

## Part III: Decisions involving neonates and other patients who have never achieved decision-making capacity

These guidelines address decisions regarding patients who now lack and have always lacked the capacity to choose for themselves with regard to life-prolonging medical treatment. They are patients for whom no 'substituted judgement' can be rendered, as their present or previous wishes and desires cannot be known. Within this group two further distinctions may be useful: 1) between those who, due to anomaly, illness, or injury, will never develop decisional capacity in the future (such as anencephalic infants, the permanently unconscious, and the severely and permanently incapacitated) and those who can be anticipated, if they survive, to develop decisional capacity to varying degrees, and 2) between those who have a natural or agreed surrogate decision-maker (for example, parents or guardian) and those who lack such a surrogate.

### Guidelines

#### QUALITY-OF-LIFE JUDGEMENTS

1. Regard for the value of life does not imply a duty always to employ life-prolonging treatment for patients in this category. In setting reasonable limits for such treatment, 'third-person' judgements about quality of life are inevitable. Responsible third-person (1) quality-of-life judgements consider, insofar as possible, how the options must appear from the perspective of one in the patient's condition and determine what would most reasonably be thought to count as quality for most such patients (2,3).
2. Assessing quality of life of these patients for purposes of medical decisions involves weighing the ratio of benefits and burdens (4).
3. In most decisions involving patients in this category, at least five sets of interests may be discerned:

- a) the patient's;
- b) the surrogate's or family's;
- c) the doctor's and those of other care-givers;
- d) the health-care institution's (where continuing or withholding treatment may have religious, financial, and legal implications or may expose it to local or national publicity);
- e) society's (including both the use of economic

resources and the need for research to help future patients).

Normally, the patient's interests should be regarded as paramount. However, difficult moral dilemmas arise when the patient's interests are unclear or clearly conflict with a number of other interests. Societies differ in their preferences for mechanisms for arbitrating conflict in these difficult cases (for example, institutional ethics committee, courts). It is important to remember, however, that in the cases most commonly encountered, the various interests are not necessarily in conflict. Often the patient's own interest is integrally interwoven with the interest of the family and the community. Part of the doctor's clinical wisdom consists of responsibly weighing interests and creatively resolving apparently irreconcilable conflicts (5).

#### COMMUNICATION WITH PATIENT'S SURROGATE

4. When the patient has a surrogate, the doctor's obligation to the patient also requires certain duties towards the surrogate. These include: a) providing accurate information about the specific clinical problems; b) being honest; c) applying skills in effective communication; d) being willing to answer any questions that are asked; e) being aware of broader social and moral implications.

To act in a way that recognises these duties to the surrogate is to be worthy of the trust that one hopes the surrogate will place in the doctor, so that a policy of mutual and shared decision-making may be fostered.

#### DOCUMENTATION OF MEDICAL CARE

5. While the doctor is required to act in a trustworthy manner towards the patient and surrogate, the range of interests that could conflict (see Part III, guideline number 3, above) demands that that same standard of trustworthiness be translated to the level of social review and professional peer relationships. Whatever patterns an individual medical culture may employ to achieve that translation of standards, the process will be enhanced by careful documentation of medical care to facilitate thoughtful review. This documentation should include the careful recording of management plans as well as the internal reasoning that led to them.

It should routinely include both medical evidence and the applications of principles which logically lead to the conclusions made about management. Such patterns of careful thinking and careful documentation constitute good clinical practice. How often review occurs and by whom may be a matter of considerable difference among various countries. Adding extra layers of mandatory audit may compromise the quality of patient care without helping to avoid the occasional bad decision (6).

#### WEIGHING BENEFITS AND BURDENS

6. When a patient lacks a surrogate, little difficulty arises when the benefit-burden ratio clearly favours administration and continuation of life-prolonging treatment. When the benefit-burden ratio is less certain or reversed, a wide variety of mechanisms have been proposed to aid or to review the doctor's decision-making (7).

7. The doctor may appropriately withdraw or withhold life-prolonging treatment when, in the view of the informed surrogate and doctor, continued treatment would lead to unacceptable burdens without sufficient compensating benefits to the patient. What counts as a benefit or a burden and the relative ratio between them depends on specific situational factors and, therefore, good decisions in this category of patients demand individual discretion. While these patients possess a vulnerability which makes them frequently subject to social discrimination and stigmatisation, their interests are not protected by the elimination of decisional discretion. On the contrary, a trustworthy doctor and the processes of appropriate review are better means of protecting the interests of vulnerable patients (8,9).

#### Notes to Part III

- (1) Third-person quality-of-life judgements are made grammatically and logically in the third person – ie judgements about the quality of 'his' or 'her' life as compared with first-person judgements about the quality of 'my' life.
- (2) This form of third-person quality-of-life judgement must be carefully distinguished from third-person quality-of-life judgements based on concepts of minimal social worth, which all delegates felt were not morally justifiable as a basis for medical decision-making in individual cases.
- (3) Some delegates argued that any attempt to consider how options appear to an infant or a person who has never been competent is misguided, since such consideration could only be an inappropriate projection of others' interests onto the infant or other incompetent person. Instead, they argue, judgements in such cases should be based entirely on what others consider to be the patient's 'best interest'. Others felt that the attempt to ascertain insofar as possible 'what most such patients would count as quality' was an undeniable responsibility of decision-makers in any decision involving quality of life.
- (4) It is recognised, however, that the language of benefits and burdens will not by itself resolve the most difficult dilemmas, since irreconcilable differences can always be re-expressed in terms of a claim that opposing viewpoints

overestimate burdens and underestimate benefits, or vice versa, or fail to specify whose benefits and whose burdens are involved. These terms are nonetheless useful to help focus on clinically significant variables and to avoid employing judgements of social worth.

- (5) Delegates acknowledged that there is some distrust of doctors' ability to fulfill such a role, especially if they do so without incorporating the views of others.
- (6) An interesting example of international disagreement arose around the proper mechanisms for audit of these difficult cases. The current trend in the US is toward reliance upon institutional ethics committees (IECs) to ensure a multidisciplinary forum in which all points of view on a controversial issue can be openly discussed. Except for the Netherlands, where a network of IECs has recently been established, the IEC concept is quite foreign to the patterns of professional doctors in Britain and Europe. However, the acceptance of the IEC in the US and opposition to it in Europe may be overstated. In the US doctors objected strenuously only a few years ago to any suggestion that a committee, especially a committee that includes non-doctors, might have a role in advising or overseeing their decisions. Today, many US doctors have altered their views on this, but others remain steadfastly opposed to any committee-oversight of this type. In Britain and the rest of Europe, many specialised units, such as newborn intensive care units, have assembled multidisciplinary teams of health-workers to manage the day-to-day care of patients; difficult cases will commonly be discussed at length by these teams before a decision is made. The dynamics of this procedure and the outcome may well be almost indistinguishable from IEC review in the US.

A good deal of the movement towards the IEC mechanism in the US in the past decade resulted from government interventions in the form of the Baby Doe regulations (based on Title II – Amendments to the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 [United States Statutes at Large, 98th Congress, 2nd Session 1984; 98,2: 1755]). Given the choice between committee review and no review, most US doctors would opt for no review. But when faced with a choice between committee review within their own institution and review by federal investigators, most US doctors became quite enthusiastic about the former. (Howard Brody)

- (7) A useful summary of these mechanisms appears in *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: 24–26.
- (8) It is important to the meaning of this passage to note the precise wording of the guidelines. Vulnerable patients need protection, and it is the trustworthy doctor who provides a part of this protection. This is not to say that if patients and the general public simply trust doctors all will be well. Doctors cannot expect to be trusted unless they act so as to be worthy of trust. Unilateral, closed decision-making is not conducive to trust. Decision-making in a setting where reasons and justifications are recorded and reviewed, so as to make it easy to review the decision process (whether or not a later audit occurs), demonstrates trustworthiness and provides a large part of the protection needed by these patients. The entirety of Part III of our guidelines represents a rejection of the thinking behind the 'Baby Doe Rules' proposed by the US federal government between 1982 and 1984. This is illustrated strikingly at two places, one

of which is our acceptance of quality-of-life judgements regarding seriously ill infants. Underlying the entire Baby Doe initiative was the view that quality-of-life judgements are morally unacceptable and in all cases count as inappropriate judgements of social worth. The counter-argument, accepted unanimously by this working group, is that quality-of-life judgements are unavoidable unless one adopts an indefensible, vitalist policy of treating every patient with every available technology until death. Indeed, the very exceptions to treatment contained within the Baby Doe guidelines (irreversible loss of consciousness, treatment that merely prolongs dying, and treatment that is 'virtually futile and inhumane') can readily be shown to contain implicit quality-of-life judgements. The other striking divergence from the Baby Doe approach in our consensus concerns the discretion of doctors and parents in difficult cases. While inevitable wrong decisions will be made from time to time, we felt it unacceptable medical practice and social policy to impose inappropriate treatment in thousands of cases to eliminate

bad decisions in a handful. (**Howard Brody**)

- (9) Commentary on the Baby Doe guidelines in the US ought to include recognition of the current status of the law and the amount of discretion that now exists for US doctors and parents in these cases. US neonatologists widely agree that the law is believed to require over-treatment of infants, and in practice this results in many terminally ill infants receiving inappropriately aggressive care for long periods. This is an inaccurate interpretation of what the law requires. Current US federal law simply mandates that states wishing to receive federal grants for child abuse and neglect services must have in place a mechanism to review suspected cases of 'medical neglect'. No treatment of infants is mandated by that law and no penalties against doctors, parents, or hospitals for non-treatment are contained within the law. (Murray, T H. The final anti-climactic rule on Baby Doe. *Hastings Center report* 1985; 15: 5-9. See also Angell, M. Handicapped children: Baby Doe and Uncle Sam. *New England journal of medicine* 1983; 309: 659-661).