We are privileged to provide care on lands that Indigenous peoples have called home for thousands of years.

Webinar Housekeeping

- Everyone will be muted except the host, moderator and panelists
- Ask questions through the Teams chat box
- All webinars will be recorded and posted on the internal PEaCE Hub page and on the Regional Ethics Network Website
- Please take a moment to scan the QR code to complete the evaluation
- Next month’s speaker

HHS Ethics Rounds & Community Education Sessions

Nutrition and Hydration at End-of-Life

Dawn van Engelen, RD, MHSc (Bioethics)

Conflict of Interest and bias

None to declare

Hamilton Health Sciences

Let's talk about

- What is artificial nutrition (aka tube feeding/nutrition support/AN) and artificial hydration (IV or hypodermoclysis/AH)?
- What are the potential benefits and burdens of AN and AH?
- Where does AN and AH fall within the Goals of Care of patient care?

- What are the religious and cultural considerations on artificial nutrition and hydration?
- Comfort Feeding at EoL

Artificial Nutrition (AN)

- AKA – tube feeding, nutrition support, enteral nutrition, medical nutrition therapy, clinically assisted nutrition
- is a way of providing nutritional needs via an intestinal route
- can be nasal or gastric
- **Artificial Hydration (AH)** - IV or hypodermoclysis

Potential Benefits for AN and AH (best interest)

- An enhanced piece of mind for both patient and family
- reduced fatigue and anxiety around eating
- improvement quality of life and well being
- enhanced symptom control including alertness, reduced confusion, a moist mouth

- ? Safe nutrition with dysphagia
- honor previously expressed wish

Potential Burdens for AN and AH

(balance between harm and benefits)

- moderate to high risk of aspiration
- restrictions on mobility and independence
- potential for GI symptoms such as diarrhea, constipation, abdo cramps, and vomiting
- inconsistent with some cultural and religious beliefs
- may increase suffering with dyspnea, edema, etc

- ? need to withdraw vs. withhold AN

Food and Fluid at End of Life

Latimer, EJ. Maters of the Heart… Feeding and Hydration in palliative care. The Can J. of CME. March 2002, 97-106

- Nutrition and Hydration are needed for survival; not providing may be seen as not fostering survival

  - "dying of thirst"

  - "starving to death "

- **Consider**:

  - individual patient – wishes, goals, plans, hopes

  - is intake for comfort and peace of mind for patient and family vs. optimum intake of food and fluids with the goal of prolonging life

Ethical Aspects of Artificially Administered Nutrition and Hydration: ASPEN position paper

Schwartz et.al. Nutr Clin Pract. 2021;36:254-267

- Not recommended in end-stage illness by current scientific evidence
  - Advanced dementia
  - Cancer
  - Eating Disorders
  - End-stage Disease/Terminal Illness

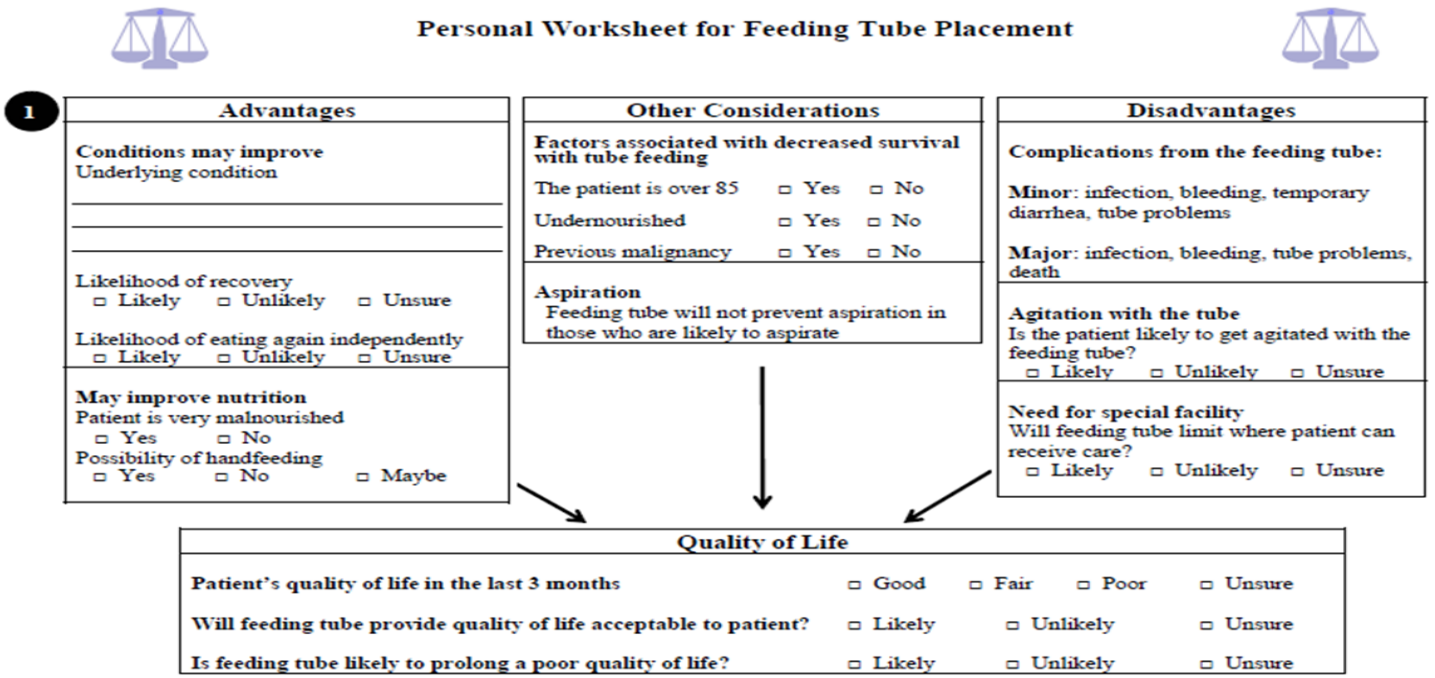
AN and AH –Decision making in Clinical Practice

Schwartz, et al, Nutrition in Clin Pract 2024;39;1475-1482

- 4 ethical principles of (1) autonomy; (2) beneficence; (3) non-maleficence; and (4) justice
  - consider equal value for the relational health care approach of providing 'the right therapy for the right individual in the right situation'
  - Patient –centered care must include to respect individual preferences and values while incorporating them into all clinical decisions
  - AN and/or AH is a medical treatment

- An interdisciplinary approach to decision making that strongly combines ethical, cultural sensitivity, and spiritual (human connectedness) competencies regarding AN and AH

http://decisionaid.ohri.ca/docs/Tube_Feeding_DA/PDF/TubeFeeding.pdf



Personal Worksheet for Feeding Tube Placement

1

Advantages

Conditions may improve
Underlying condition

_____

_____

_____

Likelihood of recovery
☐ Likely ☐ Unlikely ☐ Unsure

Likelihood of eating again independently
☐ Likely ☐ Unlikely ☐ Unsure

May improve nutrition
Patient is very malnourished
☐ Yes ☐ No
Possibility of handfeeding
☐ Yes ☐ No ☐ Maybe

Other Considerations

Factors associated with decreased survival with tube feeding

The patient is over 85 ☐ Yes ☐ No

Undernourished ☐ Yes ☐ No

Previous malignancy ☐ Yes ☐ No

Aspiration
Feeding tube will not prevent aspiration in those who are likely to aspirate

Disadvantages

Complications from the feeding tube:

Minor: infection, bleeding, temporary diarrhea, tube problems

Major: infection, bleeding, tube problems, death

Agitation with the tube
Is the patient likely to get agitated with the feeding tube?
☐ Likely ☐ Unlikely ☐ Unsure

Need for special facility
Will feeding tube limit where patient can receive care?
☐ Likely ☐ Unlikely ☐ Unsure

Quality of Life

Patient's quality of life in the last 3 months	☐ Good	☐ Fair	☐ Poor	☐ Unsure
Will feeding tube provide quality of life acceptable to patient?	☐ Likely	☐ Unlikely		☐ Unsure
Is feeding tube likely to prolong a poor quality of life?	☐ Likely	☐ Unlikely		☐ Unsure

HHS Patient Education Resource

– PD 4801 – 02/2003 – written by Dr. Elizabeth Latimer, Palliative Care Consultant Physician, Hamilton Health Sciences

Hamilton Health Sciences
PATIENT EDUCATION

Food and fluids when nearing the end of life

When people are near the end of life, it is natural that they may slow down or stop their intake of food and fluids by mouth.

Religious Beliefs and Cultural Values Concerns with AN and AH

- 1st – think about the patient rather than the disease
  - patient beliefs, values
- Who makes the decisions in your family?
- Would you like that individual to be involved in your healthcare decisions?
- How is she/he/they related to you?
- Do you prefer to make medical decisions about future test or treatments for yourself, or would you prefer that someone else does?
- Are there religious and /or cultural observances that you wish to practice/honour?

- **There is diversity within - cultural values and religious beliefs - diversity and that always exceptions to the rule** - **Schwartz, D.B. and Barrocas, A. Chapter 39 Ethics and Law. The ASPEN Nutrition Support Care Curriculum 3rd ed. 2017 (as accessed from HHSC e-book library)**

Catholicism- according to 2021 Canadian Census- 29% of Hamilton population

- June 2018 6th edition of the Ethical and Religious Directives for Catholic Health Care Services – http://www.acbc.catholic.org

  - In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally
  - Medically AN and AH becomes morally optional when they cannot reasonably be expected to prolong life or when they will be "excessively burdensome for the pt or cause significant physical discomfort.

  - The individual has a moral obligation to use ordinary or proportionate means of preserving his or her life but many forgo extraordinary or disproportionate means to sustain life

Islam – Muslim (Sunni and Shia) according to 2021 Canadian Census- 6.8% of Hamilton population

- Belief: premature death should be prevented
- Culture and religion can play a role in a family's decision making – Who makes decisions in you're your family?

- treatments can be withheld and withdrawn of terminally ill when the physician is certain about intimate of death, and if the treatment will not improve condition of quality of life
- End of life care must never be to hasten death

Hinduism - according to 2021 Canadian Census- 1.8% of Hamilton population

- Believe in karma, a causal law where all acts and human thoughts have consequences
- May see health care choice as duty based not rights based

- View death as a passage to a new life, the way a person dies is an important factor in determining what new life will be like
- View the time of death as determined by one's destiny and accepts death and illness as part of life

- Usually accept or desire a DNR order because death should be peaceful
- May have community leader or a Pandit (Hindu priest) present

Sikhism - according to 2021 Canadian Census- 1.3% of Hamilton population

- A Sikh lifestyle focuses on introspective, ethical, and distributive life based on a doctrine of love and justice

- Sikhs are encouraged to accept illness and death as a part of Divine will
- In terminal care and in final stages of a fatal illness, a Sikh scholar or Sikh Granthi (a Sikh minister) may be present
- family members should be consulted for end of life care

Buddhism - according to 2021 Canadian Census- 0.8% of Hamilton population

- May not believe in a mandatory or moral obligation to preserve life at all costs

- Lack specific teachings on artificial nutrition and hydration for individuals in a persistent vegetative state
- Support availability of terminal care and hospice care

Judaism - according to 2021 Canadian Census- 0.5% of Hamilton population

- Over-riding principle is the preservation of life
- Three main branches: Orthodox, Conservative, and Reform –each having their own practices according to how they interpret Jewish law

- May consult a Rabbi regarding the decision for life-support and tube feeding
- May consider food and fluid to be basic needs and not treatment
- Can permit the withholding of food and fluid, if that is the individual's expressed wishes esp when the individual is approaching final days of life; when food and fluids may cause suffering and complications
- May not allow withdrawal of tube feed but withholding is allowed as part of the dying process and is a clear wish of the patient

Greek Orthodox

- Do not allow artificial nutrition to be withheld or withdrawn, even if there is no prospect of recovery

Indigenous

- Hamilton sits on the traditional territory of the Mississauga, Haudenosaunee and Anishnaabe and within the lands protected by the Dish with One Spoon wampum agreement

- “HHS continues to work toward creating a more culturally aware, safe and inclusive health care experience for Indigenous staff, patients and their families"
- Deena Klodt, an Indigenous patient navigator in the Regional Cancer Program based at Juravinski Cancer Centre, and co-chair of the Indigenous Healing Spaces Steering Committee

- development of dedicated Indigenous healing spaces at Juravinski Hospital and Cancer Centre (JHCC), Hamilton General Hospital (HGH), St. Peter's Hospital (SPH) and the new West Lincoln Memorial Hospital (WLMH)
- Palliative Care Toolkit for Indigenous Communities - This toolkit includes resources and reference material for First Nations, Métis and Inuit families and communities. It can be used to help support people with cancer who have palliative care needs.

Hispanic

- Prefer less-aggressive, comfort-focused end of life care
- Favour a family centered decision making over individual patient autonomy

- May value a consensus-centered decision-making approach
- Consider family members, rather than individual patient, as holding decision-making power regarding life support

Chinese

- Believe food represents more than a source of energy; it embodies family, love, and caring
- Prefer a family-centered decision making approach to care decisions

Asian

- Belief the older adult should not be burdened with bad news
- Consider illness to be a family event rather than something for the individual patient

Alternatives to AN and AH

- “Comfort Feeding Only" order

“Comfort Feeding Only” order

- Goal:
  - Maintain social closeness
  - Provide food and drink as long as eating remains enjoyable, safe, and comfortable
  - Not forcing a person to eat or make them feel guilty if they don’t
  - ‘nourish the soul, spirit, and mind instead of the body’

Sunnynet

"Comfort Feeding Only" in the Veterans Centre

Sunnybrook Health Sciences Centre		Policy No:	PC-152
Title	"Comfort Feeding Only" in the Veterans Centre	Original: (mm/dd/yyyy)	01/28/2011
Category	Patient Care	Reviewed: (mm/dd/yyyy)	
Sub-Category	Veterans Centre	Revised: (mm/dd/yyyy)	
Issued By:	Veterans Centre Program Council		
Approved By:	Veterans Centre Program Council		

The Sunnybrook Intranet document is considered the most current. Please ensure that you have reviewed all linked documents and other referenced materials within this page.

POLICY STATEMENT:

Residents* with severe dementia or other end stage diseases eat less as part of the natural progression of their disease. Research at end of life suggests that as residents eat and drink less they do not suffer from hunger or thirst. Symptoms such as dry mouth can be alleviated with minimal oral intake and/or oral care.

EoL nurturing

- Keep lips and mouth moist
- Gentle massaging the skin with lotion
- Reminiscing about earlier times and happenings
- Play favorite music
- Sit in silence and share time
- Read a book to loved one
- Pray with them
- Bring in favorite photos and flowers near the bed
- Arrange for visits with family pets
- Go outside for a walk in good weather
- Bring in a favorite quilt or pillow

www.hamiltonhealthsciences.ca

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