Forgoing Artificial Hydration and Nutrition at End of Life

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Goals

- Define artificial hydration and nutrition.
- Discuss the medical, ethical and legal aspects of artificial hydration and nutrition (AHN) at the end of life (EOL).
- Identify and explore our personal beliefs and values about AHN at EOL.
- Develop a knowledge base to participate in discussions about forgoing AHN.

HPI

- 10 month old male, ex 28 week premie with CP and tracheostomy without ventilator dependence, Gtube.
- Presents s/p cardiac arrest at home secondary to blockage of tracheostomy.
- Home care nurse not able to clear blockage or change tracheostomy.
- CPR for approximately 25 minutes before return of spontaneous conduction. Airway not reestablished until arrival at ED.

Hospital course

- In the 72 hours post arrest…
  - Myoclonus that ceases by day two
  - Vital signs remain stable
  - MRI on day 2 shows severe HIE
  - Does not qualify for brain death criteria testing at 72h- continues to breathe
  - Neurologist gives poor prognosis

Palliative plan

- Palliative care team consultation
- DNR/DNI
- No artificial hydration or nutrition
- Morphine for comfort
- No artificial ventilation or supplemental oxygen
  - humidification to tracheostomy only
- VS Q4h
- Continue basic patient cares [physical hygiene]
- No blood work or IV access attempts
- Patient to remain in hospital for remainder of life

What is your initial reaction to the plan?
Defining palliative and end of life care

- Palliative Care
  - Approach that improves quality of life for patients and families with life-threatening illness (WHO).
  - Active total care for patient whose disease is not responsive to curative treatment (EAPC).
  - Specialist care for all people living with and dying from an eventually fatal condition; goal is quality of life (PAC).
  - Terminal care: No longer used. Last days of illness, death unavoidable, no treatment options.
- End of life care: no exact definition due to lack of clinical indicators to predict time of death, therefore it is impossible and unreasonable to define the time period of end of life care.
- PICU lens: EOL often more predictable due to withdrawal of withholding of medical intervention.

Defining AHN

- Artificial = medical
  - AHN require an order from a licensed prescriber and include any fluid or food delivered via nasal/oral gastric tube, G/J tube or intravenous catheter.
- “Natural” feeding must be taken orally and involve the action of swallowing and includes breast/bottle feeding and assisted self feeding.
- ESPEN includes oral nutritional supplements as artificial nutrition.

AHN Facts

- Patients without artificial hydration die comfortably and do not suffer.
- Artificial enteral nutrition has no benefit in arresting or reversing wasting process associated with the dying process.
- Cessation of food/drink is a normal part of dying.
- Symptoms of dehydration, hunger not common at end of life.
- Forgoing AHN is not starvation or euthanasia.
- “Evidence suggests that feeding at the end of life is futile”.

Risks and side effects of AHN

- Fluid overload
- Increased urination leading to frequent incontinence
- Need for catheterization
- Skin break down
- Respiratory tract secretions
- Increased gastric secretions increasing the risk of aspiration
- Increased ICP resulting in coma, twitching, irritability
- Stomach overload
- Refeeding syndrome
- Rapid feeding, loss of sphincter control, tube migration
- Nasal, esophageal erosions and necrosis
- Psych: disturbed body image with NG and risk of malnutrition
- Predisposition for aspiration pneumonia
- Need for physical restraint for tube maintenance
- Continued administration of inappropriate medication
- Medical costs

Legal

- Withdrawing vs withholding
- A brief history of AHN in America
- Addressing quality of life
Withholding vs Withdrawing

There is **no** legal or ethical distinction between withholding and withdrawing AHN or other life sustaining therapies.

American Medical Association, 2005; Tsai, 2011

**A very brief history of AHN in America**

- 1973: Child abuse and Neglect Prevention Act
- 1982: Baby Doe
- 1983: Baby Jane Doe
- 1988: Baby Doe Amendment to Child Abuse and Treatment Act

White, 2011; Brand et al., 2016

**Legal Summary:**

When is it appropriate to withhold medical treatment?

- Chronically and irreversibly comatose
- Treatment would prolong dying
- Provision of treatment would be futile in terms of survival and treatment would be inhumane.
- Decision made by physician(s) based on rational medical judgement

The opposing view: quality of life

- The Baby Doe Amendment seen as unequivocal.
- Law does not consider quality of life.
- Prior to the Baby Doe Amendment, the AMA had already endorsed the quality of life standard.

Ethics and Morality

- **AUTONOMY**
- **BENEFICENCE AND NON-MALIFICENCE**
- **FOOD AND WATER ARE BASIC**
- **PARENTAL EXPERIENCES**

Autonomy

- Autonomy recognizes the right of a person to make a personal choice.
- Autonomy does **NOT** mean that a patient has the right to obtain every treatment he/she wishes or requests if the treatment is not medically indicated.
- Parental Authority vs Autonomy.
Beneficence and non-maleficence

- The Ethical Test: Risk/Burden Vs. Benefits.
- Prolonging life is not always the goal, especially when it prolongs the dying phase.
- If a therapy is stopped, standard care of palliative care (comfort) must be provided.
- If AHN is started, it must be reviewed at regular intervals to determine continued medical justification.

Food and water are BASIC

- Children who are capable of eating and drinking, are thirsty or hungry and have no medical contraindications should be given food/drink by mouth.
- BASIC does not mean morally necessary.
- Medical treatment that is judged to be harmful, of no benefit or futile is inappropriate and should not be offered or provided.
- Eating is a social behavior.

Guilt and suffering

- Concern for increased suffering.
- No medical evidence that forgoing AHN increases suffering.
- Must have consciousness to suffer.
- Common parental fears are “starvation”, “dehydration”.
- “You just can’t let her die”. The fear of not doing anything/everything.
- Majority of parents are happy with the decision to forgo AHN.
- Many parents felt child comfort was increased.

Navigating discussions about AHN at EOL

1. Identify the Goals of Care with patient/family.
   - Prolong life? Provide comfort? Avoid suffering?
2. Develop a comprehensive plan of care based on goals of care.
   - Involve parents (and patient if possible) in all decisions.

Navigating discussions about AHN at EOL: continued

3. During subsequent conversations with the family, focus on goals of care not withdrawing/withholding treatment.
4. Parents emphasized that the team speak in one voice.
   - Opinions of dissenting team members should not be shared with the family.
   - Perceived or actual confusion of plan among the medical team can lead to feelings of being negatively judged.

References