Clinical Practice:

Should Sedation Be Terminal?

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Terminal sedation (TS) has become an important but controversial issue in bioethics during the last several years, especially in light of the ongoing debate about assisted suicide. TS has been both condemned and embraced by people on either side of the assisted suicide debate. It has been called an ethical form of end-of-life care, a legal alternative to assisted suicide, and slow euthanasia.

Although the term “terminal sedation” was unknown in 1980, the Vatican’s Declaration on Euthanasia cites Pope Pius XII’s 1957 statement endorsing the use of sufficient medication to control pain, even if there was a risk of unconsciousness or hastening death. However, the Declaration also added the caveat that the intention must be “simply to relieve pain effectively,” in keeping with Pope Pius XII’s view that such measures are appropriate when “no other means exist” and that should “not prevent the carrying out of other religious and moral duties.” He also warned “it is not right to deprive the dying person of consciousness without a serious reason.”

Today, supporters define terminal sedation as the deliberate “termination of awareness” for “relief of intractable pain when specific pain relieving protocols or interventions are ineffective” and/or “relief of intractable emotional or spiritual an-

1Sacred Congregation for the Doctrine of the Faith, Declaration on Euthanasia, May 5, 1980.
guish (existential suffering, psychological distress, emotional exhaustion).” Although deep sedation can be provided as a temporary respite, once the decision is made to provide TS, it is considered irrevocable as soon as the person is unconscious. TS is then continued until death occurs.

Thus, terminal sedation has evolved from being a last resort for relieving the pain of the dying to a method of permanently relieving nonphysical psychological or spiritual distress. Ironically, it has been just this kind of relief of psychological suffering, rather than the relief of unbearable pain, that has been cited as one of the primary motivations by people seeking to die under Oregon’s physician-assisted suicide law.  

The Changing Face of Terminal Sedation

The term “terminal sedation” has only come into use in recent years but already there are proposals to change TS to such terms as “total sedation” or “palliative sedation.” The proposed changes in terminology are more than just cosmetic.

The use of the word “terminal” has been eschewed by many supporters because of the connotations that TS itself causes death or that the person must be imminently dying to receive TS. Other commentators support more user-friendly terms like “palliative sedation” or another form of “comfort care” to describe permanent deep sedation for other categories of patients “who have no substantial prospect of recovery.”

An often-crucial component of TS is the withholding or withdrawing of life-sustaining treatment, primarily food and water, but routine medications such as insulin or blood pressure medicine are also rarely continued. But while there is universal agreement that treatment or care which is medically futile or excessively burdensome can be ethically forgone, TS itself does not depend on such determinations.

For example, in their article “Responding to Intractable Terminal Suffering,” Drs. Timothy Quill and Ira Byock describe the case of a retired radiologist with an

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4“A startling 63% of these patients (compared to 26% in 1999 and only 12% in 1998) cited fear of being a ‘burden on family, friends or caregivers’ as a reason for their suicide. The most commonly cited reason for suicide was a concern about ‘loss of autonomy’ (cited by 93% in 2000, compared to 78% in 1999).” NCCB Secretariat for Pro-Life Activities, “Oregon’s Third Year of Physician-Assisted Suicide: Details and Concerns,” *Life at Risk: A Chronicle of Euthanasia Trends in America*, 11.1 (January/February 2001).


6Ibid.
eventually lethal brain tumor who “feared becoming a burden to his family and developing progressive loss of mental capacity.” Concerns about the beginning signs of impending decline motivated the radiologist to talk to his doctor about his decision to stop eating, drinking, and taking his medication with the stated intention of hastening his death. His doctor agreed to help him remain comfortable during the process.

After nine days with a continuous low dose of morphine to control discomfort, the radiologist became confused and agitated, which are some of the symptoms associated with dehydration. TS was then started and maintained until his death.

Quill and Byock justify this manner of death by stating that voluntary refusal of food and water has “the ethical advantage [of] being neither physician-ordered nor directed.” They do admit, however, that this “requires the support of the family, physician, and health care team, who must provide appropriate palliative care as the dying process unfolds.”

While Dr. Quill is a prominent supporter of assisted suicide and Dr. Byock is an equally prominent opponent, both consider TS with voluntary refusal of food, water, and other life-sustaining measures to be a valid alternative to assisted suicide and an expression of patient autonomy.

I disagree. We cannot ignore the fact that this radiologist’s death was actually accomplished with the physical as well as psychological support of the health care providers. The radiologist could not starve and dehydrate himself without prescribed medication to relieve the suffering. This is far from a natural death and indeed turns the trusted hospice philosophy of neither prolonging nor hastening dying on its head.

TS supporters point to the accepted principle of the “double effect” in these cases. The intention of the doctor is considered paramount, and the good effect of relieving unbearable suffering takes precedence over the bad effect of foreseen death. This is more than a little disingenuous. Even doctors like Jack Kevorkian have used this as a legal and moral defense when obviously lethal injections were given.

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7“Terminal sedation is done with the full knowledge that no further active treatment will be done and that patients, as rapidly as possible, will now die as a result of their underlying disease process. The claim is made that such a way of proceeding is aimed at providing maximal relief of pain and suffering—the death of the patient is ‘not intended.’ But that is, to say the least, disingenuous. Patients are intentionally kept asleep, their vital functions are deliberately not artificially supported, and they are allowed to die in comfort. That they should die in comfort is clearly the goal—and I would argue the legitimate goal—of terminal sedation.” Erich H. Loewy, M.D., “Terminal Sedation, Self-Starvation, and Orchestrating the End of Life,” Archives of Internal Medicine 161.3 (February 12, 2001): 329–332.

8“The best-known American advocate of physician-assisted death, Dr. Jack Kevorkian, is serving a 10-to-25-year sentence in a Michigan prison for the death of an ALS patient. Kevorkian’s lawyer, Mayer Morganroth, is appealing the sentence in both state and federal courts. His contention: The trial was unfair because, among other things, the judge wouldn’t allow eyewitnesses to testify. A physician has the right to administer medicine which will alleviate pain and suffering, even if it causes death, Morganroth says.” Ed Edelson, “Euthanasia in the Netherlands Stirs Concern,” HealthScoutNews, May 22, 2002. Available at kevxml2a.infospace.com/_1_300313__info.sbug/health/hlt-story.htm&qid=507309&qt=4, last visited on August 30, 2002.
In the case of the radiologist above, he clearly stated that his own intention was to cause death. The doctors themselves had to expand the definition of unbearable suffering to include psychological suffering, which, disturbingly, is now also being used in Holland to justify the practice of euthanasia for physically healthy people.

The Pontifical Council’s 1994 *Charter for Health Care Workers* makes another important point when it warns that sometimes the systematic use of narcotics which reduce the consciousness of the patient is a cloak for the frequently unconscious wish of the health care worker to discontinue relating to the dying person. In this case it is not so much the alleviation of the patient’s suffering that is sought as the convenience of those in attendance. The dying person is deprived of the possibility of “living his own life,” by reducing him to a state of unconsciousness unworthy of a human being. This is why the administration of narcotics for the sole purpose of depriving the dying person of a conscious end is “a truly deplorable practice.”

In the end, we must also consider the outcome if the doctors had refused to participate in the radiologist’s desire to end his life prematurely and instead had affirmed the value of his life, however diminished in the future. Would the radiologist have then really persisted in his intention to die as soon as possible, or would he have instead reconsidered his decision because of the doctors’ commitment to helping him die comfortably and naturally at a later time?

We will never know.

**Nonvoluntary Terminal Sedation?**

Although most discussions of TS primarily involve dying cancer patients who request it, supporters of TS now even include incapacitated patients. The rationale for this is supplied by TS supporters such as Dr. Perry Fine who point to an advance directive “that sufficiently suggests or requests sedation in the face of unrelieved distress” or, in the absence of such a directive, asks “a health care proxy” to make the decision.

In reality, however, decisions to terminate awareness or ensure unawareness are often being made for incapacitated patients with a variety of conditions, some of which are not necessarily terminal.

For example, it is not unusual to see withdrawal-or-withholding-of-treatment decisions made for patients with conditions such as brain injury or dementia auto-

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11“Throughout the United States, physicians who support euthanasia are routinely utilizing a special form of ‘terminal sedation,’ not as a means of pain control, but with the explicit intention of intentionally causing death. This is routinely being used on patients who are not in immediate danger of dying, but are in other ways considered ‘incurable’ or ‘hopeless.’” Brian Johnston, commentary “Deathly Quiet,” *WorldNetDaily*, April 13, 2002. Available at www.worldnetdaily.com/news/article.asp?ARTICLE_ID=27217, last visited on August 30, 2002.
automatically accompanied by pain medicine and/or sedation to ensure that the patient feels no discomfort. It is also common to see continuous sedation and/or pain medication initiated or increased when a ventilator is stopped with the expectation—if not the actual hope—that the patient will not resume breathing.12

Even when a person has a potentially survivable but severe stroke, many families accept doctors’ predictions of poor future recovery and agree to only give comfort care because “Mom wouldn’t want to live like that.” Medications given under these circumstances are usually called “comfort care” rather than TS even though the result is almost always unconsciousness or a patient too sleepy to safely eat by mouth.

In one case, an elderly woman I will call Kay was admitted to a hospital with a massive stroke that the doctors deemed a terminal event. Kay had an advance directive from an anti-euthanasia group and had named her sister as the person to make her health care decisions if or when Kay became incapacitated. This particular advance directive was similar to most others except that it was quite specific that basic life-sustaining care, especially food and water, should be provided unless medically contraindicated or if death was inevitable and imminent.

After several days, one of Kay’s nieces called me and said that she was concerned because Kay was still alive and breathing although unconscious. The relative wanted to know if Kay’s unconsciousness meant that she was indeed terminal and, if not, should she now receive food and water?

One of the first questions I asked was if Kay was receiving morphine. The niece said Kay was indeed on an intravenous morphine drip, which the doctor had prescribed as comfort care.

Cerebral vascular accidents, commonly known as “strokes,” are not usually terminal and also rarely cause pain beyond sometimes an initial headache. The length of time since the stroke argued against Kay’s stroke being automatically terminal and therefore also argued for the provision of basic medical treatment, including the requested food and water.

At my suggestion, the niece talked to Kay’s sister about stopping or reducing the morphine to assess Kay’s level of awareness and to see if she were indeed in any pain. Kay’s sister agreed to have Kay fed if she woke up.

12Robert D. Truog, M.D. et al., “Pharmacologic Paralysis and Withdrawal of Mechanical Ventilation at the End of Life,” New England Journal of Medicine 342.7 (February 17, 2000): 508–511. Also “terminal sedation should be distinguished from the common occurrence of a dying patient gradually slipping into an obtunded state as death approaches; this occurrence is a combination of the metabolic changes of dying and the results of usual palliative treatments. Terminal sedation is also distinct from the sedation that occasionally occurs as an unintended side effect of high-dose opioid therapy, which is used to relieve severe terminal pain. In contrast, terminal sedation involves an explicit decision to render the patient unconscious to prevent or respond to otherwise unrelievable physical distress. Terminal sedation is also used regularly in critical care practice to treat symptoms of suffocation in dying patients who are discontinuing mechanical ventilation.” Quill and Byock, “Responding to Intractable Terminal Suffering.”
The cousin later reported that Kay started to respond not long after the morphine was reduced. She opened her eyes, looked at people when they spoke to her and even seemed to recognize her relatives. However, Kay’s sister said a priest told her that such apparent reactions were merely “reflexes” and she had the morphine drip restarted. It was not surprising that Kay died two weeks after her stroke, especially since no one can live without food and water for an extended period of time. The niece and some other concerned relatives had briefly considered talking to a lawyer about enforcing Kay’s advance directive before she died but they finally decided against it because they were reluctant to divide the family even further.

While Kay’s case evolved at a distance and I was unable to personally review her medical records at the time, her case resonates with my own experiences and those of other nurses around the country who have told me similar stories. Unfortunately, cases like Kay’s seem to be increasingly common, and they illustrate the growing concerns about both the controversial practice of TS and the expanding categories of conditions included in end-of-life care.

Although no one would deny an incapacitated or critically ill patient sufficient medication to control pain or other symptoms, traditional comfort care has not included decisions to ensure unawareness until recently.

A Nursing Perspective

After thirty-four years as a nurse, working in such areas as medical-surgical units, home health/hospice, oncology, and ICU, I have had a wide range of experience in end-of-life care for patients as well as for members of my own family. I have also had to work under doctors at all points on the ethical and competency scale, from doctors who magnificently care for their patients’ emotional, spiritual, and physical needs to doctors who avoid their dying patients as much as possible.

I have been frustrated both by doctors who will not order adequate pain medication or sedation in even imminently dying patients because of addiction fears and doctors who have demanded that we nurses keep increasing morphine drips “until the patient stops breathing.”

I have also cared for patients and even families who run the gamut from passively accepting any recommendation from a doctor to patients or families who adamantly demand that we doctors and nurses put them out of their misery.

End-of-life issues now occur almost anywhere in the health care system, from hospitals to nursing homes to the patient’s own home. Nurses are a necessary component in implementing and evaluating such care, including standard holistic care as well as controversial interventions such as TS.

Unlike doctors, however, nurses ordinarily cannot pick and choose among the patients they care for because nurses are assigned to their patients. A refusal to participate in the care of a particular patient because of ethical concerns can be seen as an unreasonable demand on other, overworked staff or even as a refusal to honor a patient’s legal rights, especially when there is an absence of any protection for the rights of conscience. Thus, nurses can even face termination for refusing to compromise their professional and ethical principles.
With the welcome advent of the campaign to make evaluation of pain “the fifth vital sign,” nurses are charged with constantly monitoring the success or failure of pain relief interventions in all patients who experience pain, whatever its etiology, and making adjustments or recommendations to the doctor. For the effort to control pain to be truly effective, however, nurses—as well as doctors—must have a thorough education both in the techniques of pain management in various scenarios and the ethical considerations involved. But while clinical guidelines for pain management are usually rather straightforward and accepted, controversial interventions such as TS depend on a more subjective determination of what constitutes unbearable suffering and evoke ethical concerns in regard to causing or hastening death. Sooner or later, we must answer a critical question: is medical ethics a matter of personal or legal interpretation or are there workable, universal principles upon which a consensus can be built?

The Future of Terminal Sedation

Rather than seeing TS as a rarely used last resort, even the few studies on it report the prevalence of terminal sedation to range from three to fifty-two percent in the terminally ill.13 When the unknown actual incidence of terminating awareness or ensuring unawareness in patients with stroke, dementias, or other serious illnesses is factored in, the use of TS as a form of “comfort care” may well be approaching epidemic proportions, even outside the hospice area.

Legally, TS may be impossible to regulate. Being a process rather than a single lethal overdose, TS can even be technically distinguished from assisted suicide.14 But what is legal is not necessarily ethical, and, unfortunately, even well-meaning medical professionals and ethicists may feel a need to “hurry up” the dying process or just spare a patient and his or her family from a perceived poor quality of life.

In addition, the newer health care system problems of cost-containment and stressed, overburdened health care professionals can make TS even more attractive—and dangerous—to patients and caregivers alike.

But alternatives to TS do exist, even in the case of terminal illness.

For years, the usual and trusted approach to severe pain has been to gradually increase dosages of pain medications until a sufficiently strong and effective dosage is reached. When combined with anti-anxiety or sedative medication, this plan almost always helps the patient achieve the highest level of pain control while allowing the person to remain as calm and alert as possible.

Of course, no mere pill or injection can substitute for the genuine compassion and reassurance that are also crucial aspects of good pain management.


Short- or longer-term deep sedation may be indicated in some very rare cases. As long as basic medical care, including even medically-assisted feeding, if the patient needs and can tolerate it, is continued, the concern about hastening or causing death should be alleviated.

But death is not a purely physical event, as Elisabeth Kubler-Ross’s groundbreaking work on the emotional stages of dying showed us decades ago. It has been my experience that patients facing a terminal illness fluctuate between welcoming and fearing death, hope and despair, and weakness and strength. Coming to terms with death is often harder than the dying process itself, but I have been privileged to accompany many people on this final, most important journey. This journey is rarely easy or smooth, but the rewards to patients, families, and health professionals are enormous.

The allure of preempting any suffering by dying unconscious may well appeal to a great number of terminally-ill patients as well as the frail elderly, the disabled, the chronically ill, and others. Sometimes no matter how hard we try, some patients, families, and even medical professionals may still demand the right to choose a hastened death.

In those circumstances, as with assisted suicide and euthanasia, the best and only answer should still be “No.”

\[15\] As ecumenical witness in defense of life develops, a great teaching effort is needed to clarify the substantive moral difference between discontinuing medical procedures that may be burdensome, dangerous or disproportionate to the expected outcome—which the Catechism of the Catholic Church calls ‘the refusal of ‘over-zealous’ treatment’ (No. 2278; cf. Evangelium vitae, n. 65)—and taking away the ordinary means of preserving life, such as feeding, hydration and normal medical care. The statement of the United States Bishops’ Pro-Life Committee, Nutrition and Hydration: Moral and Pastoral Considerations, rightly emphasizes that the omission of nutrition and hydration intended to cause a patient’s death must be rejected and that, while giving careful consideration to all the factors involved, the presumption should be in favor of providing medically assisted nutrition and hydration to all patients who need them. To blur this distinction is to introduce a source of countless injustices and much additional anguish, affecting both those already suffering from ill health or the deterioration which comes with age, and their loved ones.” Pope John Paul II, ad limina address to the Bishops of California, Nevada, and Hawaii, October 2, 1998, n. 4.