Ethical decisions at the end of life

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A conference organised by Dr Gillian Ford, on behalf of the College Ethical and Palliative Medicine Committees, was held at the Royal College of Physicians of London on 24 March 1999. It attracted over 200 delegates, two-thirds of whom were doctors. Issues covered included hydration and dehydration in the dying patient, talking to patients and their families, the management of futility, caring for patients at home, listening to children, the limits of autonomy and a debate on the principle of 'double effect'.

Opening the conference, Professor George Alberti, the President of the College, expressed his concerns that doctors were not handling ethical decisions very well. All too often, rather than recognising man's inherent mortality, doctors were striving too officiously to keep dying patients alive. Sadly, such efforts could often be deemed to be not only futile, but also costly and uncomfortable.

Recalling a French aphorism, Professor David London (Chairman of the College Ethical Committee) reminded the delegates that a doctor's duties are 'to cure sometimes, to relieve often and to comfort always'. Four things are important. First, doctors must determine what the patient wants. Second, they must work in partnership with others. Third, medical management decisions must be correct. Fourth, doctors must decide justly who should be treated and how they should be treated, bearing in mind that sometimes the things that patients and relatives want cannot be delivered within the limitations of the law, the responsibilities of the profession and distributive justice.

Hydration and dehydration in the dying patient

Dr John Ellershaw (Medical Director, Marie Curie Centre, Liverpool) advocated three basic principles for doctors to follow when considering the question of withholding or withdrawing hydration from the dying patient. First, look for and treat correctable causes, such as dehydration due to overtreatment with diuretics and sedation, recurrent vomiting, diarrhoea and hypercalcaemia. Second, recognise that the treatment of pain in dying patients rarely leads to difficulties in taking fluids; heavy sedation is usually not a sign of good palliative care. Third, remember that the decision to withdraw hydration is only taken after the medical decision has been made that the patient has irrevocably entered the dying phase of life. A phase that usually lasts for a few hours, and rarely lasts for two or more days, involves close, active involvement, with the staff and the family.

Drawing attention to the National Council for Hospice and Specialist Care Services paper on artificial hydration for people who are terminally ill, Dr Ellershaw distinguished between questions of hydration in the dying phase of life and tube feeding of patients with persistent vegetative states (PVS) or stroke illness. Good practice suggests that decisions involving artificial hydration should involve a multiprofessional team, the patient and the relatives and carers; however, the ultimate responsibility rests with the senior doctor. There can be no hard and fast rules.

During the dying phase, staff and relatives often express concern about the lack of artificial hydration. Quoting two observational studies Dr Ellershaw concluded that there was no association in dying patients between fluid intake and thirst. Although fluids can be administered subcutaneously, this approach makes little difference to symptoms and can bring complications of infection as well; rather, he advocated excellence in mouth care and local measures such as sips of pleasant drinks.

Responding to questions, Dr Ellershaw defined the dying state as one that is well recognised in hospices as a semi-comatose state, not drinking, taking sips of fluid, bed bound and clearly dying, but this may not necessarily be the same in patients dying from illnesses other than cancer. Questions concerning oversedation of psychiatric illnesses, advanced directives and different cultural beliefs were also raised. 'Never say never' was Dr Ellershaw's response.

Talking to patients and their families

The importance of talking to patients and their families was sensitively considered by Professor Ilora Finlay (Consultant in Palliative Medicine and Medical Director, Holme Tower Marie Curie Centre, Penarth). Her comment on the 'family from hell' will always remain with me, as will her description of ushering in one family at the front of the hospice while the patient's second family disappears from the back. Hospices differ from hospitals. They could even be considered to be idealised versions of family and to suffer from chronic niceness. Yet life is not really like that. We must always remember that death does not only involve the patient; it involves those around them as well, including ourselves and our feelings. A doctor's duty to care is also a duty to listen, to the patient, to the family and to other professionals.

Issues concerning the impact of place, age, family and society culture on decisions were raised by questioners.
Much of the discussion focused on the inappropriate use of 'do not resuscitate' orders and the use of 'spray on terms' such as 'the right to die' and 'resuscitation'. Resuscitation was considered to be an unhelpful term, because 'not to be resuscitated' gave the impression that staff would not give appropriate nursing and medical care.

The management of futility

Dr Michael Platt (Consultant in Anaesthesia and Pain, St Mary's Hospital, London), noting how modern intensive care is both intensive and invasive, posed the question 'When does it become futile?' Anaesthetists now deal with the pre-, peri- and postoperative care of immensely complicated patients. Much can now be done to preserve life and to postpone death, so when is it appropriate to stop?

Intensive care is a microcosm of ethics. Although the principles of autonomy, beneficence, non-maleficence and justice are useful starting points, they are insufficient to deal with the problems that doctors face. Doctors cannot abdicate the responsibility for their decisions to others. Age alone is an inadequate indicator of need, for an 89-year-old, ultra-fit, marathon runner differs from a 20-year-old with AIDS and terminal lymphoma. Good medicine knows its limits. A decision not to treat or to withdraw treatment is not euthanasia, so long as the medical decision has been made that death is inevitable and the burden of the treatment is considered to outweigh the benefit that will be gained.

During discussion a heartfelt plea came from a young doctor that medical schools should teach more about medical ethics and philosophy. Other discussants raised the issues of medical uncertainty, of the need for integrated pathways of care, for teaching about the difficulties in weighing the burdens and benefits. The first aphorism of Hippocrates states: 'Life is short, the art is long, experience fallacious and judgement difficult, it is the duty of the doctor to ensure that the patient, the attendant and the externals cooperate with him in treatment.'

Caring for patients at home

Dr Stephen Barclay (General Practitioner and Health Services Research Training Fellow at the University of Cambridge) showed photographs of patients and their carers (usually a husband or wife) in their own homes. Examples included severe, intractable pain in a 78-year-old man with osteo-arthritis; breathlessness in a 70-year-old woman with severe emphysema and in an 85-year-old woman with cardiac failure; problems with speech and swallowing in a 72-year-old patient with motor neurone disease. He posed questions throughout about the limits of palliative medicine and its boundaries and raised issues concerning the imprimit hard choices that have to be made when relating patient resources to quality of care, especially in a society that is shifting the responsibility for long-term care from the state to the family. He reminded us that hospices only dealt with 10% of deaths. He concluded that, even though euthanasia was practised in Holland, it should never be an option here.

Conflicting views about the place of euthanasia and the Dutch experience were expressed in the discussion that followed. Comments about slippery slopes, Pandora's box and fear driving forward euthanasia led to Dr Barclay's closing comment that 'we should never forget that issues related to loss of dignity and loss of independence must be acknowledged by all who care.'

Listening to children

Dr Richard Lansdown (Clinical Psychologist and Honorary Senior Lecturer, Institute of Child Health, London) used four clinical cases and a video to illustrate his talk on listening to children: an 8-year-old with cancer who wanted no more treatment; a 10-year-old with facial disfigurement who did not want a further operation; a 12-year-old with leukaemia who changed his mind; and an 8-year-old who refused blood tests and had to be restrained while they were done. All posed questions concerning the limits of childhood competence and the definitions of understanding. Through the medium of a taped interview with a 5-year-old who was dying, Dr Lansdown sensitively showed us how much a child understands about life and death.

Four basic principles should be followed when talking to children. First, inform children about their problems. Second, listen to them. Third, take account of their views. Fourth, respect them. Finally, Dr Lansdown developed a framework for decision-making that takes into account both the heaviness of the decision and its effect on others. He concluded that the more a decision impacts on others, the more the right to autonomy decreases, and the heavier the decision, the more difficult it is. Finally, he reminded us that 'we must always listen to children, but sometimes they must listen to us'. Discussion focused on the need for correct evidence and guidance in legal assessments and on the question of pre-bereavement counselling.

The limits of autonomy

Dr Fiona Randall (Consultant in Palliative Medicine with a philosophy degree, Christchurch Hospital, discussed whether 'autonomy is absolute'. In 1758 Kant limited the right to self-determination consequent upon the self-governing rule that 'the actions that I take must apply to everyone'. Latterly, advocates of patient autonomy have sought to remove the governing principle of the community to drive forward an agenda of individual rights. Without Kant's balancing factor concerning the needs of the community, one cannot oppose the push towards euthanasia or medically assisted suicide. Without community limits society will simply become the survival of the most autonomous. Dr Randall argued that public policy must seek to meet the needs of all patients and to protect the vulnerable. Defining medical responsibility within the
limits of the law, the General Medical Council and peer review protects the best interests of the patient and the autonomy of the doctor.

The ‘double effect’ principle

Introducing the debate on ‘double effect’, Dr Bobby Farsides (Lecturer in Medical Ethics, King’s College, London) reminded the audience of the deontological roots of the principle which involves questions of rights and duties, morally prohibited and right actions, and absolute prohibitions. Morally, the good effect must not be obtainable by other means. In all circumstances, the bad effect must be trumped by the good effect.

Professor Roger Higgs (Professor of Primary Care, Guy’s, King’s and St. Thomas’ School of Medicine, London) who founded the Institute of Medical Ethics, argued that death should not always be seen as a bad thing. Illustrating his talk with humorous anecdotes, Dr Higgs stated that there would seem to be a lot of sense in allowing patients to die the deaths they wanted. Dying was a sensitive and difficult issue; and many people wanted to be in control at the end of their lives. Death is an inevitable process at the end of a good life. Surely, he argued, it should be appropriate within the law, within professional codes of conduct and within realms of conscience, to provide patients who want to die with the means to end their life. Is it really wrong that the patient of a doctor who thinks death is appropriate should not be allowed to choose to die?

Dr Heather Draper (Lecturer in Medical Ethics, University of Birmingham Medical School) reminded delegates of the criminal law concerning matters of direct intent. The principle of double effect is important because it states that the primary action must be morally good. Legally, if an action taken has the primary intent of bringing about the consequences, or if the action is taken with the intent of bringing about the consequences, then the actor is liable in law for those consequences. It is the doctor’s intention behind the act taken that must be judged. That is why doctors seeking to withdraw nutritional support from PVS patients need to gain permission from the courts.

Ms Penny Lewis (Lecturer in Law, King’s College, London) wondered how one could regulate in law a defence of necessity. There would be conflicting duties concerning preservation of life, and the prevention of suffering. Would it be possible to rely on good faith? Furthermore, there would need to be a specific evaluation of the consequences and of the intent.

Speakers from the floor supporting the principle of double effect spoke about its historical roots in the justification of war, the necessity to resist the strong pressures to shorten the dying process, the economic pressures that would be placed upon doctors, the tempting short cuts and the tension that different legal rules would create in an evolving health care system. Other speakers did not agree, for they saw no reason why a patient who wanted death should not receive it.

The conference concluded with a lecture on the ‘The value and quality of life’ given by Professor Robin Downie (University of Glasgow), in which he expressed grave doubts about attempts to quantify a dying person’s quality of life. (See pages 378–81, this issue.)

Great credit goes to the palliative care movement for the efforts they have made and are making to define the issues around medical responsibility and decision-making at the end of life. Moving from cancer to palliation of longer lasting, non-terminal illnesses will no doubt change the scenario. How the world will change is unknown, yet the seeds of the future are sown in the soil of the present.

Reference

1 Report of a working party of the National Council for Hospice and Specialist Palliative Care Services. Ethical decision-making in palliative care: Artificial hydration for people who are terminally ill. London: National Council for Hospice and Specialist Palliative Care Services, 1998.

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