Artificial Nutrition and Hydration in Terminally Ill Patients

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Objectives

• Palliative care and dietitians
• Quick overview of ANH
• Terminal population
• Benefit versus burden
  – Physiology
  – Family
• Does ANH work?
• What do healthcare providers do now re: ANH?
Palliative Care & Dietitians

"You're doing GREAT! Tomorrow you should be able to eat hospital food!"
Goals of Healthcare Professionals

Figure 6. Goals of healthcare professionals.

NIH CC Palliative Care Team

It takes a nurturing interdisciplinary team to practice the nature of palliative care.

Core Team
- Comprehensive Assessment
- Coordinate Interventions
- Discharge Planning

Co-morbidity Concomitant Disorder

Disease Process

Individuals' Quality of Life

Suffering
- Psychological Predisposition
- Level of Function
- Economic Burden
- Grief
- Emotional State
- Roles and Relationships Isolation

Symptoms

Therapeutic
- Recreational Therapy
  - Relaxation
  - Stress Management
  - Pet, Music, & Art Therapy

Rehabilitation
- Functional Interventions
- Assistive Devices
- Energy Conservation

Social Work
- Socioeconomic Support
- Community Resources
- Coping Skills

Pharmacy
- Pharmacological Counseling
- Equianalgesia
- Adjuvant Agents

Thanatology
- Grief Counseling
  - Family Support, End-of-Life Issues
  - Community Transition

Clinical Trials Protocol

Complementary
- Acupuncture/Acupressure
- Tai Chi
- Trigger Point Release

Spiritual Ministry
- Pastoral Presence
- Prayer
- Hope & Peace

Nutrition
- Satiation, Dysphagia
- Nausea
- Intake Modification, TPN/Tube Feedings
The Goal of Nutrition in PC

• Individually tailored nutrition
• Enhances patient comfort
• Enhances patient quality of life

• **Treatment Stage**: Restore/maintain nutritional and functional status

• **End-of-life Stage**: Relief from suffering and further complications, and other factors that impact QoL negatively

Palliative Nutrition

• Nutrition assessment early (ideally at diagnosis) and regularly

• Alleviate or control symptoms as possible
  – Nausea, vomiting

• Educate the family on drawbacks of aggressive feeding or over-feeding
  – Be ready for conflict between you, the patient, and the family as food becomes a discomfort

Palliative Nutrition

• Provide dietary advice and counseling
  – Do they feel sick after eating a certain food or meal? Do some foods or drinks sit better than others?
• Liberate strict diets to allow for patient food preferences
• Support the patient

Examples

• **Present favorite foods; present on attractive trays/plates**

• Fraction meals into 6 to 8 small portions per day

• Suppress strong smells – note that hot foods are more aromatic than room-temp or cold foods

• Modify meal texture as appropriate

• Advise the patient to avoid drinking during meals

• Encourage taking a breath of fresh air before meals

• Educate family to not nag the patient; but to gently encourage

• Make meals as social and cheerful as possible

Which looks more appetizing?
Examples

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Overview of ANH
Definition

“Artificial nutrition and hydration (ANH) is the provision of nutrition and fluids by any method other than normal eating and drinking.”
Methods of delivering ANH

Parenteral

• Large central vein
  – TPN (total parenteral nutrition)

Enteral

• Stomach (G-tube)
  – PEG (percutaneous endoscopic gastrostomy)
• Intestines
  – J-tube (jejunostomy feeding tube)
The Traditional Goals of ANH

1. Prolong life
2. Prevent aspiration pneumonia
3. Maintain independence and physical function
4. Decrease suffering and discomfort at the end of life

What patients are we talking about today?
The Terminal Population

Patients affected by:
- Cancer
- Stroke
- CVA
- Dementia
- Alzheimer’s Dementia
- Heart Disease
- CHF

- Pulmonary Disease
- COPD
- Emphysema
- Liver Disease
- Renal Disease
- AIDS
- ALS
- Failure to Thrive
The Terminal Population

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- Stroke
- CVA
- Dementia
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- Heart Disease
- CHF
- Pulmonary Disease
- COPD
- Emphysema
- Liver Disease
- Renal Disease
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- ALS
- Failure to Thrive
Terminal Cancer – Quality of Life

Multidimensional
• Functional status
• Psychosocial well-being
• Health perceptions
• Disease and/or treatment-related symptoms

= Health factors
Which are largely affected by nutritional factors

Lis, G. et al (2012)
Routine interventions cause discomfort

- Daily lab tests
- Regular radiographic exams
- Vital sign checking
- Weight determination
- Pulmonary hygiene
- Frequent turning
- Debridement of pressure sores
Why is ANH even an issue?

- Reduced oral intake in adv. cancer due to any or all:
  - Anorexia
  - Dysphagia
  - Nausea
  - Vomiting
  - GI obstruction

Rajimakers et al (2011)
Benefit versus Burden
Arguments for and against
For

• Basic human need
• Prevents confusion, agitation, neuromuscular irritability, prevents OIN, relieves thirst
• Does not prolong life to a meaningful degree
• Minimum standard of care
• Maintains bond with patient

Against

• Interferes with patient acceptance of terminal condition
• Painful and intrusive IV therapy
• Prolongs suffering/dying process
• Avoid incontinence, catheter
• Reduce nausea and vomiting
• Reduce secretions and coughing
• Minimize ascites and edema
• Ketones act as a natural anesthetic to decrease suffering
• May lead to restraints

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- Basic human need
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Ethically responsible

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- Interferes with patient acceptance of terminal condition
- Painful and intrusive IV therapy
- Prolongs suffering/dying process
- Avoid incontinence, catheter
- Reduces use of restraints
- Reduces coughing
- Minimize ascites and edema
- Ketones act as a natural anesthetic to decrease suffering
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Patient Discomfort
Patients report discomfort from ANH

- Nausea
- Vomiting
- Diarrhea
- Esophageal perforation
- Electrolyte imbalances
- Edema (peripheral or pulmonary)
- Dyspnea
- Increased urinary output
- Incontinence
- Ascites
- Pulmonary secretions
- Increased intestinal drainage
- Iatrogenic infections

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- **Vomiting**
- **Diarrhea**
- **Esophageal perforation**
- **Electrolyte imbalances**
- **Edema** (peripheral or pulmonary)
- **Dyspnea**
- **Increased urinary output**
- **Incontinence**
- **Ascites**
- **Pulmonary secretions**
- **Increased intestinal drainage**
- **Iatrogenic infections**

Increased comfort from NOT giving ANH

“Ironically, ANH can prevent the ketosis and dehydration that are a protective mechanism against potentially painful symptoms of dying.”


- ↓ pain and suffering
- ↓ dyspnea
- ↓ edema and ascites
- ↑ mental acuity

Comfort from Forgoing ANH

Adapted from Smith, S.A. (1997)

Decreased intake

- Dehydration
- Ketoacidosis

- Dynorphin production
  - Analgesia

- Endorphin production
  - Reduced hunger
  - Analgesia, Anesthesia
Comfort from Forgoing Hydration

- Decreased intake
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    - Dynorphin production
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  - Ketoacidosis
    - Endorphin production
      - Reduced hunger
    - Analgesia, Anesthesia

Adapted from Smith, S.A. (1997)
As death approaches, the body’s need for nourishment decreases

- Impaired gag reflex
  - Dysphagia
  - Reduced oral intake

- Reduced kidney function
  - Decreased urine output

Durham et al (1997); AMA (1999)
Why does AH make some patients feel discomfort?

Adapted from Smith, S.A. (1997)
Dehydration differs in terminally ill patients

Healthy Individuals

- Cessation of fluid intake
- Thirst, dry mouth
- Headache, fatigue

Labs:
- High BUN (6-20 mg/dL)
- High creatinine (0.7-1.3 M, 0.6-1.1 mg/dL F)
- Low sodium (135-143 mEq/L)

Terminally Ill Individuals

- Fatigue, drowsiness
- Cessation of fluid intake
- Thirst and dry mouth unrelated to hydration

Labs:
- Relatively normal

Dunlop, R.J. (1995); NIH MedlinePlus
Three types of dehydration

Hyponatremic dehydration
- Sodium loss
- Occurs with fluid intake in absence of food intake

Hypernatremic dehydration
- Water loss
- Lack of fluid intake, but sodium received from medication or food

Eutremic (Isotonic) dehydration
- End-stage/terminal dehydration
- Gradual; proportionate decrease in sodium and water

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- Gradual; proportionate decrease in sodium and water

Adapted from Smith, S.A. (1997)
Morita, et al. - Background

- **Purpose**: explore association between hydration volume and lab values; between fluid balance and changes in dehydration signs & fluid retention
- **Population**: terminally ill cancer patients, last week of life
- **Study design**: secondary analysis of large multicenter prospective observational study
- **N=125**, abdominal cancers
- **Groupings**: Hydration (n=44), Nonhydration (n=81)
  - Hydration defined as >1L hydration/day both 1 and 3 weeks before death
Morita, et al. - Findings

• Albumin
  – Mean albumin level 1 week before death lower in hydration group

• BUN/creatinine, sodium, potassium
  – No significant difference

• Fluid balance, nonhydration
  – (-)521 mL/d 1 week before death
• Albumin
  – Significant interaction between albumin decrease and hydration
    • 3 weeks to 24 hrs before death: P=0.015
    • Difference at 1 week: P=0.005

<table>
<thead>
<tr>
<th>Albumin levels (mg/dL)</th>
<th>Hydration Group</th>
<th>Nonhydration Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 wks before death</td>
<td>2.8 ± 0.68</td>
<td>2.8 ± 0.53</td>
</tr>
<tr>
<td>1 wk before death</td>
<td>2.4 ± 0.52</td>
<td>2.7 ± 0.50</td>
</tr>
<tr>
<td>24 hrs before death</td>
<td>2.4 ± 0.56</td>
<td>2.6 ± 0.45</td>
</tr>
</tbody>
</table>

Fig. 1. Association between hydration practice and changes in laboratory findings. (○) Hydration group (n = 37); (●) nonhydration group (n = 56).

Morita, et al. - Findings

• Hypoalbuminemia with excessive fluid therapy
  – Mechanism: dilution
  – Findings support assumption that excessive AH can result in fluid retention via decreased colloid osmotic pressure
Morita, T. et al. (2006) - Findings

- BUN/creatinine, sodium, potassium
  - Sodium and potassium normal even in nonhydration group
  - Points to differences in water metabolism

<table>
<thead>
<tr>
<th>Lab values 1 week before death</th>
<th>Hydration Group</th>
<th>Nonhydration Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>BUN/creatinine</td>
<td>46 ± 20</td>
<td>40 ± 21</td>
</tr>
<tr>
<td>Sodium (mmol/L)</td>
<td>135 ± 6.4</td>
<td>136 ± 0.48</td>
</tr>
<tr>
<td>Potassium (mmol/L)</td>
<td>4.4 ± 0.72</td>
<td>4.4 ± 0.88</td>
</tr>
</tbody>
</table>
Fig. 1. Association between hydration practice and changes in laboratory findings. (○) Hydration group (n = 37); (●) nonhydration group (n = 56).

Dehydration in terminal patients

Comfort from Forgoing Nutrition

Adapted from Smith, S.A. (1997)

Decreased intake
  - Dehydration
  - Ketoacidosis
    - Dynorphin production
    - Endorphin production
      - Analgesia
      - Reduced hunger
      - Analgesia, Anesthesia

Adapted from Smith, S.A. (1997)
As death approaches, the body’s need for nourishment decreases

- Impaired gag reflex
  - Dysphagia
  - Reduced oral intake
- Gastrointestinal motility decreases
  - Increased risk of fecal impaction
  - Sphincter relaxation – increased risk of incontinence if continued to be fed
  - Abdominal distress if fed

Durham et al (1997); AMA (1999)
How do you decide?
Decision making

- Tailor the decision to each case
- Utilize the support and perspective of a multidisciplinary team
  - Physician
  - Nurses
  - Social workers
  - Chaplain
  - Dietitian
- Communicate and empathize with the family
- Support one another, the patient, and the family

“It is highly recommended that decision making regarding hydration be highly individualized, with a multidisciplinary focus, in which team members (such as nurses, social worker, chaplain, dietitian) not only share their opinions but also support each other and the patient and their family, in these decisions.”

- Dalal, S. et al (2009), see references for clinical guide
Familial and Cultural Considerations

“We associate eating with life itself; it is something never to be denied.”

- Smith, S.A. (1997)
“Feeding has a powerful symbolic and social significance for patients and their family. Difficulty in eating and drinking often cause an anxiety in the patients’ entourage, who worry that the patient will starve to death.”

- Prevost, V. and Grach, M.C. (2012)
Food versus Nutrition

- **Food and drink = social**
  - Nurturing, caring
  - Social connections
  - Socially normative way and tools
    - Via mouth, using utensils

- **Nutrition and hydration = medical**
  - Not gaining social connection from feeding
  - Socially nonnormative way and tools
    - Not via mouth, using tube or IV

The Family’s Perspective

• Patient not eating -----> their fatigue

• Eating, providing food = caring, love, support

• Not providing ANH (food/drink) = abandonment
Helping the family cope

- Correcting the misconception
  - Replace “feeding tube” with the term “gastric tube” or “stomach tube”
  - Removes the emotion from the term

- Explain that loss of appetite is normal and that food or drink may cause discomfort

- Teach them other ways to “care”

Does ANH work?
The Traditional Goals of ANH

1. Prolong life
2. Prevent aspiration pneumonia
3. Maintain independence and physical function
4. Decrease suffering and discomfort at the end of life

“Studies show that tube feeding does not appear to prolong life; moreover, complications from tube placement may increase mortality.”

Goals versus Reality

Goals
1. Prolong life

Reality
1. Some studies report longer survival times without ANH

Goals versus Reality

Goals

1. Prolong life
2. Prevent aspiration pneumonia

Reality

1. Some studies report longer survival times without ANH
2. Aspiration pneumonia can result from ANH

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3. ANH restricts family life and social involvement

Goals versus Reality

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**Reality**

1. Some studies report longer survival times without ANH
2. Aspiration pneumonia can result from ANH
3. ANH restricts family life and social involvement
4. A dying body does not assimilate nutrients and fluids well, often leading to discomfort. Ketosis and endorphins reduce suffering.

Goals versus Reality

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Reality
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2. Aspiration pneumonia can result from ANH
3. ANH restricts family life and social involvement
4. A dying body does not assimilate nutrients and fluids well, often leading to discomfort. Ketosis and endorphins reduce suffering.
When is ANH clinically indicated?
Situations of EoL care where ANH helps

• Opioid induced delirium
• Myoclonus
• Hallucinations
• Agitation

Delirium

Final Days/Hours

• Does not respond to hydration

General Dying Stage

• Irreversible delirium from hypoxia or organ failure
• Reversible opioid-induced neurotoxicity (OIN)
  – Reverse with <1000 mL/day fluids, without causing discomfort from overhydration
  – Rotate between hydration and opioids

Practice versus Evidence
ANH as a medical last rite

“Many physicians believe that ANH occupies a unique niche as both life-extending and palliative.”

“Thus, it has been relatively difficult to convince health care professionals that it is appropriate to withdraw ANH, despite ethical guidelines and court decisions that support the practice.”

Example Advance Directive Form

2. **These are My Directives about Prolonging My Life:**

   In those situations **I have initialed** in Section 1, I direct that my health care providers (initial only one):

   ________ may withhold or withdraw life-prolonging measures.

   ________ shall withhold or withdraw life-prolonging measures.

   **Up to the physician**

   **Don’t do it!**

3. **Exceptions – “Artificial Nutrition or Hydration”**

   EVEN THOUGH I do not want my life prolonged in those situations I have initialed in Section 1 (initial only one):

   ________ I *DO* want to receive BOTH artificial hydration AND artificial nutrition (for example, through tubes) in those situations.

   ________ I *DO* want to receive ONLY artificial hydration (for example, through tubes) in those situations.

   ________ I *DO* want to receive ONLY artificial nutrition (for example, through tubes) in those situations.

   **Initial a choice in Section 3 only if you want to make an exception to your instructions in Section 2**

   **Initial only one**
ANH and Quality of Life (QoL)

• Zhang, B. et al (2012) identified factors important for QoL in terminal patients

• **Use of a feeding tube** in the final week of life was **negatively correlated with QoL**

They concluded that limiting “intensive life-prolonging care [such as] chemotherapy and feeding tubes...may be an effective strategy to enhance QoL at the end of life.”
ANH as a medical last rite

• Thinking of ANH as a necessary treatment until the last breath of life is unwarranted because:
  – Death after withdrawal of ANH is usually comfortable
  – Continued ANH can cause discomfort

Status indicators

• At end-of-life, medical attention should be focused on **patient comfort**

• However, an empirical survey found that **laboratory values still compromise an important factor** when physicians are deciding if ANH is indicated

Status indicators

• Empirical studies have shown that laboratory values should not be used as endpoints for ANH in the terminal stages of cancer
  – BUN and creatinine constantly increase in the last 3 weeks of life regardless of ANH
  – Sodium and potassium levels are essentially normal and are unaffected by AH
  – Water metabolism in terminal stage cancer differs from healthy and acute stage patients

Hospice versus Acute Care

• The majority of fluid deficient terminally ill patients almost always receive AH in acute care, but almost never in hospice.

• Most PC caregivers don’t believe that ANH alleviates symptoms; and think of ANH as an additional burden at the end of life

“The frequent practice of providing ANH during the last days of life is not based on evidence of its effectiveness.”

So why does it happen?

- Lack of evidence dissemination
- Positive attitude of terminal patients and relatives towards ANH in the last week of life
- Because we can.

“Technological and medical advances have created a conflict between the application of autonomy, nonmaleficence, beneficence, and justice and certain kinds of medical treatment.”

— AND Position Paper

“When medicine is no longer able to cure, physicians may still positively and significantly influence the lives of their patients...preventing unnecessary hospitalizations and receipt of life-prolonging care, physicians can enable their patients to live their last days with the highest possible level of comfort and care.”

In Sum

• ANH can cause discomfort in terminal, end-of-life cancer patients

• Forgoing ANH can increase comfort and aid in a better death

• There are situations where small amounts of AH can reverse symptoms in this population

• Decisions should be made case-by-case and take into account all perspectives
Position Papers

Academy of Nutrition and Dietetics
Japanese National Guidelines
American Society of Parenteral and Enteral Nutrition
Withdrawal of ANH: Legal, Ethical Perspective
“It is the position of the ADA (AND) that individuals have the right to request or refuse nutrition and hydration as medical treatment. RDs should work collaboratively to make recommendations on providing, withdrawing, or withholding nutrition and hydration in individual cases and serve as active members of institutional ethics committees.”
American Society of Parenteral and Enteral Nutrition

“Decisions regarding ANH should be based on evidence-based medicine, best practices, and clinical experience and judgment in discussion with the patient, family, or significant others.”

“From a scientific, ethical, and legal perspective there should be no differentiation between withholding and withdrawing of ANH, thus [ASPEN] employs the term “forgoing” for both, recognizing that withdrawing is more emotionally laden than withholding, especially within specific cultures.”
ANH at the End-of-Life
Japanese National Guidelines

“Dehydration and/or water depletion in the terminal stage does not always cause discomfort for patients. Improvement in objective findings, such as laboratory findings, urine volume, and central venous pressure, are not primary end points in artificial hydration therapy.”

“Artificial hydration therapy of 1000 mL/d or more can deteriorate distress related to ascites, pleural effusion, peripheral edema, pleural effusion, and bronchial secretions in terminally ill patients with cancer.”
American Society of Parenteral and Enteral Nutrition

“Artificial nutrition in terminally ill patients can lead to discomfort due to fluid overload, pulmonary and generalized edema, shortness of breath, etc. and may be discontinued on clinical and ethical grounds provided such discontinuation is not in conflict with existing laws, institutional polices and consent/consensus of decision makers.”
Thank you for your time!

Questions?
References
References


References


References

Additional Resources
Decision Making


Recommendation for clinical decision-making when considering hydration at end of life consists of the following points:

(1) initial assessment;
   (a) determine the presence of fluid deficits (history, physical examination);
   (b) determine symptom burden (multidimensional assessment tools; relationship to one);
   (c) determine impact of symptoms on quality of life, patient/family distress, function;
(2) determine benefits against burden of artificial hydration;
   (a) hydration may be beneficial if cognitive changes, delirium, OIN;
   (b) may not be beneficial for symptoms of thirst/dry mouth;
   (c) determine disadvantages (hospitalization, mobility, discomfort; not an issue with HDC);
(3) determine patient/family preferences and goals;
   (a) discuss both benefits and burdens of hydration;
   (b) disclose uncertainties in this area;
   (c) discuss trial of hydration to determine benefit;
   (d) provide alternatives if hydration not considered;
   (e) emotional support;
   (f) inform patient that hydration can be ethically withheld and withdrawn;
(4) if hydration considered;
   (a) consider HDC;
   (b) administer appropriate volumes (usually less than 1000ml per day);
   (c) consider discontinuation if no perceived benefit.
### Benefits versus burdens of nutrition

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Burdens</th>
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<tbody>
<tr>
<td><strong>Oral Nutrition</strong></td>
<td></td>
</tr>
<tr>
<td>Natural</td>
<td>Alertness required</td>
</tr>
<tr>
<td>Easy</td>
<td>Aspiration</td>
</tr>
<tr>
<td>Sensuous</td>
<td>Feeding assistance may be required</td>
</tr>
<tr>
<td>Symbolic</td>
<td>Religious/dietary restrictions</td>
</tr>
<tr>
<td>Inexpensive</td>
<td>Taste, appetite dependent</td>
</tr>
<tr>
<td><strong>Enteral Nutrition</strong></td>
<td></td>
</tr>
<tr>
<td>Alertness not required</td>
<td>Requires supervision</td>
</tr>
<tr>
<td>Convenient</td>
<td>Aspiration</td>
</tr>
<tr>
<td>Relatively safe</td>
<td>Metabolic</td>
</tr>
<tr>
<td>Mildly invasive</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Inexpensive</td>
<td>Requires access</td>
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<tr>
<td>Maintenance, restoration of</td>
<td>Bloating, early satiety</td>
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<tr>
<td>mucosal integrity</td>
<td></td>
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<tr>
<td><strong>Parenteral Nutrition</strong></td>
<td></td>
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<tr>
<td>Gut not required</td>
<td>Metabolic complications</td>
</tr>
<tr>
<td>Specific nutrients provided</td>
<td>Increased monitoring required</td>
</tr>
<tr>
<td>Independent of appetite</td>
<td>Requires access</td>
</tr>
<tr>
<td>Precise Intake</td>
<td>Catheter infections and thrombosis</td>
</tr>
<tr>
<td></td>
<td>Relatively more expensive</td>
</tr>
</tbody>
</table>
A Suggested Approach

An expansion of the 9Cs proposed by Barrocas\(^\text{16}\) provides a template for dealing with the three forces (technology, ethics, and law) that may conflict. The 12Cs are as follows:

1. Common sense
2. Common decency
3. Competence
4. Commitment
5. Communications
6. Consultation
7. Collaboration
8. Consent/consensus
9. Concern
10. Care
11. Compassion
12. Comfort

The 12Cs of Decision Making in ANH