

“Thou shalt not die in pain”: Treatment decisions at the end of life

A recent paper, *Consensus Guidelines on Analgesia and Sedation in Dying Intensive Care Unit Patients* (L.A. Hawryluck, W.R.C. Harvey, L. Lemieux-Charles and P.A. Singer, University of Toronto, March 2002) attracted a great deal of media attention. In the process, some confusion about the ethics and law of treating the pain and suffering of dying people, in particular, those in intensive care units, was revealed. So, what are the current bottom-line ethical and legal rules?

Patient-centred decisionmaking...

First, decision making about treatment must be patient-centred — in the past, it was physician-centred. Requiring the patient’s — or the incompetent patient’s representative’s — informed consent to giving, withholding or withdrawing treatment, ensures patient-centredness.

At a certain point, terminally ill patients — or their representatives — will decide not to continue treatment that has a goal of prolonging life, and to change to palliative treatment that has a primary goal of treating pain and suffering. Note: this is a decision to change the nature of the treatment received and not a decision to cease treatment or an informed refusal of treatment. In the past, it was not uncommon for physicians to say to dying patients, “There is nothing more we can

do for you”. That statement would, now, encapsulate the antithesis of good, contemporary palliative medicine.

Changing to palliative care...

The care dying patients receive when they change to palliative treatment can vary widely. When they move to a designated palliative care unit, all the staff are trained to provide the care they need. That is not true when they are dying in other facilities, such as an intensive care unit (ICU). The guidelines referred to above, seek to deal with that situation.

Intensivists are rightly trained to act very aggressively to save or prolong life, and they are not trained in palliative care. Consequently, where possible, a palliative care specialist should be involved in caring for dying people in ICUs. While the guidelines recognize that ICU physicians could learn from palliative care specialists, they do not expressly recommend that. Moreover, the consensus process on which the guidelines are based did not include palliative care specialists. That weakens them.

Refusal of treatment...

Competent adults have the right to refuse treatment, including life support or life prolonging treatment, either at the time or in advance through “advance directives” (living wills and appointment of a substitute decision makers). This right flows

from the right to inviolability, the right not to be touched without one's consent, including by medical treatment. It is a right to have one's bodily integrity respected, not a right to die, although, where life depends on the continuation of treatment — for instance, respiratory support — withdrawal of that treatment will result in the person's death. Both ethics and law regard death in these circumstances as being caused by the patient's underlying disease — for example, a failed respiratory system. Consequently, *withdrawal of treatment* because the patient or their representative refuses it, is *not euthanasia*, *not suicide*, and *not physician-assisted suicide*.

Disagreement between patients and physicians...

Difficult questions arise when there is disagreement between the patient and/or the patient's family, on the one hand, and the health care team, on the other, concerning whether treatment should be continued. In most of the situations that have ended up in court, physicians have wanted to withdraw treatment, usually on the basis that it was futile or too burdensome for the patient, and patients and families have objected. Unless the treatment is “medically futile” — that is, would have no medical effect — courts have recognized that it is for patients and/or their families to decide on the basis of their values (and not for physicians to decide the basis on their values) whether treatment should be withdrawn. In other words,

there must be informed consent to withdrawing treatment that is not medically futile.

Pain relief treatment...

Patients have a right to be offered all necessary pain relief treatment even if, where it is necessary to relieve pain, that treatment could or would shorten life — a rare situation. (Indeed, adequate pain relief treatment probably prolongs life, as the patient’s physiological and psychological resources are not being exhausted trying to cope with the pain.) To wrongfully fail to offer people fully adequate pain relief treatment is: unethical; unprofessional conduct that should result in professional disciplinary measures; medical malpractice; and, in extreme cases, could be criminal negligence.

People who advocate the legalization of euthanasia have focused on pain relief treatment that could or would shorten life to support their case. They argue that it is really euthanasia and, therefore, in recognizing such treatment as ethically and legally acceptable, we are, in practice, also accepting euthanasia. Thus, they say, we should change the law to recognize euthanasia. They also argue that physicians use pain relief treatment as a cover for intentionally carrying out euthanasia — that is, they practice euthanasia in disguise or, as they call it, “slow euthanasia”. That term refers to physicians, over a period of time, giving levels of pain relief

treatment that *very substantially exceed* what is needed to relieve the patient's pain, with the intention of causing death. That would be euthanasia. But euthanasia and the provision of *necessary* pain relief treatment differ in ethics and law in a fundamental way.

The intent in giving pain relief treatment is to kill the pain, not the patient with the pain. In euthanasia, the primary intention is to kill the patient. The law accommodates situations where pain relief treatment could, as an unwanted consequence, shorten life, through the "doctrine of double effect". Provided the physician's primary intention is to relieve pain and not to shorten life, and the treatment given is necessary to relieve the pain, the physician will not be legally liable for providing it. Indeed, as pointed out above, the physician might well be legally liable for failing to offer such treatment to the patient.

Relief of suffering...

Difficulties arise when the justification of the treatment that could shorten life is extended, as in the *Consensus Guidelines*, beyond pain and other symptoms of serious physical distress, to include suffering. Suffering includes existential suffering. To justify giving a treatment that could or would shorten life, on the basis that it was given with a primary intent to relieve suffering in general, would amount to justifying euthanasia: In euthanasia the primary intent in killing the

patient is to relieve the patient's suffering. Consequently, our language must be very carefully crafted to ensure that we can continue to give all necessary treatment for the relief of pain and other symptoms of serious physical distress, but that in doing so we do not legitimate euthanasia.

Terminal sedation...

The *Consensus Guidelines* also address the issue of terminal sedation — totally sedating the patient until death occurs naturally. Such treatment is justified in certain, rare cases, where the patient's pain or other symptoms of serious physical distress are not otherwise able to be relieved. Some statements in the guidelines are, however, of concern in this regard. They discuss withdrawing a respirator from a sedated patient artificially paralysed with neuromuscular blockers, the effects of which have not been reversed. Were the artificial paralysis to kill the patient, rather than the patient dying from their underlying disease, the withdrawal of the respirator would probably constitute euthanasia.

Intention...

A problem with the *Consensus Guidelines* is that they can be interpreted as saying that the only condition necessary to justify providing pain relief treatment that could shorten life, is that the physician states that it is his or her intention to relieve pain. While it is true that pain must be assessed on an individual basis from the

patient's perspective and, likewise, the treatment that is required to relieve it, it is not true that a physician can simply state that his or her intent is to palliate a dying patient and, as a result, any measures taken to achieve that palliation are thereby ethically and legally justified. The treatment given must be within the bounds of what is reasonably necessary to accomplish such palliation. Physicians should definitely err on the side of ensuring that pain is relieved. But doses that are grossly excessive by any reasonable standard, could indicate that the physician's primary intention was to kill the patient.

Pain-relief expertise...

Finally, we should be aware that physicians, other than palliative care physicians or pain specialists, often vastly over-estimate their knowledge about pain relief. In one study of oncologists, who encounter serious pain on a daily basis, nine out of ten said that they thought that they had good pain relief knowledge. But when tested on their knowledge, only four out of ten passed. With respect to patients being left in pain, perhaps the only thing more dangerous than a physician who does not have the necessary knowledge, is one who does not, but thinks that he or she does.

Conclusion...

The *Consensus Guidelines* will help ICU physicians to recognize their serious obligations to offer dying people fully adequate pain relief treatment and, certainly, delivering that message is of the utmost importance. But, it is also important to recognize that they do not provide — and from their title were not intended to provide — a comprehensive guide to decision making about treatment at the end-of-life.