

# Terminal Sedation: *Pulling the Sheet over Our Eyes*

BY MARGARET P. BATTIN

Terminal sedation—also called “palliative sedation,” “continuous deep sedation,” or “primary deep continuous sedation”—has become a new favorite in end-of-life care, a seeming compromise in the debate over physician-assisted dying. Like all compromises, it offers something to each side of a dispute. But it is not a real down-the-middle compromise. It sells out on most of the things that may be important—to both sides. To corrupt an already awkward metaphor, terminal sedation pulls the sheet over our eyes. Terminal sedation may still be an important option in end-of-life care, but we should not present it as the only option in difficult deaths.

Proponents of assisted dying point to autonomy and mercy. The principle of autonomy holds that people are entitled to be the architects, as much as possible, of how they die. (Of course, autonomy has limits—one cannot inflict harm on others—and when one is no longer competent, values and interests may be expressed only indirectly; advance directives or surrogate decision-makers must be brought into play. But the principle itself is clear enough.) The principle of mercy requires that pain and suffering be relieved to the extent possible. These two principles operate in tandem to underwrite physician-assisted dying: physician assistance in bringing about death is to be provided just when the person voluntari-

ly seeks it and just when it serves to avoid pain and suffering or the prospect of them. *Both* requirements must be met.

Opponents base their objections to physician-assisted dying on two other concerns. One is the sanctity of life, a religious or secular absolute respect for life that is held to entail the wrongness of killing, suicide, and murder. This principled objection holds regardless of whether a patient seeks assistance in dying in the face of pain and suffering. The second objection is that physician-assisted dying might lead to abuse. This concern is often spelled out in two ways: physician-assisted dying risks undercutting the integrity of the medical profession, and institutional or social pressures might make people victims of assisted dying they did not want.

These latter objections operate independently. One could be opposed to aid in dying on sanctity-of-life grounds even without fearing the slippery slope, and one could worry about the slippery slope without accepting the sanctity-of-life concerns. Often, however, these two concerns are fused in a general objection—a joint claim that it is wrong for doctors to kill and that if doctors *do* kill, even in sympathetic cases like that of the seriously suffering and already dying patient who begs for help, then they might start killing in other, more worrisome cases as well. In short, it’s autonomy *and* mercy on the one side, sanctity of life *and/or* the possibility of abuse on the other. That’s the standoff over physician-assisted dying, argued in a kaleidoscope of ways over the past several decades.

Terminal sedation is often proffered as an alternative last resort measure that can overcome these practical and ideological disputes. In the 1997 cases *Washington v. Glucksberg* and *Vacco v. Quill*, the Supreme Court recognized the legality of providing pain relief in palliative care even if doing so might shorten life, provided the intention was to relieve pain. But careful scrutiny of terminal sedation—particularly sedation to unconsciousness, in which nutrition and hydration are withheld—suggests that it is not much of a compromise after all.

## An Inadequate Compromise

Consider how terminal sedation fails to meet the concerns that underlie the dispute.

**Autonomy.** Consent of the person affected is central to the concept of autonomy, but it is not and—as a consequence of some political interpretations—*cannot* be honored in decisions to use terminal sedation. First, terminal sedation is often used for patients suffering from severe pain, for whom pain management has failed, but if pain is severe enough, reflective, unimpaired consent may no longer be possible. Decision-making must be deflected to a second party. (Of course, voluntary, informed consent is often challenged by pain: consider women in the throes of labor consenting to an epidural or a caesarean, or trauma victims consenting to surgery.)

More importantly, even when the decision is made in advance of the onset of intense pain, the focus of consent is obscured. Terminal sedation may end pain, but it also ends life. It does so in two ways: it immediately ends sentient life and the possibility for social interaction, and then, because artifi-

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cial nutrition and hydration are usually withheld, it also ends biological life. But because the assumption is that sedation is used just to end pain, without the *intention* of ending life, the patient cannot be asked for consent to end his or her life, but only to relieve his or her pain. Of course, the consent process could include some mention of the possibility that relieving pain might inadvertently shorten life, but if the acknowledgment that life will be ended is stronger than that, the question of what is intended will arise. Thus, the focus of consent is on avoiding pain, but it should be on causing death.

The new euphemism, “palliative sedation,” now often used instead of the more distressing “terminal sedation,” only reinforces this problem. By avoiding the word “terminal” and hence any suggestion that death may be coming, the most important feature of this practice is obscured and terminal sedation is confused with “palliative care.” Thus, the patient cannot consent to the really significant decision—whether his or her life shall be ended now. Autonomy is therefore undercut whether the patient’s capacity for reflection is impaired by severe pain or not.

**Mercy.** Terminal sedation is typically used only at the very end of the downhill course, and only when the patient’s pain has become extreme and other palliative measures are not effective. A broad study of pooled data over the last forty years on pain in cancer found that 59 percent of patients on anticancer treatment and 64 percent of patients with advanced metastatic disease experience pain.<sup>1</sup> Agitation, delirium, dyspnea, seizures, urinary and fecal retention, and nausea and protracted vomiting are also problems. Bernard Lo and Gordon Rubinfeld, writing in the *Journal of the American Medical Association*, discuss a forty-nine-year-old cancer patient given very high doses of morphine who developed myoclonus: seizures in the extremities and eventually in the whole body, producing intense pain.<sup>2</sup> As they say of palliative sedation for her and other dying patients: “We turn to it when everything else hasn’t worked.”

Terminal sedation to unconsciousness can certainly provide relief from such suffering, but some patients wish to avoid this long downhill course—especially the last stages of it. The use of terminal sedation “to relieve pain” presupposes that the patient is *already* experiencing pain. It provides no rationale for sedating a patient who is not currently in pain. Thus, the rationale for the use of terminal sedation in effect *requires* that the patient suffer.

**The sanctity of life.** The dispute over the principle of the wrongness of killing, or the sanctity of life, has focused mainly on ending a person’s life before it would “naturally” end. Terminal sedation does not honor this principle. Rather, it unarguably causes death, and it does so in a way that is not “natural.”

It is important to be perfectly clear about the process. Terminal sedation commonly involves two components: 1) inducing sedation, and 2) withholding the administration of fluids and nutrition. The first is not intrinsically lethal,<sup>3</sup> but the second is, if pursued long enough. Patients who are sedated to the degree involved in terminal sedation cannot eat or

drink, and without “artificial” nutrition and hydration will necessarily die, virtually always before they would have died otherwise. Patients are sometimes sedated to unconsciousness with food and fluids continued—a practice that extends the dying period (and the cost), but this is not the usual form.

The death itself is not “natural,” either. The airy, rather romantic notion of “natural” death usually refers to death that results from an underlying disease, but in terminal sedation death typically results from or is accelerated by dehydration. This is not “natural” dehydration; it is induced by a physician. If respect for the sanctity of life means that a patient’s life should not be caused to end, but rather that death must occur only as the result of the underlying disease process, then terminal sedation does not honor this principle.

**The possibility of abuse.** This concern takes two general forms: 1) concern that the integrity of the medical profession will be undercut, and 2) concern that various familial, institutional, or social pressures will maneuver the patient into death when that would have been neither her choice nor in accord with her interests. Yet there is nothing in the practice of terminal sedation that offers greater protection against the possibility of abuse in either of these forms than does direct physician-assisted dying. Is the integrity of the medical profession likely to be undercut? There are many vivid forms of this charge leveled against direct physician-assisted dying—that physicians are overworked, anxious to cover their mistakes, unwilling to work with patients they dislike, biased against patients of certain class or racial backgrounds, beholden to cost pressures from their HMOs, and so on—but there is no reason to assume that terminal sedation would be less subject to these abuses than direct aid in dying. Indeed, direct aid in dying, at least as it is legally practiced in Oregon, requires a series of safeguards—confirmation of a terminal diagnosis, oral and written consent, a waiting period, and more—that do not come into play in terminal sedation. Terminal sedation has no institutional safeguards built in.

What about the sorts of familial, institutional, or social pressures that opponents claim would maneuver a patient into choosing death when that would not have been his choice? In terminal sedation, the choice a patient faces is already obscured: it is not framed as a choice of death versus life, but only as pain versus the relief of pain—a seemingly far easier choice to make, and hence one presumably far more easily shaped by external pressures from greedy family members, overworked or intolerant physicians, or the agents of cost-conscious institutions. *You don’t need to suffer like this* is all they need to say.

In short, terminal sedation offers no greater protection against abuse than do the institutional safeguards established for (direct) physician aid in dying.

### The Case in Favor of Terminal Sedation

Several writers in the field have argued, as I have, that terminal sedation fails to satisfy fully any of the major principles on either side of the aid in dying disputes. Timothy Quill,

describing in close detail the “ambiguity of clinical intentions,” has pointed out that it is virtually impossible for the clinician administering terminal sedation to intend palliation but not intend that death occur.<sup>4</sup> David Orentlicher lambasted the 1997 Supreme Court decision in *Washington v. Glucksberg* and *Vacco v. Quill* for “rejecting physician-assisted suicide, embracing euthanasia.”<sup>5</sup> Tim Quill, Rebecca Dresser, and Dan Brock have skewered the Court’s tortuous use of double-effect reasoning in supporting the practice of terminal sedation while rejecting voluntary, patient-requested physician-assisted suicide.<sup>6</sup>

Just the same, a case may be made for terminal sedation. It offers a definitive response to uncontrollable suffering. The gradual induction of death over the several days or more that terminal sedation takes may appeal to some patients and their families, especially if this slow process is perceived as gentler and easier for the patient, and as permitting the family more time to absorb the reality of their loss. It may also be perceived as less final than physician-assisted death: some forms of palliative sedation involve lightening up on the level of sedation periodically—for example, once a day—to see if the patient is still suffering.

The argument in favor of terminal sedation is one of perceptions: it may *feel* natural (even if it is not), it may *feel* safer (even if it offers less protection from abuse), it may *feel* like something the patient can openly choose (even if the choice is constructed in a way that obscures its real nature), and it may *feel* to the physician as if it is more in keeping with medical codes that prohibit killing (even if it still brings about death). We live in a society that tolerates many obfuscations and hypocrisies, and this may be another one we ought to embrace.

### The Need for Guidelines

But we should do so with caution, and with a measure of skepticism about efforts to promote it. Some months before the November ballot that would include the state of Washington’s measure I-1000, which is modeled on Oregon’s Death with Dignity Act, the American Medical Association Council on Ethical and Judicial Affairs issued a report on “Sedation to Unconsciousness in End-of-Life Care.”<sup>7</sup> This report makes an earnest effort to try to preclude many of the practical and ethical difficulties with palliative sedation. For example, the report acknowledges the importance of patient or surrogate consent. It insists that the patient’s symptoms really

warrant this measure. It emphasizes the importance of interdisciplinary consultation and careful monitoring. And it distinguishes between physical and existential suffering, insisting that palliative sedation may be appropriate in the former but that measures like social supports are to be used for the latter.

However, in its effort to distinguish palliative sedation (it avoids the expression “terminal sedation”) from euthanasia, the report undercuts its own courage in addressing these difficult issues by trying to argue that palliative sedation (the permissible strategy) has nothing in common with euthanasia (the impermissible strategy). It does not distinguish between voluntary euthanasia (legal in the Netherlands and Belgium),

nonvoluntary euthanasia (of a patient no longer capable of expressing his wishes or of giving legal consent), and involuntary euthanasia (against the patient’s wishes). It fails to notice that the Dutch and the Nazi senses of “euthanasia” are entirely different, and that one could welcome the former while reviling the latter.

The AMA report distinguishes palliative sedation from euthanasia (or physician-assisted suicide or aid in dying) on the basis of intention—an application of the well-worn principle of double effect—and then attempts to infer intent from the pattern of practice. “One large dose” or “rapidly accelerating doses” of morphine may signify a bad intention—seeking to

cause death—whereas “repeated doses or continuous infusions” are benign. This is naive in the extreme. It’s the slyest courtier who poisons the emperor gradually; what could equally well be inferred from repeated doses and continuous infusions is a clever attempt to cover one’s tracks. Nor is it clear what counts as “large doses” or other treatment measures in this simplistic dichotomy.

Is a fentanyl patch in a fentanyl-naïve patient “rapidly accelerating” or “continuously infusing” when opioid tolerance may be in question? If a hydromorphone infusion for a patient with myoclonus is increased overnight from forty milligrams per hour to one hundred, does the increase count as “rapidly accelerating”? Are one hundred milligram boluses of hydromorphone given every fifteen to thirty minutes on top of a one hundred milligram/hour infusion considered to be “large doses,” or are they merely “repeated” doses? What about the doses involved in initiating palliative sedation for this patient: a loading dose of phenobarbital and maintenance on a continuous phenobarbital infusion, together with intravenous dantrolene to lessen the myoclonus? In the case of the forty-nine-year-old cancer patient discussed by Lo and Rubinfeld,

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the patient died within approximately four hours of the initiation of palliative sedation. Indeed, the average survival in terminal sedation cases is just 1.5 to 3.1 days.<sup>8</sup>

What is astonishing is the AMA's attempt to try to differentiate between different sorts of clinical intentions on the basis of observed practice, when it is simply not possible—nor morally defensible—to draw this false bright line between them. These unworkable distinctions can only exacerbate the unease and legal dread in physicians who work to ease their patients' dying.

It's not that palliative sedation/sedation to unconsciousness/terminal sedation is wrong. It's that it can be practiced hypocritically, as the AMA report seems to ensure. Because there is so much anxiety that it might be confused with euthanasia, the features that it shares with euthanasia are obscured or sanitized. This is where the sheet is pulled over our eyes. The implausible effort to draw a completely bright line between continuous terminal sedation and euthanasia makes the practice of terminal sedation both more dangerous and more dishonest than it should be—and makes what can be a decent and humane practice morally problematic.

Another factor that hasn't been adequately explored is where terminal sedation ought to fit on a spectrum of end-of-life options: much of the "compromise" discussion seems to suggest that terminal sedation is the one and only way to deal with difficult deaths. But there are many last resort options, including patient-elected cessation of eating and drinking and direct physician-assisted dying. Terminal sedation is not an acceptable "compromise" if it overshadows these alternatives.

There is no reason why everyone facing a predictable, potentially difficult death should die in the same way. Knowing that pain is likely in some diseases and that even with the best palliative care not all pain can be relieved, some patients will prefer to avoid the worst, so to speak, and choose an earlier, gentler way out. Some will want to hang on as long as possible, in spite of everything. There is no reason that terminal sedation should not be recognized as an option, but there are excellent reasons why it should not be seen as the *only* option—or even the best option—for easing a bad death.

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## Reference

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