

Editorial

Palliative care ethics: non-provision of artificial nutrition and hydration to terminally ill sedated patients

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In this issue of the journal Dr Gillian Craig (1) and her commentator Dr Eric Wilkes (2) raise a variety of important questions about ethical aspects of palliative care medicine that deserve careful reflection. Perhaps the most difficult – and contentious – of the issues raised by Dr Craig are (a) the question of withholding or withdrawing of artificial nutrition and hydration from terminally ill patients who, because of pain or severe suffering, have been sedated; and (b) the question of how to deal with disagreement between the patient's health care workers and the patient's family members, if this arises when the patient cannot be consulted directly.

So far as the first question is concerned, Dr Craig is clear that except at the time of actual dying (easier to identify in retrospect than in prospect), 'I do not think it is morally acceptable to leave a sedated patient for long without hydration' – by which, the context makes quite clear, she means that if the patient is too sedated to take sufficient fluids by mouth then a drip should be put up so as to attain the normal medical standards of adequate hydration. As she also writes, 'Others would dissent from this view using words such as "meddlesome" and "unethical" if intravenous fluids are suggested under such circumstances'. However, so far as she is concerned, 'To take a decision to sedate a person, without hydration, until he/she dies is a very dangerous policy, medically, ethically and legally.'

For Dr Craig 'The only way to ensure that a life will not be shortened is to maintain hydration during sedation in all cases where inability to eat and drink is a direct consequence of sedation, unless the relatives request no further intervention, or if the patient has made his/her wishes known to this effect ... the responsible medical staff must face the fact that prolonged sedation without hydration or nutrition will end in death, whatever the underlying pathology' – and she points out that 'even a fit Bedu tribesman riding in the desert in cool weather can only survive for seven days without food or water'.

The issues of killing and letting die have been addressed before in these columns (3–4). In summary, while it has been very thoroughly demonstrated by example and philosophical

argument that there is no necessary moral distinction to be drawn between killing and letting die, they are not necessarily morally equivalent. Moral distinctions between killing and letting die may arise:

- as a result of religious commitments;
- as a result of legal obligations;
- as a result of differences in the overall benefits and harms resulting from policies that forbid all intentional killings (of non-aggressors) versus those that would result from policies that would also forbid all intentional allowings to die;
- as a result of differences in the motives and intentions of the agent, and
- as a result of differences in the duties of care owed by agents to the persons who are killed or allowed to die.

In practical ethical terms, doctors are both morally and legally justified in withholding or withdrawing any treatments that are not beneficial to their patients, and are morally and legally required to withhold or withdraw any treatments that are harmful.

The fact that withholding or withdrawing non-beneficial or positively harmful medical interventions would or might result in the patient's death earlier than would otherwise have been the case if the medical intervention had been instituted or maintained does not, it is widely agreed, demonstrate that such withholding or withdrawing is either wrong or illegal (5–10). On the contrary, as the lawyer Professor Skegg put it, 'Doctors are sometimes free – sometimes indeed required – to allow a patient to die' (11). Thus, *pace* Dr Craig, concern about 'the only way to ensure that a life will not be shortened' is widely held to be less important than the traditional medico-moral objective of benefiting the patient with minimal harm, and the legal translation of this into the doctor's obligation to fulfil his or her duty of care. Artificial hydration and nutrition may or may not be ways of fulfilling those moral and legal obligations.

While in normal circumstances it is in principle possible to ask the patient about his or her preferences concerning such treatment – and different patients in similar predicaments may well

have very different preferences – Dr Craig raises four important complicating concerns. The first is the terminally ill patient who is sedated because of severe distress and/or pain. The second is the terminally ill patient who is also mentally ill and who is sedated because of increased agitation caused either by deterioration in the primary mental disorder or by the agony of impending death – so called terminal agitated delirium. The third complicating factor is disagreement about the appropriate management between, on the one hand the medical and nursing staff, and on the other hand close members of the patient's family. And Dr Craig's fourth complicating factor concerns family members who disagree with the medical carers and who are themselves medically qualified or otherwise medically 'knowledgeable'.

A variety of guidelines are available to help medical and nursing staff in such cases, whether in hospices or hospitals (6–9). The Appleton international consensus guidelines (8), similar to the British Medical Association (BMA) guidelines, make it clear that the patient's own views are preferable where available and willingly provided. Where the patient is not sufficiently mentally competent for such discussion to be reliable, it may be possible to reduce the sedation or otherwise wait for a lucid period in which the patient's autonomous views may be obtained. If not, relatives or friends may function as proxies for the patient. Again the preferable situation is where the patient has already nominated the person or persons preferred as proxy. Where this has not happened, those close to the patient, preferably those who are in a position to know what the patient's own values and preferences would be, should be consulted.

As the BMA advise (6), in deciding whether life-prolonging treatment is in the best interests of the patient the health team should consider three main factors:

- the possibility of extending life under humane and comfortable conditions;
- the patient's values about life and the way it should be lived, and
- the patient's likely reaction to sickness, suffering and medical intervention.

And the BMA add that 'although doctors should not give treatment simply because it is available, in cases of doubt about the best interests of the patient, the presumption should be in favour of prolonging life. This is particularly so if most people would consider that life to be of acceptable quality' (6).

Thus, when the patient is unable (or unwilling) to provide information about his or her own preferences, doctors should try to consult a family member or close friend who knows the patient's own views.

In cases of disagreement between doctors and patients' proxies, whether family or friends, the BMA recommend 'counselling, discussion and further medical opinion', with time and effort being put into

resolving the conflict, and a preference for avoiding the need to go to court (6). The Appleton and the Hastings guidelines add that some form of conflict-resolving mechanism should be in place. Like the BMA, the Appleton consensus recommends in the first instance 'counselling, discussion, consultation and other informal interventions'. If there is disagreement between different members of the patient's family or circle of friends, then doctors should prefer the advice of those who are 'emotionally and socially close' to the patient and 'may disregard the claims of the more tangential party'. If, however, disagreement remains with someone close to the patient then 'the physician should not generally override that view without resorting to more formal conflict resolution processes' (8).

The sort of conflicts alluded to by Dr Craig seem precisely the sort that would require formal mediation. One can imagine a situation in which a medically qualified family member feels outraged at the proposed medical management of a severely disturbed terminally ill close relative by sedation and withholding of artificial nutrition and hydration. One can equally well imagine the response of the medical team to a proposal by such a medically qualified family member that the patient ought to have a drip. As suggested by Dr Wilkes in his commentary, 'we need to be tactfully resistant to sacrificing the interests of our patient to the emotional distress of the relatives' (2).

However, should it come to a straightforward unresolvable disagreement between a relative acting as proxy and the health care team about whether prolonging the life of a terminally ill patient by artificial hydration is in the patient's interests, then it seems important for the dispute to be referred for some sort of formal mediation procedure. Is it not time that British hospitals and hospices developed such procedures? There certainly seems no obvious reason to assume that in such disputes the doctors and medical teams are always right, if indeed there is a clearly 'right' answer. But even if the doctors were always or usually right, not only should justice be done, it should also be seen to be done.

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- (6) See reference (2): 34: para 4.13.
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