Ethics and end of life decisions

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Learning objectives

• Know the basic principles of biomedical ethics

• Be able to define key associated principles

• Know how to apply an advance directive

• Be conversant in key case law that defines withdrawal and withholding treatment
Ethics - Definition

• Traditionally the study of what makes things “right” or “wrong”

• Morality of the situation /Science of Morals

• Study of principle of Human Duty

• Rules of conduct
Ethical decision making

• Rarely “right” and “wrong” decisions
• No one simple framework for decision making
• Questioning, discussion, multi-disciplinary decision making and reflection are important
• Decisions are made by weighing risks/benefits and facts/values
• Use of the four basic ethical principles
The cornerstones of medical ethics

• Autonomy

• Beneficence

• Non-maleficence

• Justice (just and legal)
Autonomy

- The principle for respect for autonomy acknowledges the right of a patient to have control over his or her own life.

- This includes decisions about how his/her life should end. Thus competent persons should be able to refuse life saving treatment in both current situations and future foreseeable situations.
Autonomy – the questions

• Should respect for autonomy mean that a person can request assistance in ending his/her life?

• Some would argue that this is the case but as assisted suicide is illegal in this country this is not an issue that a clinical ethics committee should need to consider.

• Does respect for autonomy mean that a patient can request treatment that the clinician does not think is in his/her best interests, or treatment that is futile?

• In these situations the principle of respect for autonomy comes into conflict with other ethical considerations, such as non-maleficence or justice.
Beneficence

• The duty of beneficence, that is to act in a way that benefits the patient, is an important ethical principle in health care.

• In treatment decisions at the end of life the dilemma often revolves around what course of action will be in the patient’s best interests.

• It is difficult to see how death can be a benefit or in the patient’s interests, but in some circumstances, if existing quality of life is so poor, or treatment is very burdensome, then the balance of harms and benefits may suggest that continuing treatment is not a benefit to the patient.
Nonmaleficence

• The concept of nonmaleficence - an obligation not to inflict harm intentionally, is distinct from that of beneficence - an obligation to help others.

• In codes of medical practice the principle of nonmaleficence has been a fundamental tenet.

• However, in the context of health care it can sometimes be difficult to comply with this principle depending on the definition of harm.

• Many medical treatments may have harmful side effects but save or improve lives e.g. chemotherapy.

• In end of life decisions the question of how much harm is caused by the treatment needs to be considered, as does the question of whether death itself is always a harm.
Justice

• Justice can be applied in different ways depending on your own interpretation of the word
• Fair sharing of resources
• Equity of treatment/support
• Legal implications of decisions
• NICE – national guidelines
• NMC code and ethics
Some other key terms

Sanctity of life doctrine
Acts of omission
Doctrine of the double effect
Advanced Decisions
Sanctity of life doctrine

- The argument underpinning this doctrine is that all human life has worth and therefore it is wrong to take steps to end a person's life, directly or indirectly, no matter what the quality of that life.

- One challenge to this principle in the context of health care is to ask should life be preserved at all costs. Is there no place for consideration of quality of life?

- One of the problems with considering quality of life is the question of how this is defined and by whom. An objective view of someone's life may be very different to the view of the person who is living that life. However, this problem does not remove the challenge to the sanctity of life doctrine.

- There may be some circumstances where a person's quality of life, however defined, is so poor that it should not be maintained even if it is possible to do so.
Acts or omissions?

• Is doing something better or worse than not doing something (if the end result is the same)?

• This distinction argues that there is a difference between actively killing someone and refraining from an action that may save or preserve that person's life.

• In a medical context this distinction would mean that a doctor could not give a patient a lethal injection to end his/her life, whatever the circumstances, but could, withhold treatment that may sustain it.

• Withholding treatment would only be permissible if the patient's quality of life was so poor, and the burden of treatment so great, that it would not to be in the patient's best interests to continue treatment.
Doctrine of double effect

- This doctrine says that if doing something morally good has a morally bad side-effect it's ethically OK to do it providing the bad side-effect wasn't intended. This is true even if you foresaw that the bad effect would probably happen.
- The principle is used to justify the case where a doctor gives drugs to a patient to relieve distressing symptoms even though he knows doing this may shorten the patient's life.
- This is because the doctor is not aiming directly at killing the patient - the bad result of the patient's death is a side-effect of the good result of reducing the patient's pain.
- Many doctors use this doctrine to justify the use of high doses of drugs such as morphine for the purpose of relieving suffering in terminally-ill patients even though they know the drugs are likely to cause the patient to die sooner.
• Factors involved in the doctrine of double effect

• The good result must be achieved independently of the bad one: the bad result must not be the means of achieving the good one. So if the only way the drug relieves the patient's pain is by killing him, the doctrine of double effect doesn't apply.
• **The action must be proportional to the cause:** If a patient is given a dose of drugs so large that it is certain to kill them, and that is also far greater than the dose needed to control their pain, I can't use the Doctrine of Double Effect to say that what I did was right.

• **The action must be appropriate:** also have to give the patient the right medicine. If I give the patient a fatal dose of pain-killing drugs, it's no use saying that my intention was to relieve their symptoms of vomiting if the drug doesn't have any effect on vomiting.
Advanced decisions or directives

• You can use an advance decision (also called advance directive) to indicate your wish to refuse all or some forms of medical treatment if you lose mental capacity in the future. You can't use it to request treatment.

• A valid advance decision has the same effect as a refusal of treatment by a person with capacity: the treatment cannot lawfully be given - if it were the doctor might face civil liability or criminal prosecution.

• You can't use an advance decision to:
  ask for your life to be ended
  force doctors to act against their professional judgement
  nominate someone else to decide about treatment on your behalf
Valid decisions

• From April 2007, to be valid an advance decision needs to:
  be made by a person who is 18 or over and has the capacity to make it
  specify the treatment to be refused (it can do this in lay terms)
  specify the circumstances in which this refusal would apply
  not have been made under the influence or harassment of anyone else
  not have been modified verbally or in writing since it was made

• Advance decisions refusing life-sustaining treatment will need to:
  be in writing (it can be written by a family member, recorded in medical
  notes by a doctor or on an electronic record)
  be signed and witnessed (it can be signed by someone else at the persons
  direction - the witness is to confirm the signature not the content of the
  advance directive)
  include an express statement that the decision stands 'even if life is at risk'
Not acting on a directive?

- A doctor might not act on an advance decision if:
  - The person has done anything clearly inconsistent with the advance decision which affects its validity (for example, a change in religious faith)
  - The current circumstances would not have been anticipated by the person and would have affected their decision (for example, a recent development in treatment that radically changes the outlook for their particular condition)
  - It isn’t clear about what should happen
  - The person has been treated under the Mental Health Act
Professional Guidance

BMA

GMC
• This document emphasises the importance of assessing a patient’s quality of life in determining whether continuation of treatment is in the patient’s best interests:

• *Section 1.2:* Prolonging a patient's life usually, but not always, provides a health benefit to that patient. It is not an appropriate goal of medicine to prolong life at all costs, with no regard to its quality or the burdens of treatment.

• *Section 3.5:* Oral nutrition and hydration form part of a patient's basic care and should not be withdrawn.

• The guidance notes the lack of a moral distinction between withholding and withdrawing treatment:

• *Section 6:* Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions.
• 19. “Where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation to provide it and therefore no need to make a distinction between not starting the treatment and withdrawing it”.

The Law

To bring the theory into practice
Pretty (Pretty v UK
(Application 2346/02) [2002] 2 FLR 45)

• Dianne Pretty suffered from motor neurone disease which left her paralysed. She wanted her husband to be able to assist her suicide without fear of prosecution (assisting a suicide is a crime under the Suicide Act 1961) so that she could choose the time of her death and die with dignity. She argued that Article 2 (right to life) of the European Convention on Human Rights protects the right to life and the right to choose the manner of death.

• However the House of Lords and the European Court did not find that Article 2 created a right to die and indeed that the need to protect vulnerable citizens justified the prohibition of assisted suicide.
Anthony Bland was 21 years old when overcrowding at the Hillsborough football stadium lead to him being badly crushed. He was left permanently unconscious, in persistent vegetative state. Three years later the hospital Trust applied to the court for a ruling whether it would be lawful to discontinue artificial hydration and nutrition, resulting inevitably in his death. The House of Lords considered that:

- Artificial nutrition and hydration is regarded as a form of medical treatment.
- There is no distinction between an omission to treat a patient (withholding) and discontinuance of treatment once commenced (withdrawing).
- In making the decision whether or not to provide medical treatment the question to be asked is whether it is in the best interests of the patient that his life should be prolonged.
- Previously stated wishes of the patient should be taken into account in the assessment of best interest.
Case Law

• It is illegal to actively bring about someone’s death, either with or without the person’s consent. This covers both physician assisted suicide and the situation of giving a lethal injection to an incompetent patient.

• An omission to act that (intentionally) results in the patient's death is permissible where it is not in the patient's interests to continue treatment (Airedale NHS Trust v Bland [1993] 1 All ER 821).

• Court approval should be sought in all cases where treatment is proposed to be withheld / withdrawn from a patient in Permanent Vegetative State (Airedale NHS Trust v Bland [1993] 1 All ER 821).

• Withholding and withdrawing treatment are both considered omissions to act.
Case Law

• A competent patient can refuse treatment, including requesting that ongoing treatment is withdrawn, even if that results in the patient's death (*Re B Consent to treatment:Capacity*, 2002). The clinician would not be assisting a suicide. Treatment given in the face of a refusal would amount to battery.

• A competent patient cannot request that a positive act is taken to end his/her life (*R (on the Application of Pretty) v DPP [2002] 1 All ER 1*). This would amount to assisted suicide. No right of self-determination in relation to death is created by the Human Rights Act 1998.

• Where a clinician owes a duty of care to provide treatment to a patient then failure to do so will be a culpable omission. However, a doctor is not under a duty to treat where it is not in the best interests of the patient, for example where treatment would be futile (e.g. a patient in PVS) or unduly burdensome.

• If, as a side effect of giving pain - relieving drugs, the life of a terminally ill patient is thereby shortened, this is lawful under the doctrine of double effect (see above) where the intention is to relieve pain.
The cases

Over to you....
Case 1

• Mr Z made a written advance directive 5 years ago. Mr Z suffers from chronic obstructive pulmonary disease and the advance statement provides that if he is admitted in respiratory failure he will not be ventilated. The advance directive is placed in his notes. Mr Z is brought into A&E in respiratory failure and is acutely confused because of low oxygen levels in his blood. He says that he wants 'everything done' in order to save him. The doctor in charge of his care decides to ventilate him.

• What issues does this raise? Do you agree with the decision?
Case 1 feedback

• "Where there are good grounds for genuine doubt about the validity of an advance refusal, there should be a presumption in favour of life and emergency treatment should be provided. Treatment may, however, be withdrawn at a later stage should the validity, or existence, of a valid advance directive become clear."

• ".. doctors must respect any valid advance refusal of treatment - one made when the patient was competent - which is clearly applicable in the circumstances and where there is no reason to believe the patient has changed his/her mind."
Case 3

• John is a 55 year old man with lung cancer which initially responded to chemotherapy but has now relapsed. He is now nearing the end of a trial of a new chemotherapy regime with no sign of remission of his cancer. In discussion with the medical team John expresses a belief that he may respond to treatment although his consultant has told him that no further chemotherapy is possible and that he has only a few weeks left to live. As a result of his advanced disease, it is likely that he will develop renal and cardiac failure. The consensus of opinion from the medical team is that, if John has a cardiac arrest while on the ward, attempts at resuscitation would not be appropriate. This is because it is highly unlikely to be successful and it would inflict damage because of John's fragile ribs (he has rib secondaries) and because he will die very shortly from his cancer. After discussion with his consultant John says he wants everything done for him, including CPR.

• How would you manage this situation
• Would you offer CPR?
Case 3 feedback

• "Doctors cannot be required to give treatment contrary to their clinical judgement, but should, whenever possible, respect patients' wishes to receive treatment which carries only a very small chance of success or benefit."