constipation
- Sore or dry mouth
- Changes in taste perception
- Medication

- ↓ gastric motility
- Cachexia/Anorexia
- Liver & kidney failure
- Tumor growth
- Bowel obstruction
- Inability to swallow
- Shortness of breath
- Dementia
- GI tract shuts down
Anorexia, Cachexia, & Starvation

- **Anorexia**
  - loss of desire to eat

- **Cachexia**
  - condition of weight loss, particularly involving muscle & fat tissue
  - cytokine-induced wasting of protein energy stores, caused by the disease – cancer, CHF, AIDS, RA, COPD

- **Starvation & malnutrition**
Nutrition in Advanced Disease

- Nutritional needs change as illness advances.
- Frequently more than one body system is failing, which may cause changes in digestion & absorption.
- The disease process has altered the person’s desire to eat.
- The experience of eating can change from a pleasant one to a distressing one.
- Food cravings can change from one moment to the next.
Nearing Death

- The body starts to say that it doesn’t need as much food.
- Eating more can actually lead to more discomfort.
- Functional decline is due to the dying process not ↓ intake.
- ↑ intake will not reverse the process.
- The body goes into a state of "ketosis."
- Change in metabolism leads to a release of natural endorphins that actually may cause a feeling of mild euphoria or well-being.
Families’ Reactions to Change in Patients’ Nutrition

- Frustration, anger
- Weaker, smaller but “won’t eat”
- Try harder
- Conflict
- “We can’t just let him/her starve to death.”

Adapted from Laurie Silver’s presentation at the Dietitians of Canada Conference, June 2009
Understanding how Families Respond when a Loved One Doesn’t Eat or Drink

Three sub processes:
- Fighting back
- Letting nature take its course
- Waffling

McClement et al, 2003
Fighting Back

- Fear the patient will “starve to death” or have a painful hastened death
- (HCP) Caregivers often accused of neglect
- ↓ intake not viewed as part of the dying process
- the ↓ intake is seen as largely responsible for declining status
- Patients report feeling upset & angry

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009; McClement et al, 2001-2002.
Letting Nature Take It’s Course

- Families focus on nurturing activities & being present as opposed to nutritional care.
- Offer & assist with eating & drinking which is driven by the pt.’s desire; realize that a declining intake is an expected occurrence.
- Appreciate that aggressive nutritional intervention will not change the outcome.
- Patients appreciated not being made to feel as if they were not trying & not being coaxed to eat.

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009; McClement et al, 2001-2002.
Waffling

- Fluctuate b/t fighting back & letting nature take its course.
- Struggle to reconcile b/t declining intake as normal & something that is not normal (and they want to prevent).

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009; McClement et al, 2001-2002.
Research tells us ...

- Many family members have significant information gaps regarding:
  - the causes of cancer anorexia & cachexia
  - interventions to manage anorexia & cachexia
  - why interventions like tube feedings, TPN are not appropriate in the face of advanced, progressive disease
Crucial Conversations

- Discussion is important.
- Decisions are difficult.
- Need to discuss interventions in the context of “will it meet the goals of care”.
“With communication comes understanding & clarity; With understanding, Fear diminishes; In the absence of fear, Hope emerges; And in the presence Of hope, Anything is possible.”

Ellen Stovall
Palliative Nutrition Support

- Assess
- Identify goal(s)
- Provide nutritional & supportive counseling
- Fix the fixable
- Educate & Inform
- Enhance the patient’s tradition; check our own agenda
Guiding Principles

- Honor the experience of the patient & family
- Promote quality comfort care
- Promote autonomy & choice
- Facilitate informed choice through truth telling
- Improve the quality of the patient & family experience
- Focus on dignity & respect for all

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009
Tips for Caregivers: Acknowledging & Looking Beyond the Obvious

- Canadian Virtual Hospice web site, 2010
Nutrition Support Options

- Oral feeding
  - Oral supplements (↑ energy, ↑ protein)
- Artificial Nutrition
  - Enteral Nutrition
  - Parenteral Nutrition
- Pharmacologic agents
- Nutritional Counseling
- Hydration
Oral feeding

- Creativity!
- Individual preferences
- Appealing presentation
- Personalized portions
- Adapted consistency
- Flexible timetables
- Conducive environment
- Family involvement
- Staff participation
Artificial Nutrition

- Not offering AN is ethically acceptable if benefits do not outweigh the risks for a particular individual.
- Decisions about AN in patients receiving palliative care need to include an assessment of both the benefit & burden of treatments.
- Optimal timing & strategy for providing artificial nutrition is not well understood.
Artificial Nutrition

- When to Consider:
  - Severe dysphagia
  - Severe anorexia
  - Decreased food intake (hunger)
Artificial Nutrition

When to Avoid:

- Risk vs. benefit – increased complications
- Practical issues – eg. difficulties in home care implementation
- Cost
- Ethical dilemmas
Artificial Nutrition

- Need clear goals, expectations & parameters
- Need to set a time limit on when to reassess
- Poor tolerance & complications are due to the dying process
- GI tract shutting down
- Manipulating the feeding will not correct the problems

Myths about Enteral Nutrition
- It is ordinary care like spoon feeding
- It interrupts the cycle of eating, aspiration and pneumonia

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009
Pharmacological Agents

- Corticosteroids
- Progestational agents - Megesterol (megace) - ↑ DVTs; may start seeing effect as early as 2 days usually takes a wk. to improve appetite & a few wks. before wt. gain is seen (start at 160mg/day – 480-800mg/day optimal for wt. gain)
- Cannabinoids - dronabinol
Nutritional Counseling

- Limited research & evidence about the effects of nutritional counseling on patients receiving palliative care.
- Focus really needs to be the caregiver(s).
- Reframing from “starving to death” to irreversible (usually) metabolic abnormalities
"I wonder about drinking enough fluids. If we can feel better by not eating, should we try to stay hydrated? Or should we have IV fluids so we're more comfortable? " 
Hydration

- Stopping fluids at end-of-life won't necessarily hasten death but will probably make the person more comfortable.
- Too much fluid could put an extra strain on one’s heart & cause fluid retention – pressure sores, respiratory impact.
- Dying patients report that they do not experience hunger or thirst beyond what can be alleviated with swabs or ice chips.
# Thirst

## Effects of Dehydration
- Decreased urine output
- Decreased production of gastric fluids
- Decreased pulmonary secretions
- Decreased edema and ascites
- Decreased need for pain medications

## Effects of Fluid Over Load
- Edema
- Increased urinary output
- Pulmonary edema and increased secretions
- Increased gastrointestinal secretions
- Twitching

Adapted from Laurie Silver’s presentation at the Dietitian’s of Canada Conference, June 2009
Hydration

When to Consider:

- Patient comfort
- Dehydration – delirium & renal failure
- Opioid toxicity delirium
- hypercalcemia
Subcutaneous Hydration

- Hypodermoclysis
- Check Zone specific policy
Does Setting Matter?

- 42 year old male with metastatic esophageal cancer admitted to an in-patient medical unit
  - Presented with small bowel obstruction
  - Cachectic, nauseated
  - No PEG – should there be one?

- 65 year old female with metastatic breast cancer to liver admitted to ICU
  - Respiratory distress
  - Persistent wt. loss
  - No desire to eat
  - Increasing nausea … “How do we feed her?”
Does Setting Matter?

- 73 year old male very debilitated post stroke admitted to a **Nursing Home**
  - Frail
  - Bedbound
  - Cachectic

- 59 year old female with extensive stage lung cancer admitted to the **Palliative Care Unit**
  - Looks well, ambulating, SOB with activity
  - “So now I just starve to death?”
Don’t just stand there - do something
(how we’ve been trained)

vs

Don’t just do something - stand there
(what is most often needed)

Blair Henry, 2006
Key Take Away Message

- The meaning of nutrition is dynamic; understand what nutrition means to the person & family.
- Focus on relieving suffering & improving quality of living & dying; symptom management is key.
- **Appreciate that the change in nutritional status is often more difficult for families.**
- Optimal timing & strategy for providing nutritional support is not known.
- Artificial Nutrition may or may not have a fit. What are the patient’s needs & goals?
- Not offering Artificial Nutrition is ethically acceptable if benefits do not outweigh the risks for a particular individual.
Thank you!

Any Questions or Comments?
References


Helpful Internet Sites

- Canadian Hospice Palliative Care Association
  - www.chpca.net
- International Psycho-Oncology Society
  - www.ipos-aspboa.org
- Pallium
  - www.pallium.ca
- Project on Death in America
  - www.soros.org/death
- University of Ottawa (Institute for Palliative Care)
  - www.pallcare.org
- Canadian Virtual Hospice
  - www.virtualhospice.ca