Food and fluids in Palliative and End of Life care

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Learning Objectives

- Understand issues related to food and fluids along the palliative care trajectory
- Describe potential benefits and burdens of artificial hydration and nutrition at the end of life
- Understand the appropriate use of hydration and nutrition at the end of life and how to discuss this with patients their relatives and carers

(Independent review of the Liverpool care pathway 2013, recommendation 1.64, pg 28)

Literature

- Decreased oral intake of food and fluids and anorexia is a frequent problem at the end of life - 39-82% of patients receiving palliative care (1-3)
- Loss of appetite is one of the most common symptoms in patients when referred to palliative care (2)
- Causes considerable emotional distress for relatives (3&4)
- Literature tends to focus on artificial hydration and nutrition (practices, clinical effects, attitudes, ethics) (6-13)

Oral intake

- Dry mouth
  - Decreased secretion of saliva
  - Diseased buccal mucosa
  - Excessive evaporation of fluid
- Caused by the cancer
- By treatment
  - Radiotherapy, surgery, stomatitis
  - Drugs (opioids, diuretics, anticholinergics)
- Related to Ca or debility
  - anxiety, depression dehydration, infection

Abnormal taste

- Sour
- Bitter
- Sweet
- Salt
- Why?
  - decreased sensitivity of taste bud, decreased numbers, toxic dysfunction, nutritional deficiencies or drugs
- Exacerbated by:
  - Poor oral hygiene
  - Oral candidiasis (thrush)
- Sense of smell decreases with age
Reduced oral intake: Address reversible causes

- Fear of vomiting
- Food
  - Unappetising
  - Too much
- Early satiety
- Dehydration
- Constipation
- Sore mouth
- Pain
- Fatigue
- Malodour
- Heartburn
- Biochemical
  - Hypercalcemia
  - Hypoaesthesia
  - Uraemia
- Secondary to treatment
  - Drugs
  - Radiotherapy
  - Chemotherapy
- Disease process
  - Obstructions and obstructions, loss of swallow reflex
- Anxiety
- Depression

Food and fluids in EOL care

- The patients son is concerned that his mother is not drinking or eating he asks you “what will happen about now, how will she get fluids”?

COMMEND study

COMMunication regarding food and fluids towards the END of life

- **AIM:** To gain insight regarding communication related to food and fluids at the end of life in a specialist palliative care service in NZ
- **METHODS** Observational, qualitative research
  - Participant observations
  - Interviews (staff and bereaved relatives)
  - QODD questionnaire

Key themes: relatives (23)

- **Meaning of oral intake at the EOL for family members**
  - Nutrition
  - Enjoyment
  - Social time
  - Structure – the ‘rhythm’ of the day
  - Accommodating and tempting
- **Interpreting and responding to decreased oral intake included recognising**
  - Changes as part of the process
  - The vicious circle
  - The patients choice/ their choices
- **Communication**

Vicious circle

- Will try to eat for family, although no interest at all
- Is distressing (mentally and physically)
- ‘Feels the distress of family due to not eating’
- ‘Don’t want family to be upset’
- ‘Don’t want to waste food’
- ‘Want patient to eat (more)’
- ‘You have to eat’
- ‘Still eating, thus not dying’
- ‘Temping, will try everything’
- ‘Don’t realize not eating due to dying, think will die if not eating’
- ‘Keeping eachother in the dark’

Overall conclusions

- Decreasing oral intake at the end of life has multiple meanings
- Psychological and social aspects of oral intake at the end of life are significant and need to be openly addressed
- Perceptions of decreasing oral intake are interconnected with awareness of dying
- Communication with health care professionals regarding oral intake at the end of life seems limited
- An opportunity to communicate about oral intake (including written material), and importantly, about dying
Artificial nutrition and hydration in the last week of life in cancer patients: practices and effects. A systematic literature review

Questions
(1) how and how often is AN and/or AH provided in the last week of life of cancer patients; and

(2) what is the effect of AN and/or AH during the last week of life on the quality of life of cancer patients; and

(3) does providing or not providing AN and/or AH hasten death or prolong life?

Results

• 2198 papers – 16 (11 from Asia)

• Reported percentages of cancer patients receiving AN or AH in the last week of life varied from 3% to 53% and from 12% to 88%, respectively.

• Five studies reported on the effects of AH: two reported positive effects (less chronic nausea after 48h and less physical signs of dehydration after AH), two reported negative effects (more ascites 24h before death and more intestinal drainage after AH) and four reported no effects on other outcomes, such as terminal delirium, thirst, chronic nausea and fluid overload.

• No study reported on the sole effect of AN. ANH was in one study found not to change patients’ comfort or survival time.

Conclusion

• Providing AN or AH to cancer patients who are in the last week of life has been reported to be a frequent practice. Evidence on the effects on quality of life and length of survival of its provision or non-provision is scarce. Further research will contribute to better understanding of this important topic in end-of-life care.

Cochrane

(Level A evidence - eg RCTs and high quality prospective controlled studies)

• Currently insufficient evidence to make recommendations for practice regarding medically assisted hydration and nutrition in palliative care patients.

Benefits and burdens

“For a treatment to be morally justified, there has to be greater benefit than burden.”

Artificial hydration – yes, maybe….!

- Symptom for which dehydration is most likely the cause
  - (thirst, malaise, delirium)
- Increased oral intake not feasible
- Anticipation it will relieve symptoms
  - (severe dysphagia, vomiting or diarrhoea)
- Patients underlying physical condition is generally good
  - (e.g. some people with head and neck cancer)

- Patient is willing
- Patient and family understand the purpose is to relieve symptoms and not cure.

It is advisable initially to give a provisional time limit for parental hydration, e.g. 2-3 days, after which it will be reviewed and if not helpful discontinued.

Likely burdensome when

- The patient requests not to have an invasive procedure
- The burdens out weigh the likely benefits
  - Likely to be ‘harmful’ if at risk of fluid overload (e.g. renal failure, congestive heart failure).
  - Likely to be harmful if albumin low normal range 35-45gL (3rd spacing – impact on tissue integrity and patient discomfort)
  - Likely to be harmful if IV access an issue and/or recanulation required
  - Likely to be harmful if precludes preferred place of care
- The patient is moribund for reasons other than dehydration

Quotes: Frank Brennan

- Standing on the platform. Stories and reflections from palliative care

  - Too often, as doctors, we speak practically and are heard emotionally (pg 17)

  - That death, that unique loss, will be remembered by that family and the story told over and over. What we do, how we do it and what we say will enter the narrative of that family forever. We now know that families have extraordinary recall of those last days – where they were, what they wore, what the doctor or nurse said when they entered the room. All of it shall be remembered (pg 59)

Food and fluids are often a source of concern

“The ethical situation is not that the patient is failing to drink and therefore will die, but that the patient is dying and therefore does not wish to drink”.

References


