Handout

Withholding and Withdrawing Life-sustaining Treatment

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Notes on Case 1

- Do subcutaneous fluids provide any worthwhile benefit?
- Do artificial fluids prolong life?
- What are the likely benefits and risks of receiving ANH?
- What causes thirst?
  - *Does this diminish at the end of life, and if not, do artificial fluids offer better relief than other methods?*

Case 1: The Evidence About Fluids

- Cancer cachexia syndrome removes feelings of hunger for most patients (Davis 2004)
- Desire for fluids has been found to lessen towards end of life (McCann 1994)
- Biochemical analysis in last few days of life conflicting
- Hydration may be harmful in producing symptoms associated with fluid accumulation

Case 1: The Evidence About Fluids

- Delirium may be improved with fluids possibly by preventing accumulation of opioid metabolites
- Thirst probably not helped
- Experience in UK suggests most people die peacefully without fluids and are helped by good mouth care but hard to evidence base this
- Disputed by other authors suggesting end of life care can be improved with fluids
- Conflicting evidence about practical issues with parenteral hydration and whether subcutaneous route is best

Case 1: The Evidence About Fluids

- A fair summary?
  - To consider fluids for agitation and signs of opioid toxicity e.g. myoclonus
  - To avoid fluids in patients with (or at risk from) ascites, effusions and oedema
  - Subcutaneous route should be sufficient
- If a patient is not imminently dying and declines ANH then hunger tends to disappear after 1-2 days and death occurs in 7-14 days (Sullivan 1993, Ganzini 2003)

Case 1: The Evidence: ANH in MND and Dementia

- MND
  - Conflicting evidence with some studies suggesting improved survival and quality of life and others not
  - Poor recovery from procedures if respiratory function impaired
- Dementia
  - No convincing evidence that survival or quality of life improved.
  - Swallowing problems usually a sign of limited prognosis and many practical problems with tubes

Case 1: The Decision Making Process

- Does the patient have capacity to be involved in decision making?
- Has the patient made any advanced decisions?
- What is the patient’s quality of life?
- What are the likely future complications, benefits and nature of death?

Case 1: The Decision Making Process

- For patients who lack capacity, what is in their best interests?
  - Is life still sweeter than death? Is dignity being preserved? Is comfort better?
  - Not motivated by a desire to hasten death
  - 2nd opinion

Case 1: The Decision Making Process

- How much weight should the team give to the views of the family?
- How should the full multidisciplinary team be involved in the decision making?
- What is your bottom line? If the family insist in a dying patient would you give artificial fluids?

Communicating and Exploring Ideas, Concerns and Expectations

- How to answer relatives' questions
  - "While there's life there's hope"?
  - "You can't just let him starve / dehydrate to death"
- What are the common concerns of families?
- What do people understand about the use of ANH at the end of life?
- What happens when people don't die as soon as expected?

Case 1: Concerns of Families

- Taking away an act they can do
- Shortening life
- Causing more discomfort
- Perceive thirst as dehydration
- When people don't die as soon as expected this affects:
  - The burden on the family
  - The trust in health care professionals
  - Different approach to fluids as the current guidance applies mainly to last 48 hours or so

Further Reading

- Artificial nutrition and hydration in the adult palliative care setting. Guidance from the Association for Palliative Medicine and National Council for Palliative Care. Due out soon.
- Fainsinger R. Hydration in Gastrointestinal symptoms in advanced cancer (2002). Editors: Ripamonti C and Bruera E. Oxford University Press, Oxford.

Notes on Case 2: Outcomes from CPR

- 41% of patients in hospital survive the immediate CPR attempt
- 13% survive to discharge *[Ebell 1998]*
- In cancer patients:
  - 22% survival for patients suffering a sudden, unanticipated cardiac arrest
  - 0-2% survival for patients with an anticipated arrest due to pre-existing condition unresponsive to treatment
  - Patients spending >50% of time in bed have a 2-3% chance of survival *[Vitelli 1991 Ewer 2001 Wallace 2002]*

Case 2: Outcomes from CPR

- **Good outcome with**:
  - Reversible medical condition
  - Sudden, witnessed heart rhythm disturbance
  - In hospital
- **Poor outcome with**:
  - Non-witnessed arrest
  - Outside hospital
  - Co-morbid disease: pneumonia, renal & heart failure, sepsis, hypoxia
  - Prolonged attempt
- Neither metastatic disease or age per se are predictive of response to CPR

Case 2: Patients' Views

- TV suggests better outcomes than real life *[Gordon et al 1998, Diem 1996.]*
- Feel it is always successful
- Feel Drs should discuss CPR *[Mead & Turnbull 1995]*
- Patients less likely than Drs to want CPR
  - Agreement between two groups is poor in both directions

Case 2: Long-term Outcomes

- Generally some impairment but quality of life considered satisfactory by patients
- But only ~ 2/3 of survivors could be studied because the rest were too poorly or died shortly after discharge
- Quality of life related to duration of arrest and condition pre-arrest *[Nichol 1999, de Vos 1999]*

Case 2: The Decision Making Process for a Patient with Capacity

- What are the expected benefits and harms of a CPR attempt?
- What are the patient's views on receiving information and being involved in decision-making?
- How much information needs to be given in order to make an autonomous decision?
- How does the patient perceive their quality of life?

Case 2: The Decision Making Process for a Patient with Capacity

- What are the likely future complications and nature of death?
- How should the full multidisciplinary team be involved in decision making?
- Can a compromise be reached about some active treatment but not CPR?
- What is your bottom line? If the patient insists on CPR attempts would you initiate it?

Communicating and Exploring Ideas, Concerns and Expectations

- Are you asking a question or passing on a decision already made?
- Are you discussing just CPR or a general approach to end of life care?
- What are the burdens on patients and families of such discussions?
- What is understood about CPR – the processes and outcomes?
- Does Trust policy conflict with what you see as being ‘good practice?

Communicating and Exploring Ideas, Concerns and Expectations

- What are the effects on the family if they feel they are responsible for decisions to either initiate or withhold CPR?
- Is the aim to work together towards a decision or towards clarifying a decision already made?
- Avoid misleading people by creating an impression they have a choice when they do not

Notes on Case 3: Key Decision Making Points

- Consultation with respiratory physician regarding wishes for ventilation
- Admission to critical care for respiratory support
- Decision to start invasive ventilation
- Decision to send home
- Husband’s role in deciding place of death

Notes on Case 3: The Clinical Evidence

- Patients with MND previously thought to maintain capacity but increasing evidence of frontal lobe damage and dementia
- Respiratory failure and associated infection is the usual cause of death
- Reports of patients being kept alive for long periods of time with ventilation and consequently being “locked in” i.e. totally unable to communicate
- Home ventilation is possible
- Misperceptions about the nature of death with MND and the symptom relief available

Case 3: The Decision Making Process

- Did Mrs S have capacity for each key decision?
- Was she fully informed when making the decision about each key decision?
- Was she fully informed and with sufficient capacity when decisions were made in critical care?
- Were alternatives offered to her in a balanced and fair way?

Case 3: The Decision Making Process

- What are the expected benefits and potential harms of ongoing ventilation?
- How should the husband be included in the decision-making process?
- What is your bottom line? Would you intubate and ventilate Mrs S?
- Should the advance directive be reviewed?

Communicating and Exploring Ideas, Concerns and Expectations

- What are the reasons behind Mrs S's decision to keep going with ventilation?
- Are there fears about how she will die?
- What are the key skills in communicating to Mrs S about this situation?
- How should the full multidisciplinary team be involved in the decision making?

Communicating and Exploring Ideas, Concerns and Expectations

- Should Mrs S be asked what should be done? Or merely informed of a decision already arrived at?
- How to answer the question: “You can’t just let me die?”
- What are Mr S’s fears about her being at home?
- What does Mr S feel about Mrs S’s decision?

Notes on Case 4: The Clinical Evidence

- No evidence base, as such, to refer to
- Draining the fluid from her lung and correcting her anaemia will help breathing with relatively few complications
- Admission to hospital is always associated with risks
  - Acquired infections
  - Worsening cognitive function
  - Decreased independence
  - Physically draining

Case 4: The Clinical Evidence

- Risk of dying in hospital and not fulfilling her wishes
- Palliative measures have also been shown to improve breathlessness

Case 4: The Decision Making Process

- Does Mrs B have capacity for this decision?
- What are the expected benefits and potential harms from acute admission to hospital?
- What does Mrs B understand about her condition, and on what basis has she made this decision?

Case 4: The Decision Making Process

- What do her family understand about her condition? What are their concerns in wanting her admission? What influences their views?
- To what extent were her previously expressed wishes an autonomous advanced decision?

Case 4: The Decision Making Process

- What other options are there in managing this situation – could a compromise be achieved?
  - Managing the breathlessness in other ways
  - 2nd opinion
  - Increase care package at home

Communicating and Exploring Ideas, Concerns and Expectations

- Predicting when someone is dying soon can be difficult
- What should be the priorities at this time of life?
- What do the family understand?
- Is there a burden of care on the family?

Notes on Case 5: The Clinical Evidence

- No evidence base, as such, to refer to
- Hospital can offer intravenous anti-biotics and hydration as well as watching for other complications
- Admission to hospital is always associated with risks
  - Acquired infections
  - Change from familiar nursing staff and surroundings
  - Worsening cognitive function
  - Decreased independence
  - Nursing care less aware of Mrs D's needs
- Risk of dying in hospital

Case 5: The Decision Making Process

- Did Mrs D ever make her wishes known as to what she might have wanted in this situation?
- What are the expected benefits and potential harms from acute admission to hospital?
- What does her daughter understand about her condition? What are her concerns in declining admission?
- What other options are there in managing this situation – could a compromise be achieved?
  - Managing any symptoms in other ways
  - 2nd opinion
  - Additional support for home

Communicating and Exploring Ideas, Concerns and Expectations

- What does Mrs D’s daughter understand about her condition? What are her concerns in declining admission?
- What is likely to happen next?
- How should other members of staff at the home be involved in the decision making process?