Psychological issues in nutrition and hydration towards End of Life

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Why do people eat and drink? What does it MEAN to them?

What are some of the psychological issues in End Of Life (EOL) nutrition and hydration?

Psychological effects on the patient

Hydration and nutrition at the end of life: a systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff.

Del Rio et al, 2012 Psychooncology

Comprehensive literature review.

The majority of patients, families, and health care staff believe that increasing food and liquid intake is essential to stave off physical deterioration. However, this is not supported by objective evidence.
Emotional impact of the reduction of eating on the patient

- Reduced interest in eating, a limited capacity to digest food, dysphagia, fatigue, and altered body image are all highly correlated with serious psychological distress in EOL patient.
- Maintaining conscious control over eating is an adaptive process that allows patients to confront and manage the emotional and social consequences of barriers to feeding. E.g.
  - When patients force themselves to eat out of the fear that they may die of hunger or thirst, conflict with concerns about discomfort caused by ingestion.
  - Some patients are ambivalent about ongoing life, and may use reduction in eating as a way of expressing this.

Cultural differences

Western cultures
“Reducing food intake speeds up death”.

Hindu culture
“Reducing food intake is a sign of death, not a cause”

Taiwanese culture
“If a person dies hungry, the soul becomes restless and hungry”

- How might these ideas influence family preferences?

Family beliefs about reduction of eating

- "If we keep them eating, they'll live longer/feel better."
  - Especially common in families who either:
    - A) have not had a good explanation of why food and drink should be withdrawn;
    - B) are not yet ready to face the death of their loved one.
  - Insistence on forced feeding.
  - External blaming of patient and/or staff.
  - Anger at patient for not fighting for their life.
  - Anguish, frustration, conflicts between patient and family.
  - Can generate loneliness, guilt, and helplessness in the patient.

Family beliefs about reduction of eating

- "We are doing everything we can for our loved one"
  - Few effective tools to address nutritional problems, so health care staff more likely to focus their efforts on symptoms that they can control.
  - Perception that lack of focus on the patient's nutritional status is patient negligence.
  - Can lead to family acting as "watchdogs" excessively scrutinize staff actions, becoming an obstacle for the staff and their relationship to the patient.
  - Can impact on the patient's perceived sense of control over their eating/drinking.
  - BUT this belief can promote a healthy family grieving response after the patient has died.

Family beliefs about reduction of eating

- "We accept that our loved one is dying”
  - Families that accept the evolution of the patient toward an anorexic state are better able to put their time, energy, and focus on other care-giving activities.
  - Typically accept progressive reduction of food and liquid ingestion and expect it as a process of dying.
- "We accept that our loved one is dying, but sometimes we hope that if they just eat a bit more...”
  - Believe that the lack of feeding is a cause AND believe that it is a reflection of physical decline in the patient - struggle with these two conflicting beliefs.
  - Typically seen by healthcare professionals as deeply ambivalent individuals who behave inconsistently in response to nutrition/hydration plans for the patient.

Family beliefs about reduction of eating

- "As a family, we show our love through eating together, and now this is being taken away."
  - Concern about quality of life for the patient, especially if they are known to have enjoyed food.
  - When a patient doesn’t eat, are they not accepting love from their family?
Perceptions and attitudes toward ANH

Decision-making variables in patients

- Taiwanese study on patient decision to initiate ANH:
  - (i) beliefs about the benefits that it can provide;
  - (ii) possession of control of inner health;
  - (iii) perception that the family is capable of managing care requirements of ANH;
  - (iv) perception that the doctor has a positive viewpoint of the measure.

- European study on patient decision to withdraw ANH linked to:
  - (i) certain countries;
  - (ii) being a woman;
  - (iii) over 80 years old;
  - (iv) central nervous system dysfunction (including dementia);
  - (v) mental incompetence.

Perceptions and attitudes of patients and families

- Feeding/hydration treatments may be seen as actively helping to support the life of the patient.
- Patients/families motivated by concerns over effective feeding, survival, and quality of life.
  - For starting ANH: preserving life, the palliation of symptoms, not abandoning the struggle against illness, and the presence of anxiety.
  - Against starting ANH: becoming a burden, prolonging suffering, fear of dependence.
- Low level of knowledge about actual risks/benefits of ANH. May be understood as equivalent to regular eating/drinking.

Perceptions and attitudes of staff

- Studies indicate discord between HCP opinion, practice and literature regarding ANH.
- Cultural beliefs impact on staff too!
- HCPs less involved in the care of terminally ill patients:
  - See ANH as part of minimal care
  - More likely to recommend this treatment.
- HCPs with palliative care expertise:
  - Considered ANH a form of active medical treatment
  - Preferred interventions that improved the comfort of the patient over subjecting the patient to the discomfort they associated with AH

Perceptions/attitudes among doctors and nurses

- Roles in decision-making
  - The doctor has the greatest influence in the final decision.
  - Influence of patient, nurses, and family opinions depends on the opportunities allowed to them by the doctor.
- Unease around communication with patient and family
  - This is made more difficult where patient/family in denial or perceived as highly emotive.
  - May be harder for junior or less experienced colleagues.
- Where communication has been poor and family are excluded from decision making family may deliberately go against treatment plans/medical advice: E.g:
  - Bringing in home cooked food for dysphagic patient.
  - Insist on quantities of nutritional supplements matching that of pre-EOL nutrition.
What psychological impact have you noticed on yourself in these situations?

Case study 1
Norman is a 50 year old man of Afro Caribbean descent. He has a diagnosis of oesophageal cancer, with poor prognosis (1-2 months to live).

His tumour has blocked his oesophagus. He had hoped to have a stent inserted, to enable him to eat, but has now been told that it is not possible to do this and he will need to continue with artificial nutrition until the end of life.

Food has always been an important part of family life. He now avoids meal times with his family, preferring instead to sit in another room while they eat. He has a past history of alcoholism.

- What are the psychological issues for Norman and for his family?
- How can we help the family manage this?

Managing psychology of EOL nutrition/hydration

Management - Assessment
Assessment - Understand what MAY be going?
Explore individual, family and cultural beliefs about food, about EOL.
Explore how food and drink is used within the family.
Note significant past difficulties around food (eating disorders/addictions/physical food issues e.g. IBS) and explore how the patient/family coped at the time.
Explore levels of illness/EOL acceptance/treatment beliefs within the patient and family.
Explore fears for the future.

Management - Treatment planning
Loss of control: How can we give the patient some control over eating and drinking? E.g.
1) Patient gets pleasure from food and still wants to eat but struggles to eat physically -> Mindful eating.
2) Patient is missing out on social aspects associated with food -> facilitate discussion with patient and family around other ways to connect.
3) Patient fearful about the loss of eating/drinking and how this will impact on them physically -> Education around next phase(s). Engaging patient’s support network.
4) Patient fearful of loss of control -> Engage patient and patient’s support network in helping patient recognise and retain areas of mastery (what can they still do) and pleasure (what can they still enjoy).

Management - Treatment planning
Encouraging acceptance around EOL -> mindfulness based approaches and the “here and now”: exploring patient values and how the patient can continue to live towards these in the last months and days of life.
Family frustration and its impact - how can that be discussed with the family without leaving the family to feel blamed? -> Keeping patient and family at the centre of decision making: Focus on QOL; Reflecting on what the current situation is causing.
Whatever the decision the team undertakes, ensuring that the team all know what that decision is, why, and what the communication strategy around this is.
Case study 2

Samira has recently decreased her eating and drinking. She has become very thin and ‘wasted’ and lacks the energy to mobilise. She has a history of depression and once tried to take her life.

Her husband and daughter are very anxious and keep trying to encourage her to eat, although this makes her feel sick. They want her medical team to ‘do something about this’ and request that she be given tube feeding, so that she can ‘begin rehabilitation’. They are angry with Samira for refusing to eat, and police her intake of supplements.

Her medical team believe that Samira is nearing the end of her life. Samira’s son appears to understand that this is the case and wants to make Samira comfortable.

- What are the psychological issues for Samira, her family and her team and how can they be managed?

3 minute breathing space

Resources


Book - “Mindfulness for Health” by Vidyamala Burch and Danny Penman

App - Headspace

Mindful eating - plenty of resources online!

Expression of love. Buying friendship. Easing social contact.