Ethical issues in nutrition support: a view from the coalface

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Artificial nutrition and hydration continue to stimulate debate among physicians and in the wider world. This review aims to give those involved in providing nutrition support the necessary tools to be confident in making decisions in individual cases. It examines basic ethical principles and suggests a structured approach to ensure all the relevant factors are considered in making decisions. The current legal context and in particular the provisions of the Mental Capacity Act 2005 relating to nutrition support are discussed. The review concludes by applying the ethical approach suggested to some clinical examples, demonstrating the decision making process.

Introduction

The provision of nutrition support continues to stimulate debate among physicians and in the wider world. Nutrition can be a highly emotive topic, with staff and relatives using phrases such as 'starving to death' on the one hand and 'force feeding' on the other. There is clear agreement that the provision of adequate nutrition and hydration is a basic human right when patients are able to take this independently and that this should be offered as part of basic care. Equally clear is the public outrage at the force feeding of hunger strikers from the suffragettes to detainees in Guantanamo Bay.¹ The World Medical Association's Declaration of Malta states that forcible feeding is never ethically acceptable.²

The law in America and Europe regards artificial nutrition as a medical treatment.^{3,4} The crucial difference between providing nutrition as a medical treatment and force feeding is the patient's consent to treatment. If the patient is unable to give this, any treatment given must be in their best interests.^{5,6} Those involved in providing nutritional support should have a clear understanding of the ethical and legal principles that underpin such decisions and knowledge of the benefits and burdens of the proposed treatments.

The four principles of medical ethics⁷

The underlying principles that underpin medical ethics are:

- **Autonomy** is the principle of self-determination that recognises the individual's right to make medical decisions.
- **Beneficence** is the provision of benefit.
- **Non-maleficence** is the avoidance of harm.
- **Justice** is the fair and equitable provision of available medical resources to all.

Using a structured approach ensures that all the relevant information is considered. One such approach is to analyse each case in terms of the clinical indications, patient preferences, quality of life and contextual features.⁸ Table 1 illustrates how this approach combines the questions relevant to the case with the underlying ethical principles.

The concept of futility

A futile intervention can be defined as one that is either completely ineffective or incapable of achieving a desired goal.⁹ However, patients, relatives and health-care professionals may have widely differing views on the goals of treatment and the likelihood of achieving them. The challenge is to reach agreement on these goals for a particular patient and then examine them in detail.

One commonly used technique for assessing whether or not a patient will benefit from nutritional support is a time limited trial of therapy.⁷ This allows those making the decision to gather more information on the likely benefits of treatment, but without committing the patient to long term treatment if it proves to be ineffective or too burdensome.

Consent and competence

The principle of autonomy is now the dominant ethical principle in the provision of artificial nutrition and hydration

Table 1 The four ethical principles and topics

	Beneficence	Non-maleficence	Autonomy	Justice
Clinical indications	<ul style="list-style-type: none"> • Diagnosis • Prognosis • Goals of treatment • Treatment options • Risks and benefits of each treatment option 			
Patient preferences/ best interests			Assess capacity Patient has capacity Fully informed consent Patient lacks capacity – act in the patient's best interests, weighing up the factors below Encourage patient participation Identify all relevant circumstances Find out the patient's views (advance decision) Avoid discrimination Assess whether patient might regain capacity Consult others (family/friends/carers/LPA/IMCA) Avoid restricting the patient's rights Do not make assumptions about a patient's quality of life Do not be motivated by a desire to bring about a patient's death	
Quality of life	<ul style="list-style-type: none"> • Benefits vs burdens of treatment • Likelihood of achieving goals of treatment • Likelihood of return to normal living • Avoid discrimination/bias in assessing quality of life 			
Contextual features			<ul style="list-style-type: none"> • Religion • Culture • Economics • Society • Legal requirements • Conflict of interest 	

Adapted from Jonsen *et al.*⁸

IMCA, independent mental capacity advocate; LPA, personal welfare Lasting Power of Attorney.

(ANH) in both Europe and the USA.^{3 4} Thus a competent patient has the right to accept or refuse treatment after a full explanation of the risks and benefits of doing so. They should not be treated as lacking capacity solely on the basis of making a decision that others consider unwise. However, a patient who lacks capacity is not able to exercise this right and decisions should then be made in their best interests, taking into account all of the relevant factors. In England and Wales, the Mental Capacity Act⁵ provides the legal framework for patients who lack the capacity to make decisions and a code of practice⁶ to guide those responsible for interpreting the act. Throughout the Act a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made. It stresses the importance of taking all possible steps to try and help people to make a decision for themselves. The criteria for assessing a person's ability to

make a decision are summarised in table 2. If there is any doubt about capacity, then advice from other professionals should be sought.

Best interests

One of the key principles of the Mental Capacity Act^{5 6} is that any decision made on behalf of a person who lacks capacity must be made in that person's best interests. The factors that should be considered in making such decisions are summarised in table 1. For decisions involving the provision of medical treatment, the decision maker should be the doctor or other health-care professional responsible for carrying out the particular treatment. If a Lasting Power of Attorney (LPA) (or Enduring Power of Attorney) has been made and registered, or a deputy has been appointed under a court order, the attorney or deputy will be the decision maker for decisions within the scope of their authority. The steps taken to reach a best interests decision should be fully documented.

Advance decisions

The Mental Capacity Act^{5 6} gives clear guidance on the use of advance decisions and the circumstances in which they are valid. An advance decision only applies to the refusal of treatment. Nobody has the legal right to demand specific treatment, either at the time or in advance.

The Mental Capacity Act^{5 6} recognises that ANH is a form of medical treatment and as such can be refused in an advance decision. However, as the consequence of refusing such treatment is likely to be death, the advance decision must be written, signed and witnessed and must include a clear, specific written statement from the person making the advance decision that it is to apply to the specific treatment even if life is at risk.

Lasting Power of Attorney

The Mental Capacity Act^{5 6} replaces the previous 'Enduring Power of Attorney', which covered only property and affairs, with the 'LPA' which can cover personal care as well as property and affairs. To be valid, the LPA must be a written document set out in the statutory form prescribed by regulations, fulfil the criteria set out in the Mental Capacity Act and be registered with the Office of the Public Guardian.

Independent Mental Capacity Advocate

The aim of the Independent Mental Capacity Advocate (IMCA) service is to provide independent safeguards for people who lack capacity to make certain important decisions and, at the time such decisions need to be made, have no one else (other than paid staff) to support or represent them or be consulted. The circumstances in which an IMCA must be appointed are:

- providing, withholding or stopping serious medical treatment;
- moving a person into long term care in hospital or a care home; and
- moving the person to a different hospital or care home.

The IMCA service is commissioned by local social services authorities from local advocacy providers.¹⁰ An IMCA must have specific relevant experience, have had IMCA training, have integrity and a good character, and be able to act independently.^{11 12} An IMCA providers list is available from the Social Care Institute for Excellence.¹³

Table 2 Criteria for assessing the ability to make a decision^{5 6}

Assessing ability to make a decision (Mental Capacity Act 2005)

A person must have an understanding of

- The decision they need to make and why they need to make it
- The likely consequences of making, or not making, this decision

A person must be able to

- Understand, retain, use and weigh up the information relevant to this decision
 - Communicate their decision (by talking, using sign language or any other means)
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Withdrawing and withholding treatment

There is no legal, ethical or moral distinction between withholding and withdrawing treatment.^{3 7 9} In the context of artificial nutrition, withholding a trial of treatment for fear that it may need to be withdrawn if it proved to be ineffective would be ethically inappropriate.

Landmark legal cases

There have been a number of cases in recent years which have clarified the law in relation to ANH.

Persistent vegetative state

- 1990 Nancy Cruzan (USA)⁹
- 1992 Tony Bland (UK)⁷
- 2005 Terri Schiavo (USA)⁹

The crucial features of these cases were that the diagnosis of persistent vegetative state (PVS) should be well established, that there is no difference between ANH and other forms of medical treatment and that the decision should be shown to be in the best interests of the patient and would accord with the patient's wishes, were they able to express them. In England and Wales an application to the courts must be made in order to withdraw ANH from patients in PVS. This is not the case in Scotland, although the General Medical Council¹⁴ recommends obtaining legal advice on whether a court declaration may be required in any particular case.

The right to refuse treatment

2002 Ms B¹⁵ The courts upheld the right of Ms B, who had been paralysed from the neck down, but was mentally competent, to refuse ventilation, even though the consequence was that she would die.

There is no right to demand treatment

2005 Leslie Burke¹⁶ Mr Burke sought a judicial review of the General Medical Council guidance on the withdrawal of ANH. The appeal court judges ruled that when a competent patient indicates his

or her wish to remain alive by ANH, any doctor who wilfully discontinues such treatment would be in breach of duty, and guilty of murder. However, they made it clear that there is no right to demand treatment that doctors consider adverse to the patient's clinical needs.

Specific clinical situations

Dementia

Case presentation Norman is a 75-year-old man currently living in a residential home. He was diagnosed with dementia 3 years ago. He is now refusing food and has lost over 10 kg. He does not have any surviving family or any friends that visit him in the home. He has been referred for percutaneous endoscopic gastrostomy (PEG) insertion and artificial nutritional support.

Ethical analysis

Clinical indications It is important to confirm the diagnosis of dementia and exclude other conditions preventing Norman from eating. However, it is well recognised that difficulty eating is often a marker of severe dementia, indicating that patients are entering the terminal phase of their illness. Most studies in advanced dementia do not show benefit in terms of improving nutritional status, maintaining skin integrity, preventing aspiration pneumonia, improving functional status or prolonging life.^{7,9,17}

Patient preferences An assessment of capacity to consent is essential here. As his mental condition may fluctuate this should be on more than one occasion. His GP and carers should be asked about an advance directive. As he has nobody to speak for him, an IMCA should be appointed to support and represent him. The results of studies looking at attitudes to ANH at the end of life are interesting. Opinion polls suggest that most Americans, if severely demented, would choose not to be sustained by tube feeding.¹⁸ A study of 379 nursing home residents showed that only 33% would prefer tube feeding if they were no longer able to eat because of permanent brain damage and 25% of these would change this view if feeding required physical restraint.¹⁹ In a study examining the attitudes of health-care professionals, 54% thought that ANH was used inappropriately but 42% would continue ANH at the end of life

even when other modalities of treatment were stopped.²⁰

Quality of life This may be impaired by ANH in a patient with advanced dementia. Many older patients do not experience thirst or hunger, and if ANH replaces attempts at oral feeding the patient may be deprived of social interaction and may even require physical restraint.¹⁷

Contextual features The most important consideration here is that the insertion of a PEG tube may prevent Norman from returning to his residential home as some homes do not have the staff to be able to cope with more than basic levels of care.

In summary, PEG feeding is rarely beneficial in patients with end stage dementia and on balance would not be in Norman's best interests. If there were doubts about the appropriateness of ANH, a time limited trial of ANH using a nasogastric tube might clarify the situation. If death is not imminent, a second opinion should be sought from a senior clinician not directly involved in the patient's care before withholding ANH. If there were significant conflicts of opinion, not resolved by a clinical ethics committee, then legal advice should be sought.¹⁴

Terminal disease

Case presentation Mary is a 42-year-old woman with metastatic ovarian cancer that is causing bowel obstruction. She has daily vomiting which can be controlled with an nasogastric tube but is unable to take any nutrition enterally. She has a husband and two teenage children at home and is keen to spend her last few months at home with them.

Ethical analysis

Clinical indications Without some form of parenteral hydration and nutrition, Mary's prognosis is very poor. The provision of parenteral nutrition (PN) would allow her to spend perhaps a few months at home with her family. The recent European Society for Clinical Nutrition and Metabolism guidelines on PN have concluded that long term PN should be offered to patients with incurable cancer if enteral nutrition is insufficient, expected survival due to tumour progression is longer than 2–3 months, it is expected that PN can stabilise or improve performance status and quality of life and the patient desires this mode of nutritional support.²¹

Patient preferences Mary is very clear that she wants any treatment that will allow her to spend time with her family at home.

Quality of life It is essential to have a full and frank discussion about the benefits and burdens of PN²² in the context of her underlying prognosis.

Contextual features PN is expensive with a calculated cost in 2006 of £69 000 per quality-adjusted life year.²² This is above the cut-off set by the National Institute for Clinical Excellence and so may compromise the ethical principle of justice.

Cases such as this can be very difficult to decide. While the majority of patients with terminal disease who are presented with full information on the burdens and benefits of PN will decide against it, there may be specific situations in which all agree that it is justified to achieve specific goals.

Persistent vegetative state

Case presentation Mark is a 49-year-old man who has been unresponsive since a car crash 6 months ago. He is currently being fed via a PEG tube. His wife has requested that feeding should be stopped to allow him to die naturally. Mark has stated on several occasions that he would not want to be kept alive if there was no prospect of a return to independent living. His mother, however, says that he was brought up as a Roman Catholic and that feeding should not be withdrawn.

Ethical analysis

Clinical indications for feeding in this case are to maintain nutritional status to give Mark the best chance of recovery from his brain injury. The British Medical Association recommends that the diagnosis of irreversible PVS should not be considered confirmed (and therefore treatment including ANH not be withdrawn) until the patient has been insentient for at least 12 months.

Patient preferences Although Mark has discussed this with his wife, he has not made an advance decision in writing. It is important to try and find other evidence of his wishes—for example, from his GP or other family members.

Quality of life Mark had previously enjoyed a very active lifestyle, placing high value on his work, sports and family life. He had previously expressed his

horror at the thought of being a burden on his family.

Contextual features While many family objections to the withdrawal of ANH are rooted in religious faith, most religions regard the process of dying as a special case in which treatment can be withheld or withdrawn if the burdens outweigh the benefits.^{3–9} However, religious beliefs of the patient, family and physician can influence decision making and form an important part of the context in which decisions about end of life care are made.²³

In this case the important issues that need to be resolved are the confirmation of the diagnosis of PVS, clarification of Mark's wishes, including his religious beliefs, and the need to apply to the court to be able to discontinue ANH in a patient with PVS.

Conclusion

The provision of ANH remains a contentious issue. Decision making must take into account knowledge of the underlying disease process and its prognosis, and the evidence relating the likely benefits and burdens of nutritional support in this situation. These issues must be fully discussed with the patient to enable them to make an informed decision. If the patient lacks capacity, then those involved must follow the ethical principles and legal requirements outlined above to ascertain what is in the patient's best interests.

Competing interests None.

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