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Terminal sedation

Terminal sedation: source of a restless ethical debate

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Slow euthanasia or a good palliative intervention?

here are many ways in which doctors influence the circumstances and/or the timing of a patient's death. Some of these are accepted as normal medical practice—for instance, when a disproportional treatment is forgone, others are considered tolerable only under strict conditions or even intolerable, such as non-voluntary active euthanasia. A relatively new phenomenon in the ethical discussion on end-of-life decisions is terminal sedation. Terminal sedation is used in patients with terminal illnesses where normal medical treatments cannot relieve severe symptoms such as pain and agitation, and no option is left but to take away the perception of these symptoms. Often, the decision to start terminal sedation is accompanied by the decision to forgo the provision of artificial nutrition and hydration in these patients. In The Netherlands, terminal sedation was estimated to be applied in 4-10% of all deaths in 2001.1 The combination of these two decisions have made the moral status of terminal sedation the subject of fierce ethical debates. Is it slow euthanasia2 3 or is it a good palliative intervention that should be sharply distinguished from euthanasia?4 5 One of the characteristics of this debate is that it is a very confused one: people disagree about the meaning of the term, the appropriateness of it and, of course, about the conditions under which it (what?) would be morally justified. As a matter of fact, these three discussions are deeply connected: as is often the case, a discussion about terms is a discussion about norms in disguise.

The first observation to be made is that many seemingly descriptive definitions of terminal sedation contain normative claims. Examples of this are definitions of terminal sedation in which only certain intentions (usually the intention only to relieve suffering), only certain indications (usually refractory symptoms) or only certain patients are accepted (usually those whose life expectancy is <1 week). These definitions are problematic because they obfuscate normative discussions and because they generate the question of how to call cases in which the same acts

were performed but in which other intentions, indications or patients were involved. Generally speaking, one should aim at descriptive definitions of an intervention, allowing for a separate discussion about the conditions under which this intervention would be morally acceptable. Applied to terminal sedation, this would lead to the following definition: terminal sedation is sedation until death follows.6 Note that this definition does not specify the life expectancy of the patient, nor an indication for the intervention or a specific intention. The condition that sedation is continued until death is a necessary condition for terminal sedation to discriminate this intervention from ordinary sedation during anaesthesia.

The second problem is the choice for an adjective to "sedation". The preference for "terminal" seems to be held primarily by those who want to unmask this type of sedation as a form of euthanasia, assuming that by doing so its moral status is determined as well. Those who prefer "palliative" usually argue that this type of sedation is normal medical practice and that "terminal" would induce the false belief that it is not, for instance, because of the association with the word "termination". There is some truth in both these claims and therefore a choice between them is hard to make. However, I submit that terminal should be the preferred term because it conveys the message that an end-of-life decision is involved, implying that the timing of death may be influenced. The objection that the use of the word terminal suggests a moral status of equivalence to euthanasia should be countered by insisting that this is a descriptive definition and that labelling should not substitute for decent ethical reasoning. Moreover, "palliative" runs the greater risk of being an euphemism. It may conceal the fact that, given the definition proposed above, at least some of the cases of sedation are the moral equivalents of active euthanasia. I will return to this point below.

The third point to be addressed follows on from the fact that the above-mentioned definition is descriptive only. The question of under what circumstances terminal sedation as a technique would be morally acceptable still has to be answered. The first issue to be addressed in determining the justifiability of terminal sedation is its seemingly problematic categorisation. This follows from the fact that often two modes of conduct are combined: an act (sedation) and an omission (forgoing the provision of artificial nutrition and hydration). In combining these two modes of conduct, terminal sedation ruins the peace of mind of those who equate the boundary between normal medical practice and intolerable medical conduct (such as euthanasia) with the distinction between acts and omissions. Obviously, those who reject the moral relevance of this distinction will have fewer problems.

The first point in this respect is that whenever, in a particular case, terminal sedation is combined with the forgoing of artificial hydration and nutrition, one should evaluate this decision as a whole and not as two separate decisions. The line of reasoning that terminal sedation is a form of normal medical practice because "only" palliative measures are used, and that, given the sedation, artificial nutrition and hydration should be considered as futile medical treatment,5 is a salami-slicing technique and clearly fallacious. The second point is that the categorisation problem mentioned is of little relevance, since calling a mode of conduct active or passive cannot settle its moral position.

I submit that in order to evaluate the moral status of decisions to use terminal sedation, we have to know what the patient wanted, precisely what the doctor did, what the doctor intended, what the effect of the doctor's acts were (also in terms of shortening of life), in what condition the patient was and what the nature of the disease was. This information will enable us to judge the proportionality and the subsidiarity of the intervention, which form the core of moral evaluation. We certainly need to know more than what the doctor intended. Intentions, to a large extent, are reconstructions of what one felt at the time of decision making and are hard to verify.7 If what the doctor did was the right palliative measure and if it was therefore perfectly understandable that he hoped for the end to come, why hold it against him that he acted accordingly? We may assume that the doctor did not intend to hasten the end of life, but even if we were wrong, we would evaluate the doctor's behaviour in the same way because the doctor's actions fulfilled the criteria of proportionality and subsidiarity: the bad consequence of the act was 188 EDITORIAL

the lesser evil which could not have been avoided by acting in a different way. Using these criteria, some cases will be judged as morally permissible; those cases will be called "normal medical practice". Other cases—for instance, when terminal sedation is used only as a technique to bring about death on request—will turn out to be the moral equivalent of active voluntary euthanasia. In these cases, locally applicable guidelines and/or laws concerning euthanasia will have to be followed. If that means that the intervention in these cases is forbidden, so be it.

This seemingly ambiguous position concerning the normative position of terminal sedation should not be confused with the view that terminal sedation might serve as a compromise in the discussion on euthanasia.⁸ According to that line of thought, proponents of liberalising active voluntary euthanasia should accept terminal sedation because it makes death easier for patients who want to die and adherents of the sanctity of life doctrine should accept it because terminal sedation makes it possible to hold on to this doctrine, while at the same time being sensitive to the problems

of patients. I have to disagree. Terminal sedation under certain conditions, especially when this treatment is the medical answer to a medical problem, has nothing to do with active voluntary euthanasia and will therefore fall outside the range of things that the members of "right to die societies" are pleading for. They are not campaigning for adequate medical care (although they will certainly welcome it) but for the right of the patient to ask for death. Under different conditions, terminal sedation is morally equivalent to euthanasia, not just an in-between compromise position. Obviously, this will be unacceptable to adherents of the doctrine of the sanctity of life. I conclude that although in some cases terminal sedation and euthanasia are two morally equivalent ways of hastening death, in most cases they represent essentially different clinical situations.9

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