# Sedation, Alimentation, Hydration, and Equivocation: Careful Conversation about Care at the End of Life

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**In the recent medical ethics literature, several authors have recommended terminal sedation and refusal of hydration and nutrition as important, morally acceptable, and relatively uncontroversial treatment options for end-of-life suffering. However, not all authors use these terms to refer to the same practices. This paper examines the various ways that the terms *terminal sedation* and *refusal of hydration and nutrition* have been used in the medical literature. Although some of these practices are ethically appropriate responses to end-of-life suffering, others (at least as they are currently described in the medical ethics literature) are not. This paper identifies and discusses the principles that morally distinguish these practices from one another and specifically describes different features of medical practices and moral principles that affect the moral acceptability of various medical treatments. These distinctions reveal the complexity of the issues surrounding terminal sedation and refusal of hydration and nutrition, a complexity that has not been adequately addressed in recent discussions.**

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In the recent medical literature, several authors have recommended terminal sedation and refusal of hydration and nutrition as morally acceptable and relatively uncontroversial treatment options for end-of-life suffering (1–3). Unfortunately, these terms have been used to encompass a variety of practices, some of which are morally distinct from one another in important ways. Clinicians who fail to appreciate these differences may be misled into participating in practices that oppose their moral commitments. Thus, we believe that it is critical to more carefully analyze the concepts of terminal sedation and refusal of hydration and nutrition.

## Terminal Sedation

In general, the term *terminal sedation* has been accepted to mean what is better described as *sedation of the imminently dying* (4). By this, we mean a practice in which 1) the patient is close to death (hours, days, or at most a few weeks); 2) the patient has one or more severe symptoms that are refractory to standard palliative care; 3) the patient's physician vigorously treats these symptoms with therapy known to be efficacious; 4) this therapy has a dose-dependent side effect of sedation that is a foreseen but unintended consequence of trying to relieve the patient's symptoms (5, 6); and 5) this therapy may be coupled with the withholding or withdrawing of life-sustaining treatments that are ineffective or disproportionately burdensome.

However, some authors have used terminal sedation to include a different practice—one that we will call *sedation toward death*. By this, they mean a practice in which 1) the patient need not be imminently dying (2); 2) the symptoms believed to be refractory to treatment are simply the consciousness that one is not yet dead (1); 3) the patient's physician selects therapy intended to render the patient unconscious as a means of treating the refractory symptoms; and 4) other life-sustaining treatments are withdrawn to hasten death.

We believe that these two practices are morally distinct from each other. Before explaining the difference, however, we need to clarify the second term with which we are concerned in this discussion.

## Refusal of Hydration and Nutrition

The term *refusal of hydration and nutrition* has generally been used to categorize situations that are best described as refusing artificial hydration and nutrition. By this, we mean a practice in which 1) the patient has an irreversible condition that interferes with normal appetite, digestion, or absorption of water and essential nutrients and 2) the patient has determined that the benefits of artificial nutrition are not proportionate to the burdens in this situation.

Similar to terminal sedation, however, refusal of hydration and nutrition has been used to refer to different practices. Some authors have used this term to describe a practice called *voluntarily stopping eating and drinking* (2, 3). By this, they mean a practice in which 1) the

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patient has no underlying condition that interferes with normal appetite, digestion, or absorption of water and essential nutrients and 2) the patient nevertheless intends to end his or her own life by not eating or drinking.

We believe that these two practices are morally distinct from each other. To better understand this moral difference as well as the differences between the two practices of terminal sedation, we present three clinical cases.

## CASE DESCRIPTIONS

### Case 1

*Janet is 47 years old and has advanced amyotrophic lateral sclerosis. She is not clinically depressed, and a consulting psychiatrist asserts that she retains decision-making capacity. However, Janet has severe muscle weakness and requires intermittent respiratory support. As a consequence, she fears what she sees as the impending loss of her dignity. After receiving spiritual counseling, she repeatedly asks her physician to induce a barbiturate coma and to withhold artificial hydration or nutrition. After a prolonged consent discussion, the physician agrees to grant Janet's request and she dies 4 days later.*

This case is an example of sedation toward death. Although Janet has a terminal illness, she is not imminently dying. Her physician uses therapy to bring about loss of consciousness as the means of treating her fear of a future with disability, and he withholds hydration and nutrition in order to hasten death.

### Case 2

*Joe is 30 years old and has end-stage osteogenic sarcoma. Cure is no longer possible after years of struggling with surgery and chemotherapy. He has developed myoclonus as a side effect of protracted high-dose opioid therapy, and he is dyspneic and near death. Standard doses of muscle relaxants have not controlled the myoclonus. Despite adjuvant treatments, the pain is worsening and responds only to increased doses of opioids, which exacerbate the myoclonus. Joe is groggy but alert. After a consent discussion with Joe and his family about the risk for complete sedation, his physician prescribes increasing doses of benzodiazepines until the myoclonus is controlled. The dose required to achieve this control precipitates a coma. Joe dies 2 days later.*

This case is an example of sedation of the imminently dying. Joe's physician does not intend to render him unconscious as a means of treatment and does not withhold hydration and nutrition to hasten death. By administering high doses of benzodiazepines, the physician aims to control the myoclonus. Joe's death is a foreseen but unintended outcome of this intervention.

### Case 3

*Bill is 56 years old and has a glioblastoma of the left frontoparietal area. After discussing the condition with his family, Bill decides to forgo additional radiation therapy and tells his physician to focus on symptom management. Bill is given antiseizure medications and adjuvant pain medications. Nonetheless, Bill's condition worsens. He routinely experiences focal seizures followed by severe muscle weakness. Bill tells his physician that he fears "losing control of his life" and that he would like help "to end it all quickly." Bill's physician responds that it is against the law for him to assist in suicide, but he informs Bill of his right to refuse food and fluids. If Bill chooses this route, his physician says that he will support the decision and do everything possible to ensure that Bill's death is comfortable. Three days later, Bill stops eating and drinking. One week later, he becomes severely agitated. Bill's physician prescribes sedating medication to ensure his comfort. Bill dies 2 days later.*

This case is an example of the patient voluntarily stopping eating and drinking. Bill's physician presents this option as an appropriate response to end-of-life suffering. After Bill chooses this option, the physician treats the symptoms caused by the absence of hydration and nutrition. The principal difference between this case and the other two is that the patient, not the physician, takes steps to hasten death. The physician has merely advised the patient of his right to do so.

Most clinicians will sense that the differences between these three cases are not simply descriptive. For example, many will sense that the conduct of the physician in case 2 is permissible, whereas the conduct of the physicians in cases 1 and 3 is not. How should we account for these intuitions?

## RULE OF DOUBLE EFFECT

The *rule of double effect* provides the best, albeit not necessarily the only, explanation of the moral differences between the physicians' conduct in cases 1 and 2. Some medical ethicists reject this rule (5). However, in recent

years, there have been important defenses of it in both the philosophical and medical literature (6–11). Also, the rule of double effect has been invoked in recent legal rulings concerning end-of-life issues (12). Therefore, this rule remains an important guide for ethical decision-making in medicine.

The rule of double effect calls attention to the moral difference between bringing about harm as merely a foreseen effect of an action aimed at some good end and intentionally bringing about harm as a means to that end. The rule of double effect, when applied to the issue of terminal sedation, maintains that it is not immoral to render a patient unconscious as a side effect of treating specific symptoms if 1) one does not aim at unconsciousness directly, 2) unconsciousness is not the means by which one intends to relieve symptoms, and 3) one has a "proportionate reason" for taking such action. These conditions are fulfilled in the type of terminal sedation we have called *sedation of the imminently dying*. By contrast, in sedation toward death, the clinician *aims* at rendering the patient unconscious, not to serve future consciousness but to shorten life. Reference to the rule of double effect, then, explains why the physician's conduct in case 2 is morally different from the physician's conduct in case 1.

The condition in the rule of double effect that holds that a physician must have a proportionate reason turns out, on reflection, to be important in evaluating terminal sedation. In case 2, what makes the sedation permissible is that it is a rational response to a specific physiologic condition that the physician is attempting to treat. In case 1, by contrast, the patient is suffering because of her belief that she will soon become debilitated. Although certainly grave, this kind of suffering does not justify terminal sedation. For terminal sedation to be a proportionate response to suffering, the good effects must outweigh the bad *and* it must "fit" the situation. Like the existential suffering of patients who are not terminally ill, the existential suffering of the patient in case 1 is appropriately managed not by aggressive sedation but by other specialized interventions, such as appropriate nonsedating medication, psychological counseling, or spiritual guidance. Physicians who cannot adequately provide these interventions should enlist the help of those who can. If these interventions initially prove to be ineffective, we still believe physicians should not administer terminal sedation, even at the patient's request. Good evidence suggests that many patients who are initially unresponsive to counseling respond favorably over time (13). Physicians who sedate such patients into unconsciousness will be, in effect, giving up on them.

## Objections

An important objection to the claim that the rule of double effect explains the moral difference between the physicians' conduct in cases 1 and 2 is that the physician's conduct in case 1 can be redescribed in such a way as to make it consistent with the rule of double effect (5). For example, it can be said that the physician in case 1 merely intended to treat the existential suffering of his patient and did not intend to administer medication with the aim of ending her life as a means to ending her suffering. Her death is a foreseen, but unintended, outcome of the intervention. This redescription of case 1 seems to make it morally indistinguishable from case 2.

We have two responses to this objection. First, the goals of the physician in case 1 are set by the structure of his actions. Regardless of his ultimate goal, if the physician acts to end his patient's life as a means of relieving her suffering, then although he may believe that he intended only to relieve her suffering, it will remain true that he also intended the means that brought about this end. Second, the rule of double effect maintains that a physician must have a proportionate reason for administering sedating levels of medication. Reasonable clinicians will disagree about what constitutes a proportionate reason, but the need to treat existential suffering clearly is not sufficient. If it were, then it would be ethically and medically appropriate to terminally sedate a patient with no underlying physiologic condition. This would make terminal sedation an appropriate intervention even for patients who were not terminally ill.

A second objection to our analysis is that there are important borderline cases that are not similar to case 1 or 2 and, therefore, the rule of double effect may not discriminate between them. This point is well taken. We believe that any use of terminal sedation that violates the rule of double effect is unjustified. But this rule, by itself, may not identify all the morally important factors that bear on the justifiability of terminal sedation. Nevertheless, although our analysis may not resolve every case, it is vitally important to understand the moral dif-

ferences between cases that are similar to cases 1 and 2. Not only is this important in its own right, it is a necessary starting point for thinking about the borderline cases that we have not addressed.

## The Principle of Collaboration

Looking at case 3, we recall that the physician informs his patient that he has the right to voluntarily stop eating and drinking. The physician further suggests that exercising this right is an acceptable response to end-of-life suffering. Although the issue of what constitutes suicide at the end of life is complex, a plausible case can be made that the patient's conduct in case 3 is a form of suicide (14). This means that the physician in case 3 is advising his patient that suicide is an acceptable response to end-of-life suffering.

We do not believe that all cases of voluntary refusal of hydration and nutrition are instances of suicide. We also acknowledge that many physicians will not find the physician's conduct in case 3 to be problematic. Here, we wish to pursue only a modest point: If a physician believes that suicide is impermissible, then it is impermissible for him or her to present an instance of voluntarily stopping eating and drinking that satisfies the conditions of suicide as an acceptable response to end-of-life suffering. This point explains the intuition that the physician in case 3 acted wrongly (15) since many physicians, in fact, believe that suicide is impermissible.

The failure to attend to this point has led some authors to claim mistakenly that voluntarily stopping eating and drinking is an alternative to physician-assisted suicide that avoids moral controversy (16). Because patients have a right to refuse food and fluids, these authors conclude that physicians have an ethical duty to inform terminally ill patients of their right to exercise this option. This does not follow. There is a difference between respecting the rights of a patient to refuse a treatment and telling the patient that refusing the treatment is a permissible option. If the patient has independently decided to refuse food and fluids, the physician would have to respect the patient's right to make this decision. The physician could express disapproval of the decision and perhaps transfer the patient to another physician. In case 3, however, the physician goes beyond respecting the rights of his patient. He presents refusal of food and fluids as an acceptable response to terminal suffering. Our position is that this should *not* be done if the physician believes that it would be morally wrong for the patient to engage in this practice. We take this position further. This physician should not even mention this practice to his patient because, by doing so, the patient may be tempted or influenced to choose it.

Still, some may continue to wonder how the physician's conduct in case 3 may be considered wrong, because it is the patient, not the physician, who makes the decision to stop eating and drinking. To explain why the physician is nonetheless implicated in the patient's decision, we need to examine a second principle in medical ethics—*the principle of collaboration*. This principle has been widely discussed by both theologians and secular philosophers (6, 17, 18). It holds that it is wrong to cooperate in wrongdoing. Among other things, cooperation includes advising, assisting, or tempting others to engage in wrongdoing.

Assuming that the patient's conduct in case 3 is equivalent to suicide and assuming that suicide is impermissible, this principle would explain why the physician's conduct in case 3 is wrong. By advising his patient that refusing food and fluids is an acceptable response to end-of-life suffering, the physician expresses approval, whether explicit or implicit, of this act.

To be sure, we have not established that suicide is always wrong. Our task has been to identify plausible reasons that explain the moral intuitions many clinicians have regarding cases like 1, 2, and 3. We have argued that the rule of double effect and the principle of collaboration account for these moral intuitions. Because both of these principles are firmly established in medical ethics, a strong case has emerged for our more general point: It is a mistake to combine and not distinguish among the practices we have discussed because there are important, plausible moral differences between them.

## Conclusion

We hope that our discussion has clarified that terminal sedation and voluntary refusal of hydration and nutrition are *not*, as some authors claim, ethically unproblematic alternatives for physicians who oppose physician-assisted suicide (1, 2). This claim results from a failure to consider important distinctions. These distinctions must be carefully reviewed so that physicians are

not misled into participating in practices that oppose their moral commitments.

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