

Hydration and Feeding Issues & Decision Making

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On Demand Grand Rounds Concept (MP4/Streaming) accessible at
<http://video.google.ca/videoplay?docid=-2807194588649435088>

The following presentation was first delivered as a briefing for primary care providers.

It was a plenary session at a Saskatchewan Hospice Palliative Care Association (SHPCA) conference.

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It is not intended to direct the care of individual patients, but rather to highlight the assessment and management challenges associated with hydration and feeding issues in palliative and end-of-life care service settings.

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Session Overview

- List factors to be considered when making decisions about hydration and feeding at end-of-life
- Outline decision-making process

Case Study – Patient 1

- 33 year old woman
- Final stages of breast cancer
- Death expected within a few days
- Comatose from brain metastases
- Patient's mother wants her to have hydration

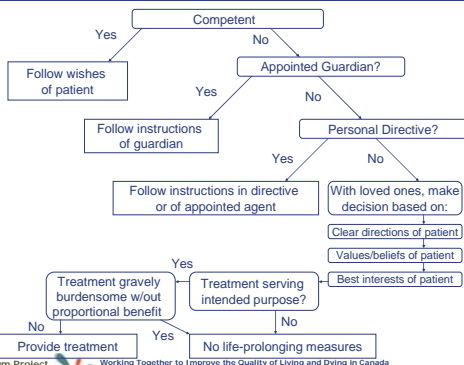
Case Study – Patient 2

- 33 year old man
- Carcinoma of colon with metastases
- SR morphine 300mg BID
- Long, slow decline over many weeks
- Anorexia, cachexia & weakness
- Receiving subcutaneous hydration
- Family questions hydration benefits

Case Study – Patient 3

- Woman in 70s
- Stroke 6 weeks ago resulting in persistent vegetative state
- PEG tube placed within first 10 days for feeding and hydration
- Palliative consultation – artificial nutrition/hydration still appropriate?

Decision-Making Framework for End-of-Life Choices

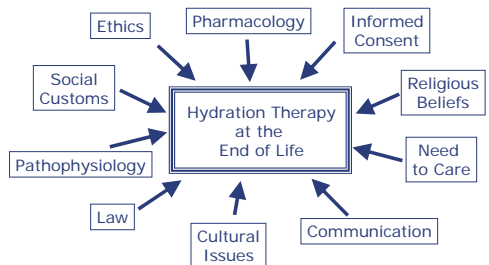


Three guiding questions...

1. Did (patient) ever say what they would want in a situation such as this?
2. Given the way (patient) made decisions/values/beliefs, what would (she/he) do if they were to come back now?
3. What do you (family member) think is in the best interest of (patient) in this situation?

Participant Comment

Often there are unresolved issues/conflicts and family members may want to prolong life in hope of some kind of pre-death resolution



Clinical arguments against...

1. Comatose patients do not experience distress
2. Parenteral fluids may prolong the dying process
3. Less urine results in less need to void, decreased incontinence and use of catheters
4. Less GI fluid & less nausea/ vomiting in patient not hydrated

Clinical arguments against...

5. ↓ pulmonary secretions resulting in ↓ respiratory tract symptoms
6. Reduced peripheral edema
7. Dehydration/electrolyte abnormalities may act as a natural CNS "anesthetic"/ ↓ level of consciousness/ ↓ suffering
8. Parenteral hydration uncomfortable/ ↓ mobility/"medicalizes" death

Clinical arguments for...

1. Dying patients more comfortable
2. No evidence fluids prolong life
3. Dehydration can cause confusion, restlessness & neuromuscular irritability
4. Oral hydration is given to dying patients complaining of thirst/ parenteral hydration should be given to those unable to drink

Clinical arguments for...

5. Parenteral hydration is a minimum standard of care
6. Withholding parenteral fluid in dying patients may compromise other patient groups
7. Dehydration results in ↓ glomerular filtration resulting in ↑ rapid accumulation of opioid metabolites – delirium, myoclonus and/or seizures

What is the best approach?

- One extreme – universal hydration for all patients!
- Other extreme – Avoid medical intervention at end-of-life!
- Reframe question – To what extent can we relieve symptoms related to dehydration? (i.e., thirst, dry mouth, ↓ urine output, delirium)

What is the best for our patients?

- View hydration at end-of-life as a therapeutic intervention (i.e., it can be a treatment option)
- Avoid firm conviction that either providing/withholding is correct
- Little evidence for either claim
- Lead from specific instance and clinical/contextual issues...

What is the best for our patients?

- Careful individual assessment
 - What are the clinical issues?
 - What socio-cultural issues and beliefs are operating?
 - What information for patients and families to make informed decisions?
 - What are the specific goals of care for this patient?

Long-term tube feeding decisions...

- Mr. Smith has advanced dementia and no longer has the cognitive capacity to feed himself or to know what to do with food when it gets into his mouth. His family is asking about "tube feeding."

Long-term tube feeding decisions...

- Mrs. Black is unable to swallow as a result of locally invasive head and neck cancer. She has been advised that a PEG might be beneficial.

Long-term tube feeding decisions...

- Following a stroke, Mr. Brown experiences swallowing difficulties. A gastric tube is suggested to manage this recurrent problem.

What do these three situations all have in common?

ANSWER

A long-term enteral feeding tube has been suggested as a medical intervention to address problems with oral intake.

How should decisions around the use of a long-term enteral feeding tube be made?

WHAT WE DID
Look at issue from a systems' perspective through a Enteral Feeding Decision-making Project

Factors impacting decision-making...

- Language/concept discrepancies
 - Supporting life or prolonging death?
 - Medical treatment or patient support?
- Inconsistency in information and clinical practices by location
- Discomfort in HOW decisions made
- Perception decisions driven by our convenience/care delivery issues

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- Perception decisions driven by our convenience/care delivery issues
- Decisions – isolation/pressure

What would **best** decisions look like?

- Involvement/in-person discussion
- Never a "right now" decision
- Individualized to person/situation
- Based in ethical principles
- Decisions are informed
- Decisions aligned with larger quality-of-life questions

Framing & synthesizing the issues...

- Clinical information
 - Person specific
 - Evidence related to appropriate use
- Values, beliefs & attitudes
 - Ethno-cultural & religious
 - Ethical and legal
 - Person specific
- Decision process proper
 - Who should be involved/what info?

What did the current evidence say?

1. About LT enteral feeding tubes
2. How tube insertion decisions made
3. Ethical principles discourse
4. Ethical decision-making frameworks
5. Use of artificial feeding and fluids in different disease-specific situations

1. About LT enteral feedings tubes...

- Not clear cut in cases of end-stage dementia (no simple answers)
- Does not prevent aspiration
- Can contribute to discomfort/ need for restraint
- At end-of-life the need for fluid and food diminishes/enteral feeding does not change nutritional status

2. How decisions are made...

- Complex context/multiple issues & made under extreme stress
- Acute care in Canada/LTC in USA
- Trigger-neurological event (Canada) /dementia (USA)
- Physicians tend to initiate discussion
- Treatment expectations do not match reality (benefits vs burdens)
- Differences in perspectives

3. Ethical principles...

- Difference – *unable vs unwilling*
- Autonomy
- Beneficence/non-maleficence
- Justice
- Other considerations
 - Views of those involved
 - Legal considerations
 - Timing
 - Assurance - continuing care/comfort

4. Ethical decision frameworks...

- Process to assess medical benefit
- Recognition/respect of choice
 - Informed decision making
 - Balance of benefits/burdens
- Alternatives within full/specific content of patient's situation
- Negotiation of a treatment plan

5. Disease specific situations...

- End-stage/terminal illness
 - No substantial medical benefit
 - No ethical distinction between withholding or withdrawing treatment
 - Religious imperative to continue with food/fluid debated in the literature
- Anorexia-cachexia syndrome
 - No medical benefit

5. Disease specific situations...

- Vegetative state
 - Differences in literature between persistent and permanent
 - Maintain physiological function only
 - Requires quality-of-life considerations
 - If and under what circumstances treatment will no longer be offered

5. Disease specific situations...

- Neurological Insult/Disease
 - May be short-term medical benefit while patient is stabilized
 - Appropriate in dysphagia associated with non-progressive diseases
 - Appropriate for debilitated but physically stable/mentally competent
 - Consideration of benefit/burdens
 - If and under what circumstances treatment will no longer be offered

5. Disease specific situations...

- Dementia
 - Literature leans to alternative methods of feeding
 - Consider both benefit and burden
 - Dementia is a progressive, terminal illness – advanced stages medical benefit is debatable/should not be common practice
 - If and under what circumstances treatment will no longer be offered

5. Disease specific situations...

- Locally invasive head/neck cancer
 - Appropriate in dysphagia associated with non-progressive/slow progression
 - Consider benefit/burdens
 - No medical benefit in end-stage disease

Where did this literature review of the evidence leave us?

Ethical decisions about long-term enteral tube feeding...

- Medical appropriateness
- Perceptions of benefit & burden on quality-of-life (all parties involved)

While respectful of...

- The diversity of medical, clinical, personal, social and ethical influences in each situation

Guiding principles...

- Person's best interest paramount
- Long-term enteral feeding tubes are a medical treatment
- Decision-making process is deliberate, set in ethical principles and based in data of benefits/burdens within individual context
- Patients/families to be given accurate information about benefits/burdens

Recommended process (CHR, Draft 8)

- Team process/attending physician-led
- Based on individual information/data
- Likely to be beneficial (offer)
- Benefits unclear (trial period possible)
- Unlikely to be beneficial (not offered)
- Discussion with patient about medical decision including benefit/burden
- Use decision tool/ethical review
- Plan for review

Mr. Smith Revisited...

- Mr. Smith has advanced dementia and no longer has the cognitive capacity to feed himself or to know what to do with food when it gets into his mouth. His family is asking about "tube feeding."

Mr. Brown Revisited...

- Following a stroke, Mr. Brown experiences swallowing difficulties. A gastric tube is suggested to manage this recurrent problem.

Mrs. Black Revisited...

- Mrs. Black is unable to swallow as a result of locally invasive head and neck cancer. She has been advised that a PEG might be beneficial.

Take Home Messages...

- Decisions about long-term enteral feeding tubes are
 - Complicated
 - Require time and discussion
 - Don't have to happen in a hurry
 - Should be bound by ethical principles
- Decisions about LT enteral feeding tubes are FIRST medical decisions and then about personal choice

Participant Experiences?

PARTICIPANT EXPERIENCE

A young, well-educated woman dying of a terminal illness who made it very clear she did not want any life prolonging therapies including hydration/had intractable pain and family opposed to this position.

The family and physician felt she should be hydrated and forced it.

PARTICIPANT EXPERIENCE 2

Sometimes people are told that artificial nutrition at end-of-life “feeds” the cancer/tumor.

PARTICIPANT EXPERIENCE 3

A patient with ALS and whether or not they would benefit from a feeding tube AND the benefit is unclear?

PARTICIPANT QUESTION

When we try to get informed consent, the patient says “I don’t want ANY treatment” and then something happens (e.g., infection) to render the patient incapable of informing their wishes/what do you do when there are interventions of reasonable benefit for the patient?

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