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The value of an ethics history?

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Doctors are often called upon to make decisions on resuscitation, ventilation, artificial feeding, dialysis, and other intensive or invasive treatments when the patient is too ill to say yes or no. Consequently, some patients will receive treatments they did not want or be denied treatment they would have wanted.[1,2] Clearly, there is much to be said for ascertaining the patient's views when he or she is competent and reasonably well—for example, when seeing a general practitioner or attending an outpatient clinic. By taking an 'ethics history' we might increase the likelihood that the patient, if later incapacitated, will receive appropriate and acceptable treatment. In this paper we review the current scene and offer a set of questions that might form the basis of such a history.

IMPACT OF THE HUMAN RIGHTS ACT

The Human Rights Act of 1998, implemented in October 2000, incorporates most of the European Convention on Human Rights into UK law. This Act declares that doctors, as public authorities, must be transparent in their decision-making, to protect the rights of patient and family. Any inconsistency between the law and the Convention can be challenged in both the European Court of Human Rights and domestic courts and lately there have been numerous court cases. The British Medical Association (BMA) and the General Medical Council (GMC) changed their guidelines substantially when the Human Rights Act came into effect.

INVOLVEMENT OF THE FAMILY IN DECISION-MAKING

In certain cases, patients or their relatives have complained that 'do not resuscitate' (DNR) orders had been written in the notes without their knowledge.[3] Some doctors prefer to talk about such matters with relatives rather than with the patient,[4] and indeed this may accord with the relatives' view that the patient should not be involved.[5] Against this is the observation that only a minority of patients wish relatives to take decisions on their behalf.[6] In view of the right to respect for privacy and family life (article 8 of the Human Rights Act) the Department of Health has issued a circular (HSC 2000/028) asking doctors to consult patients and their relatives in these matters just as they would in any other aspect of their healthcare. The Resuscitation Council (UK), the BMA and the Royal College of Nursing concur.[7]

Family members will often have knowledge of the previously held views and wishes of a now incompetent or seriously ill patient, but care must be taken not to worsen their distress by asking them to make decisions about management in the terminal phase: the ultimate decision is the doctor's and should not be delegated.

In the case of incompetent patients, involvement of family members is desirable. The law varies in different parts of the UK. The Mental Capacity Bill of England and Wales favours 'lasting powers of attorney' whereby a trusted friend or relative is able to refuse or consent to medical treatment if previously authorized to do so by the patient.[8] In Scotland, the Adults with Incapacity (Scotland) Act 2000 has since 2002 allowed a proxy's decision to be legally binding.[9]

FACTORS THAT CAN AFFECT DECISION-MAKING

Quality of life

Quality of life is a subjective concept, influenced by factors including personality, cultural background, socio-economic circumstances and health.[10] Physicians who project their own values onto their judgment of an individual's quality of life may make inconsistent, arbitrary and unfair decisions.[11]

Age

Ethical decisions should be free from ageism[12] (article 14 of the Human Rights Act specifies the right to be free from such discriminatory practices) and should be made without regard to resource constraints.[13] In practice, physicians are as likely to attempt cardiopulmonary resuscitation as to withhold it in an aged patient;[2] however, age can legitimately enter the discussion. When dealing with patients and relatives, doctors need to make clear that 'do not resuscitate' is not a sign of abandonment—in other words, the patient will continue to receive comfort, symptom control, dignified care and psychological support.

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Competence

Competence signifies that the individual comprehends and retains pertinent information, is able to believe and weigh up the information and can make a decision on treatment. The issue of mental capacity arises when an individual wants to make an 'advance statement' or when there is doubt about his or her understanding concerning a particular treatment being proposed.

An adult is presumed to be competent until the contrary is proved. The burden of proof rests on those who are ascertaining incapacity. Once someone is judged to be incompetent, this state is presumed to continue. Competence can fluctuate; a decision taken during a lucid interval is considered valid. Doctors have to ensure that decisions on treatment are made without manipulation or coercion in any form. When the patient is judged incompetent, his or her previously held wishes (where known) should be taken into account; and where these wishes are not known the doctor must act in the patient's best interest, in the light of what is known of his or her past and present feelings together with clinical factors. Information from those close to the patient (including the general practitioner) may be helpful.

Patient autonomy

There has been a move in medicine from benign paternalism to patient autonomy and shared decision-making. Patients have higher expectations than formerly, people are living longer, and doctors are increasingly facing patients with complex disorders. In the USA, under the Patient Self Determination Act, every individual has a statutory right to accept or refuse medical care and to execute a written advance directive.[14] In Britain there is no such mandatory requirement, but article 10 of the Human Rights Act (the right to hold opinions and receive information) relates to the involvement of patients in decisions.

Doctors are not always skilled in anticipating the wishes of their patients.[15] Even frail elderly patients are often pleased when their physicians initiate discussions about future choices. By raising the subject of death, doctors can allow patients to express their hopes and fears, and families too may appreciate the opportunity to talk of these things.[17] Sometimes an obstacle to such discussions is distress and lack of understanding on the part of the physician.[18]

SPECIFIC CLINICAL QUESTIONS

Cardiopulmonary resuscitation

Television dramas in which cardiopulmonary resuscitation is usually successful have given patients and relatives an erroneous impression of outcomes.[4] This may be part of the reason why lay people sometimes regard 'do not resuscitate' as amounting to euthanasia. The General Medical Council says that 'where possible' the decision should be made in advance as part of the care plan for the seriously ill patient[20] but many doctors are uncomfortable about doing this.[4,21] There is particular difficulty in broaching the concept of medical futility, which can be value-laden and impractical.[22,23]

According to article 2 of the Human Rights Act every individual has the right to life. However, it is clear that in certain circumstances—the patient with severe bronchopneumonia, or bedfast with metastatic cancer, or with sepsis and multiple organ failure, or with acute major stroke, or with dementia requiring long-term care[24]—cardiopulmonary resuscitation has a negligible chance of success. Doctors are not obliged to offer treatments they believe to be inappropriate or futile; nevertheless, dilemmas at times of crisis can often be avoided by earlier discussion and the provision of information to patient and family.

Transplantation

Some people may decide long before death to donate organs but omit to inform their close relatives; and even when the patient has made a clear decision on organ donation through an advanced statement or a donor card the relatives may still be unwilling to allow it to happen. There are no clear guidelines on whose wish is to be followed,[25] but it certainly helps if during the final illness the individual has confirmed that his or her previous wishes still apply. The same principle applies to donating the body or organs for the benefit of medical science (e.g. anatomy teaching).

Artificial nutrition and hydration

Artificial nutrition and hydration are legally established as medical treatments in the UK, though this definition is not universally accepted.[26] Under the Medical Treatment Act of 1988 the competent patient has the right to refuse these interventions in the same way as other treatments. However, if tube feeding is regarded as a means of sustaining life, withdrawal of food and fluid could lay a doctor open to a charge of murder. At present a court order is needed in England, Wales, and Northern Ireland, though not in Scotland, to withdraw these interventions in patients with persistent vegetative state or a similarly low awareness.

There is an argument for extension of these provisions to patients with advanced dementia and severe stroke.[27] In one study[28] of hypothetical life-sustaining treatment (involving 339 hospital physicians and 987 randomly selected elderly people) physicians favoured artificial feeding over cardiopulmonary resuscitation, whereas the elderly participants took the opposite view. This difference may reflect the inflated public notion of cardiopulmonary resuscitation. The professional dilemmas are illustrated by the finding that, in a hypothetical situation of metastatic cancer, physicians would want less life-sustaining treatment for themselves than they would give to an elderly patient. Current guidelines recommend the withholding or withdrawal of artificial nutrition and hydration when death is imminent or the burdens or risks of providing fluid and nutrition outweigh the benefits.[25] It would be helpful to have the patient's clearly expressed views on such treatments that delay an inevitable death, when the wishes of relatives and the judgment of the clinician are in conflict.

Ventilation

Artificial ventilation in a young person with severe asthma is very different from artificial ventilation in an 80-year-old patient with end-stage chronic obstructive pulmonary disease. Mechanical ventilation in elderly people is sometimes initiated because of lack of advance care planning.[29] Most of these patients will never previously have entered an intensive therapy unit or seen a ventilator, hence the need for earlier information and discussion when possible. Documentation in the medical notes of the patient's expressed views on matters such as ventilation would help clinicians make decisions in a crisis.

Surgery

Sometimes a patient admitted with an apparently straightforward problem (for example, collapse) turns out to have a condition such as critical aortic stenosis or leaking abdominal aortic aneurysm that would normally require major surgery. If the patient is unable to decide whether to have the operation, the doctor will again be much helped by knowing the patient's views on major surgery expressed at the time of admission or before.

ADVANCE DIRECTIVE (LIVING WILL)

An individual who has the capacity to make a medical decision can exercise the right to consent to or refuse future medical treatment by means of an advance directive (also known as a living will) should he or she lose capacity to make or communicate a decision. A living will is seen as an extension of autonomy from an ethical point of view and as the right of self-determination from a legal perspective.[12] The Mental Capacity Bill endorses this as 'advance decisions', and the BMA strongly supports the principle, recommending that 'ideally this should be part of a continuing dialogue between doctor and patient'.[26] However, health professionals and patients must be aware that there are dangers as well as benefits in making treatment decisions in advance of an illness. The course of disease can be affected by physiological and psychological factors unique to the individual at all stages of care. Additional discussions of treatment options are fundamental to good practice.

An advance directive may be a written document, a witnessed oral statement or a note in the patient's file following a discussion with a healthcare professional. An advance directive made by a competent adult is binding under common law and can relieve both the relatives and healthcare professionals of the burden of best-guessing the patient's wishes (or deciding between the views of different relatives). In these documents there is no provision for refusing, in advance, basic care of the sort needed to keep an individual comfortable. A doctor must be satisfied that a living will has not been revoked and that there is no indication of a change of mind or a change in circumstances affecting the decision. This might be confirmed during the current illness.[30] Patients are entitled to make an advance directive without discussion with family members or a doctor.[31] It would be wrong, however, to assume that those who make advance directives are opposed to aggressive treatment: a Finnish study has shown similar preferences for cardiopulmonary resuscitation between those with and without a living will.[32] Implementation of advance directives has the potential to reduce the use of health services without affecting patient satisfaction or mortality.[33] Less formal directives (e.g. informal conversation, the most frequent form of advance directive) can also help in determining the patient's values and desires and guide doctors in reaching clinical decisions.[34] In an American study[35] 15% (32/214) of individuals aged 65–90 years had written a living will and some two-thirds of respondents planned to do so. By contrast, among 74 London inpatients (mean age 81) more than three-quarters had not even heard of living wills.[36]

We suggest that doctors should initiate discussions about advance directives as part of general healthcare. The BMA supports the idea of the general practitioner or the practice nurse doing this during routine consultations, since hospital admission 'is not generally a good time to raise the subject of anticipatory choice'.[37] The main barriers are an expectation that decisions on treatment options will be made by doctors and the feeling that such issues are only relevant to those who are old or in poor health. Discussions of death and dying do not usually cause distress to the patient,[38] but some patients may feel that the signing of such a document amounts to giving up or may present a risk that they will receive less treatment than they deserve.[39] Many find the document lengthy and the wording ambiguous. For doctors the main barrier is lack of time.[40] Doctors with a positive attitude to advanced directives are the ones most likely to initiate such discussions with their patients.[41]

AN ETHICS HISTORY

In view of these considerations, should doctors routinely include an 'ethics history' in patients who are not at present seriously ill?

When such history-taking was tested in a hospital study,[5] no patient admitted to having been distressed by the questions; indeed, there is evidence[12,15] that these discussions are not as stressful to patients as doctors might suppose. A few minutes spent in this way seem greatly preferable to subsequent long conversations with relatives expressing various opinions on what should be done. Doctors should ask patients periodically whether there has been any change in previously expressed wishes.[18]

We propose the following key questions, the answers to which may be helpful in decision-making in the advent of a subsequent medical crisis.

If you were seriously ill:

- Would you wish to be fully informed about the diagnosis?
- Would you want to be consulted in all decisions relating to your treatment?
- If you do not wish to be informed, do you want someone else to be kept informed?
- Do you have any objections to your family being told about any aspect of your medical care?
- Would you wish to receive any of the following treatments: (*a*) resuscitation if you stop breathing or your heart stops beating, (*b*) breathing taken over by a machine, (*c*) artificial feeding with tubes, through the nose or directly into the stomach, (*d*) major surgery?
- Have you heard about a 'living will'? Have you made one or do you wish to do so? Do you know about 'power of attorney'?
- Are you aware that people can donate their body or organs such as eyes, kidneys, and heart after death? Do you have an opinion on the use of your own body or organs after death?

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