
Part I: Decisions involving patients who have decision-making capacity or patients who have executed an advance directive before losing this capacity (1)

In the context of the norms of medical practice summarised in the preceding preamble, five guidelines are suggested concerning requests from patients with decision-making capacity or from patients who have provided advance directives, oral or written, before losing their decision-making capacity. These guidelines fall into three categories.

Guidelines

REFUSAL OF TREATMENT

1. If a patient who has decision-making capacity rejects treatment that the doctor believes to be in the patient's interests, especially where such treatments are life-prolonging (2), the doctor should seek to explore the patient's reasons for such refusal and seek to correct any misunderstandings. However, a doctor should not impose treatment if rejected (even if the treatment is potentially life-prolonging) and should explore alternatives that might be acceptable to the patient, including transfer of the patient to the care of a doctor or institution prepared to respect the patient's wishes. In all cases, including those where a patient's refusal of a specific treatment is respected, the doctor and the health-care institution have the obligation to continue to offer supportive care and treatment for pain and suffering (3,4,5).

2. Where a patient has lost the capacity to make decisions but has given a valid advance directive to refuse treatment and/or has appointed a representative to make decisions about refusal of treatment, such directives and decisions should be respected by doctors and other health-care workers (6,7).

REQUESTS FOR TREATMENT, INCLUDING LIFE-PROLONGING TREATMENT

3. Doctors also have a strong *prima facie* obligation to respect patients' requests for life-prolonging treatment. However, certain qualifications are relevant:

(a) Doctors are not obliged to provide physiologically futile treatments (ie treatments that cannot produce the desired physiological change). Where a doctor considers a life-prolonging treatment not to be physiologically futile, but nonetheless 'futile' in another sense of the word (8) because of the low

probability of success or because of the low quality of life that would remain, then decisions about the withholding or withdrawal of such treatments should be made in the context of full and open discussion of the nature and extent of the 'futility' of the treatment with the patient or the patient's representative (9);

(b) If a requested treatment entails, according to the norms of medical practice (10), loss of function, mutilation, or pain disproportionate to benefit, the doctor is not obliged to provide it;

(c) If a doctor has a conscientious objection to a requested treatment (11), that doctor is not obliged to provide it. The doctor should explain all treatment options and his or her position regarding them. If the patient wishes, the doctor should arrange an orderly transition to another doctor of the patient's choice;

(d) Scarcity of resources may sometimes require overriding a patient's request for a life-prolonging treatment (see Part IV) (12).

4. Where a patient without decision-making capacity has previously given a valid advance directive requesting life-prolonging treatment(s) and/or appointed a representative to make such requests, doctors have a strong *prima facie* obligation to respect such requests. The same qualifications apply here as in guideline number 3 above.

REQUESTS FOR INTERVENTIONS INTENDED TO TERMINATE LIFE (VOLUNTARY EUTHANASIA)

5. Patients having decision-making capacity who are severely and irremediably suffering from incurable diseases sometimes ask for assistance in dying. Such requests for active termination of life by a medical act which directly and intentionally causes death may be morally justifiable and should be given serious consideration. Doctors have an obligation to try to provide treatment and care that will result in a peaceful, dignified, and humane death with minimal suffering. There is a particular obligation upon the doctor confronted with a request for euthanasia or other assistance in dying to undertake a scrupulously careful enquiry into the circumstances of the request to see if alternative courses of action might be helpful in removing or alleviating the cause or causes that led to the request. Attention should focus upon:

- (a) physical distress, which might be removed by better palliative treatment,
- (b) the possibility of significant mental depression, which might be susceptible to treatment, and
- (c) the perception of being an undue burden upon family members and other carers, which might be helped by counselling and more adequate support facilities.

It is recognised that participation in doctor-assisted dying for those patients who persist in their wish to die in spite of all measures to reduce their suffering will reflect different cultural and societal norms in individual countries (13). Whether statutory legalisation of the intentional termination of life by doctors is desirable is the subject of continuing international debate (14,15,16).

Dissent to Guideline 5

Requests for euthanasia by competent patients severely and irremediably suffering as a result of incurable disease may be understandable, but are not morally justified. (Shimon Glick, Arnold Rosin, David Schiedermayer and Avraham Steinberg)

Statutory legalisation of the intentional killing of patients by doctors is against basic morality as well as against the public interest. (Shimon Glick, Arnold Rosin, David Schiedermayer, Avraham Steinberg and Jan-Otto Ottosson)

Notes to Part 1

- (1) The term 'decision-making capacity' was chosen instead of 'competent' because the latter has different meanings, legal and non-legal, in different countries. A patient should be assumed to have the capacity to make a treatment decision when he or she can understand the relevant information, reflect on it in accordance with his or her values, and communicate a decision to caregivers *The Hastings Center monograph: guidelines on the termination of life-sustaining treatment and the care of the dying*. Briarcliff Manor, New York: Hastings Center, 1987: guideline 23. 'The more harmful to the patient his or her choice appears to be, the greater the level of certainty the professional should have about the assessment of capacity' (guideline 133 of the same monograph).
- (2) Examples of 'such treatments' could range from surgery or chemotherapy for cancer to artificial feeding and hydration for end-stage multiple sclerosis or renal dialysis for a quadriplegic.
- (3) The question of possible transfer of patients refusing life-prolonging treatment is fast becoming a key issue for discussion in the United States. One view is that a patient should not have to be transferred from one health-care institution to another to be able to have his or her basic human rights respected – especially if marked personal inconvenience or emotional suffering is involved in such a transfer. The essential principle of the right of the patient or surrogate to refuse life-prolonging treatment, including nutrition and hydration, has been so widely accepted in US law and ethics that institutions have little basis to claim that honouring such a refusal would intolerably violate their own moral values and moral integrity. Recent US court cases have

unanimously held that patient transfers are inappropriate in such instances. (What has not yet been tested in US courts is the right of an institution to announce in advance of patient admission that certain sorts of treatment refusals will not be honoured in that institution for moral reasons. Some passages in some court decisions suggest that an institution adopting this stance, openly stated in advance, would be allowed to insist upon transfer if the specified treatment were refused.)

Another view is that transfers between institutions may be indicated because different kinds of institutions (such as acute-care hospitals, intensive care units within hospitals, nursing homes, and hospices) habitually and routinely provide very different sorts and styles of care for the similar diagnoses and conditions. Among the documents on medical ethics, the *Hastings Center guidelines*, p24 (see Notes to Introduction, number 3) goes farthest in recognising transfer and no-transfer policies as crucial to operational medical ethics. (Howard Brody)

- (4) There is an emerging consensus in writings from the USA that is in favour of respecting autonomy, almost without regard to the circumstances. In contrast, the position in Britain is less clear-cut and is probably reflected quite accurately in the British medical Association *Report on euthanasia* (1988). The report received adverse criticism: see for example Higgs R (*British medical journal* 1988; 296: 1348) who says '... when someone has decided that he or she wishes to die we are not entitled to jump to the conclusion, as does the report, that such "expressed wishes ... make doctors wonder about the patient's competence as a decision-maker".'

Unlike the BMA euthanasia report, the British report The living will: consent to treatment at the end of life, (Age Concern, England and the Centre of Medical Law and Ethics, King's College, London; London, Edward Arnold, 1988) states that '... the physician should not strive to regard an irrational decision as incompetently based' and '... the physician should always be aware of the real possibility that a patient's values and goals may differ from his and so he should not necessarily evaluate an unreasonable or potentially damaging decision by the patient as stemming from an incompetent lack of understanding. A mere decision that is regarded as unreasonable should not in itself lead to a finding of incompetence'. The British living wills report analyses in detail the advantages and disadvantages of advance directives, with and without durable powers of attorney, and defines the alternative means of introducing living wills in Britain and the extent to which legislation may or may not be desirable. The acceptability and authority of advance directives is accorded clear significance in *The Appleton Consensus*, but again the *British Medical Association report on euthanasia* is somewhat equivocal, principally on the grounds of interpretation of wishes and the change which may take place in value judgements with increasing age. The BMA position is summarised thus: 'Any attempt to treat advance declarations as more than an indication of a patient's wishes where there are difficult decisions to be made is inappropriate. At times a judicious medical paternalism may well be the best and most realistic way to achieve a good outcome where the situation is not quite as the declarer might have envisaged it'. Further equivocation follows thus: 'But a certified and settled wish by a patient

- should be treated with the utmost respect'. (**George Robertson**)
- (5) In some religious traditions (for example Orthodox Judaism) the right to refuse clearly lifesaving treatment is not recognised as valid and, like suicide, would not be morally acceptable. (**Shimon Glick**)
 - (6) Advance directives are always less conclusive evidence than the contemporaneous statement of a competent, informed, and autonomous person. The advance directive substitutes for the latter situation only to the extent that the patient, when competent, was well-informed, acting reasonably freely, intending the instruction as now interpreted, and envisioning a situation reasonably similar to the one now faced. These concerns can be met fairly commonly, since ordinary persons giving advance directives are either giving thoughtful but broad instructions or are envisioning a future event that is known to be likely in that person's situation. One function of advance directives, naming a surrogate, is precisely to grant to a particularly trusted other person a fairly broad range of discretion in interpreting treatment-oriented directives. While the moral standing of directives in any form is equivalent, the seriousness of purpose, precision of language, and reliability of written advance directives justify policies which allow more extensive reliance on documented directives than on recollection of spoken statements. (**Joanne Lynn**)
 - (7) Due to the shortcomings and pitfalls of advance directives, and due to occasional difficulties in interpretation and even possible misinterpretation of such documents – advance directives should be considered and taken into account by doctors and other health care workers, but not automatically implemented. (**Avraham Steinberg**)
 - (8) The delegates are distinguishing here between two types of 'futility': physiological futility and common-sense futility. Narrowly understood, medical treatment is futile if it cannot produce its physiological effect. Continuing to provide heart stimulants and chest compressions during cardiopulmonary resuscitation (CPR) after the heart could no longer physiologically respond to the stimuli would be an example of physiologically futile treatment. An example of a broader, common-sense notion of futility would be continuing to administer heart stimulants and chest compressions after a time when, even if the heart responded, the condition of the patient would be brain death or a persistent vegetative state. Howard Brody's study note below outlines the different ways the term futility can be understood and highlights the areas of controversy.
 - (9) Part of the debate on futility hinges on the ambiguity of the term. For example, in recent articles on CPR in the US, 'futility' has been taken to mean at least three things: a) resuscitation will fail to restore heartbeat; b) resuscitation will restore heartbeat but only in a state of permanent unconsciousness; c) resuscitation will restore heartbeat and consciousness, but the patient will not survive long enough to leave the hospital. An important question is what empirical probability is required before any of these three categories of futility would apply. The ethics of allowing doctors to withhold requested therapy because they regard it as futile can be viewed in four categories in order of increasing controversy: 1) the treatment is likely to fail to achieve its physiological objective; 2) the treatment may achieve its physiological objective but with consequences for the patient deemed unacceptable by the medical profession (mutilation, loss of function, or pain); 3) the treatment may achieve its physiological objective but is likely to produce untoward consequences deemed unacceptable by the vast majority of people; 4) while the treatment may produce results which in the patient's eyes seem to be beneficial proportionate to the burdens imposed, in the doctor's judgement the treatment was 'futile' in the sense that the burdens would far outweigh the benefits. I believe that almost all would agree that the doctor in situation 1) is justified in withholding treatment on grounds of futility; whereas in situation 4) it is wrong both to withhold treatment and also to use the word 'futility' to describe what is happening. The interesting controversy, if I am correct, applies to situations 2) and 3). These international guidelines approve of treatment refusal in situation 1) and acknowledge that some situation 2) cases may also justify withholding treatment, although a higher level of consultation and approval is required. I believe that it would be appropriate to consider at least some applications of situation 3) under the heading of 'futility', but others might well object that that would constitute an intolerable throwback to the days of unbridled doctor paternalism. (**Howard Brody**)
 - (10) The phrase 'norms of medical practice' refers to the norms that would generally be accepted by a doctor's peers in his or her local medical community. Examples of treatments that would fall outside the norms of medical practice include amputation of a healthy limb for the purpose of avoiding military service or female circumcision.
 - (11) Examples of such treatment could include therapeutic abortion or, in medical cultures where it is legal, assisted suicide.
 - (12) This statement merely acknowledges the fact of scarcity and the consequent necessity of rationing life-prolonging treatment at some point. It would be unthinkable that in a condition of scarcity a patient could for personal or religious reasons demand to be maintained in an ICU as long as technologically possible. Precisely what should be considered when drawing such lines is left, at this point, to Part IV of this statement.
 - (13) Such participation could involve a number of acts on the part of health-care givers that are differently perceived and differently sanctioned in different cultures: including, but not limited to: a) counselling about methods of ending one's own life, including, when available, referral to information sources; b) prescribing and/or counselling about the use of drugs for ending one's own life (doctor-assisted suicide); c) providing a sustained drug-induced coma; d) acting with the deliberate intention of causing the death of the patient.
 - (14) See the dissent to this guideline registered by Shimon Glick, Arnold Rosin, David Schiedermayer, Avraham Steinberg and Jan-Otto Ottosson.
 - (15) Despite evidence of an increasing level of public opinion in favour of voluntary euthanasia (certainly this is true of the USA and Britain), all countries other than the Netherlands continue to resist efforts to give doctors legal immunity if they accede to a patient's request for euthanasia. There is also evidence, however, that a significant number of doctors are prepared to state anonymously that they have on occasion taken active steps to hasten death (Kuhse H, Singer P. *Medical journal of Australia* 1988; 148: 623).
During informal discussion at the Appleton Conference,

a few delegates formed the opinion that euthanasia, judging by polls of public and medical opinion, was in the ascendancy. In view of the constant unwillingness of legislatures to endorse euthanasia, evidence of its increasing acceptability is cause for some concern. The development of euthanasia 'through the back door' may indicate a growing frustration with advisory bodies which fail to provide clear guidelines on acceptable alternatives to euthanasia (including non-treatment) and a dangerous trend towards acting in the face of existing legislation.

The more rigorous and thoughtful application of non-treatment decisions together with the sustained

promotion of complete symptom relief in the terminally ill (come what may) could provide an effective alternative strategy to active, voluntary euthanasia. Presumably, much of the public interest in euthanasia stems from the perception and belief that there is no effective medical alternative. **(George Robertson)**

- (16) Doctors and others who urge social-policy change to allow direct and active killing have the responsibility to weigh the risks that such a policy may pose for those who are poor, disabled, inarticulate or otherwise devalued. It may well be that the risk of cultural coercion upon such persons to accept being killed is so great that the social-policy change cannot be justified. **(Joanne Lynn)**
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