Two Perspectives on Total/Terminal/Palliative Sedation

Post Date: 01/23/2002
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Issues:
End of Life

Some say that sedating a patient in unbearable, untreatable pain is appropriate, even if it is done indefinitely. Others say that doing so is tantamount to killing the person. The following debate is offered to provoke our thinking at this early stage in the discussion.

Editor's Note: This article by Kingsbury originally appeared in the Volume 7, Number 2, Summer 2001 issue of Dignity, the Center's quarterly publication. Subscriptions to Dignitas are available to CBHD Members. To learn more about the benefits of becoming a member click here.

Kingsbury - Palliative Sedation: May We Sleep Before We Die?

Sedation is a clinically important therapeutic intervention in the imminently dying patient. As the patient with an advanced, irreversible illness nears the end of life, symptoms accumulate that are progressively more difficult to manage and that may become unresponsive to standard medical interventions. The most common of these intractable symptoms are pain, agitated delirium, dyspnea and existential or psychological distress. Although sedation is a risk-laden procedure, it is sometimes necessary and maintains the physician's twin obligations to benefit patients and to "do no harm" when practiced by trained, dedicated clinicians.

Terminal sedation is a recent addition to the lexicon of palliative care. Based on a survey of 61 selected palliative care experts, Chater et al. arrived at the following definition: "Terminal sedation is Y deliberately inducing and maintaining deep sleep but not deliberately causing death in very specific circumstances." The "specific circumstances" were defined as intractable symptoms at the end of life, including "profound anguish" for which standard palliative care intervention had failed to provide adequate relief. The definition excluded
"planned temporary" sedation that is reversed. "Terminal sedation" was criticized by those surveyed for being grammatically ambiguous, as it could be interpreted as meaning either sedation intended for terminally ill patients or sedation for the purpose of terminating a patient's life. The latter interpretation has led to other vague and ambiguous terms, such as "slow euthanasia." A sedation for intractable distress in the dying patient (SIDD) was proposed as an alternative terminology. This author prefers the simpler phrase "palliative sedation" and will make reference to it throughout this article.

Ira Byock has stated that "unlike many areas of medicine in which it is the occasional case that presents an apparent ethical dilemma, care at the end of life is full of ethically poignant and emotionally charged situations." It is essential to examine the ethical implications of decisions and interactions between patient, family, and providers of care. Although the U.S. Supreme Court in its decisions regarding physician-assisted suicide fundamentally sanctioned palliative sedation, it remains a controversial intervention. This controversy will be touched upon in the remainder of this article.

Does palliative sedation shorten the life of the terminally ill patient who is experiencing refractory, intolerable symptoms particularly when it is accompanied by withholding of food and fluids? Most often, this is probably not the case. The little research that has been done suggests that the use of sedation in someone dying is largely irrelevant to the timing of death, though it may prolong life slightly. In a retrospective study of terminally ill patients, Stone et al. showed no statistically significant difference in survival from date of admission between sedated and non-sedated patients. They concluded that "the need for sedation is an indicator of impending death and not a cause of premature death." Patients who spend their last hours or days sedated are very sick. Even before they are sedated, these patients are eating or drinking substandard amounts, and artificial hydration and nutrition is usually contraindicated because it would increase the risk of pulmonary edema and other adverse effects. Patients are also often restless, delirious or anguished. Left alone, they would die in part from exhaustion.

Is palliative sedation really a form of euthanasia? Some believe it is, arguing that death is hastened by inducing dehydration. As we have already seen, however, most patients for whom palliative sedation is appropriate will have already stopped eating and drinking. Palliative sedation for intractable distress is not "slow euthanasia," but a prompt response to suffering based on informed consent and the principle of double effect.

The proper intent in palliative sedation is relief of pain and suffering. The importance of physician intent is debated. Some argue that outcomes arising from either action or inaction are more important than intent when considering physician behavior. If the intent to relieve suffering is discounted or dismissed, then to the extent that death is hastened, palliative sedation is a form of "euthanasia," as death results directly from the action of a physician.

Quill has argued, "...clinical intention may be complex, ambiguous, and often contradictory." It is true that one cannot know for certain the internal state or intent of another. This does not prohibit one from making reasonable inferences. It can reasonably be inferred that analgesics or sedatives are administered only for pain relief or distress if they are titrated to achieve specific end points (such as the absence of grimacing or moaning in patients unable to report pain) and not beyond. In contrast, the rapid administration of massive doses of medication with no effort to titrate indicates that hastening of death was a first intent.

How can a biblical perspective inform the use of terminal sedation? Human life is a gift of God and is sacred because it bears His image. All people are created by God and are not to be understood as the products of random processes. We are therefore responsible to God for our actions. We are stewards and not absolute masters of the gift of life. A follower of Jesus Christ, the Great Physician, is called to have compassion and to suffer with and support people in their suffering. We are not to remove (kill) the sufferers in order to remove their sufferings. In Galatians 6:2, Paul writes that we should "carry each other's burdens and in this way . . .
fulfill the law of Christ."

At the SSM Hospice of St Louis, we tell our patients that we value their lives and their worth and that we will not kill them. We are a "euthanasia-free zone." We promise to care for them and try our best to treat their symptoms and not to abandon them as they die. They are told that if their pain and other symptoms cannot be controlled, then they may choose to be sedated. This option is critical for patients who are profoundly fearful of suffocating to death or remaining delirious or confused or who have a crescendo of pain that fails to subside with the standard pharmacological and interventional techniques. Such patients may indeed sleep before they die if that is their choice.13

**Kingsbury's Notes**


**Ducharme - Total Sedation: A Protocol with Acidic Boundaries**

Total sedation (TS) -- called by some "terminal sedation," "palliative sedation," or "slow euthanasia" -- is a protocol recently added to the lexicon of contemporary medical interventions and is a construct actively promulgated by the National Hospice and Palliative Care Organization (NHPCO). It is defined as "the application of pharmacotherapy to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering."1 With only this much said, there may seem to be no ethical objection to TS -- a patient who is terminally ill, imminently dying, and suffering overwhelming physical pain may simply request temporary TS to get some sleep today with the hope that the pain will be endurable tomorrow. However, any quick acceptance of TS would be ill-advised because of the many "devils in the
1. TS is not limited to patients who are suffering from overwhelming physical pain from their terminal illness. TS is deemed appropriate for intractable or refractory suffering due to "overwhelming physical, emotional, or spiritual distress that is poorly relieved by other means." NHPCO advises, "there are many cases in which patients experience refractory spiritual or emotional pain, often referred to as existential suffering." TS is deemed appropriate treatment for existential distress "that is not relieved by counseling from social workers and chaplains, psychotropic medications, and other interdisciplinary interventions." Thus, the criteria for rendering a patient totally unconscious can come down to the individual's own report of the existential distress he or she feels. Those suffering from chronic depression or severe depression (e.g., parents who have lost their only child in a car accident) would qualify for TS.

2. TS is not limited to patients with terminal illness who are imminently dying. The NHPCO's policy explains that TS can be used "in the last day or two of life," but it can also be used "at multiple points" in a "patient's trajectory toward death," when the patient is not imminently dying. Thus, TS is not limited by standard clinical criteria as put forth in the AMA's policy on forgoing life-sustaining treatment (FLST) -- i.e., that the patient be terminally ill and imminently dying. Don't we all, in biological terms, cross over to the "trajectory of death" somewhere in our early twenties, even though we may be healthy? This detail in TS policy proves to be a common denominator between TS and the Dutch euthanasia protocol, where "unbearable suffering" is the principal criterion necessary to invoke the euthanasia option.

3. TS policy is not based on diagnosis, but on symptoms. TS is held to be appropriate for any patient who is suffering from a high level of unrelieved existential, emotional, or spiritual distress: "TS may be made available to patients based on their symptoms and their desire for relief regardless of diagnosis." Clearly, there are no diagnostic guidelines for the use and application of TS -- which makes it a candidate for consummate abuse.

4. TS is also deemed "appropriate for children in unrelieved distress." There are two aspects here that add to the multitude of concerns regarding TS policy. First, the suicide rate is very high among teenagers. TS adds a new and utterly dubious treatment option for dealing with the high level of emotional, social, and existential distress often experienced by teenagers. Second, parents should be involved in making medical decisions for their children; the law requires as much. But not to be missed here is the detail that TS decisions are not restricted to respect for autonomy of competent adults. The principle of autonomy is not an absolute principle upheld in TS policy.

5. TS protocol allows that the sedation may be "partial or complete," and that it can be initiated as a temporary and reversible sedation. There is no problem with this application of sedation; however, TS policy does not limit the time frame, or require reversibility, of sedation. Though the NHPCO states that "[TS] need not be considered irreversible," TS can be titrated to produce a "complete unresponsiveness of patients" with the "intent" to provide "deep sedation until death occurs, without concern for reversibility." When a permanent TS treatment is administered upon the patient's directive, it cannot be revoked; no totally unconscious patient will ever have the opportunity to reverse her directive, say, to look at the face of a loved one just one last time. By contrast, when a DNR order is in effect, it can be revoked by the patient at any time. Absolute final farewells must precede permanent TS -- just as in an act of euthanasia.

6. TS protocol also allows that any concomitant therapies may be added to the TS patient's protocol, each "based on their own merits." Thus, a terminally ill patient (e.g., an HIV+ or early-stage ALS patient) who is not imminently dying can be given TS concomitant with a decision to forego (withhold or withdraw) life-sustaining treatment (FLST). When the patient's life does depend upon the continuation of life-sustaining treatment, the cause of his death may be ambiguous. Would the immediate cause be regarded as FLST and not at all dependent upon the active interventions of TS policy? What if such a patient refuses to forego life-sustaining treatment without first undergoing TS? In such a scenario, TS is necessarily implicated in the immediate cause of the death of the patient. Such a context carries TS into the frontiers of euthanasia. Furthermore, TS plus concomitant patient decisions can place TS squarely in
the arena of euthanasia, e.g., when a TS patient elects to have her organs harvested per the Non-Heart-Beating Cadaver Donor Protocol. Here the result is an act, elsewhere argued, of "thrift-euthanasia."12

7. Another troubling aspect of TS (noted in number 4 above) is that strict respect for patient autonomy is compromised on several fronts. According to the NHPCO, "When patients do not have [autonomous] capacity, their designated decision-makers may make the decision on their behalf."13 This element of TS policy dissolves two fundamental boundaries set up to protect patients. When irreversible TS is deemed appropriate by family members (third-party, outside observers) of a non-competent patient, TS is then administered as non-voluntary or involuntary TS -- on a parallel with non-voluntary and involuntary euthanasia. Additionally, TS decisions made by substituted decision-makers will not be based on first-hand descriptions of the level of suffering experienced by the patient. Rather, they will be mere inferences based on observations and value-laden evaluations of onlookers -- who may have low pain thresholds and/or high sensitivity to the perceived suffering of others. Family members may (or may not) have the best of intentions, but they are nonetheless incapable of knowing for certain whether or not the patient has crossed over from tolerable to intolerable distress, the supposed symptom required for TS. The ugly reality is that irreversible TS may too often be treatment given to a patient for the comfort of the family.

8. Furthermore, as outlined by NHPCO, the patient need not be the one who initiates discussion of her own total sedation: "the patient or family may bring up TS or it may be offered as an intervention by the [health care] team."14 The psychological and ethical dangers here are those of communicating to the patient that it is now time for her to give up. When TS is broached by the family or health care team, the patient's first question will likely be, "What is total sedation?" The patient -- who may or may not want to die, who may or may not have asked to be euthanized -- will perceive TS as offering the same psychological and existential state as being euthanized. If the patient does want to die, then TS will be readily accepted. If she does not want to die, then simply being approached to consider TS will communicate to her that she must be a burden on others and/or that her life just cannot be worth living any longer. Such reflections by the patient may be exactly enough to shift an individual's suffering from bearable to unbearable. The psychological distress added to the patient's life by others initiating this conversation may be the existential push that takes them over the TS cliff. The parallel that TS policy has here is with PAS -- i.e., if you know that someone is in great distress, is it appropriate to suggest assisted suicide to him as a solution to his suffering? The reasons against initiating such offers are the same reasons against initiating an offer of permanent TS to patients. Furthermore, when TS becomes hospice and hospital policy, it will be incumbent on the agency to inform all patients of their TS options at admission. Therefore TS policy adds significantly to the so-called "culture of death" mentality already inundating society. Lastly, given the details unpacked above, a health care team can initiate the discussion of TS of an incompetent patient with family members and carry it out -- all without any patient involvement. This is a dire and shadowy way to end the lives of others -- via paternalistic, non-voluntary, existential euthanasia.

All in all, these "devils in the details" are sufficient reasons by themselves to reject TS policy. There is, however, another serious problem in TS policy that makes it even more objectionable.

**Total Sedation as Existential Euthanasia**

Is Permanent Total Sedation (PTS) a form of PAS or euthanasia? NHPCO's answer is that PTS is neither PAS nor euthanasia. They argue, "The intent of assisted suicide or euthanasia is to end the patient's life. By contrast, the intent of TS is to relieve suffering," and the appeal made by some defenders of TS to the Principle of Double Effect "is not appropriate for justifying the use of total sedation" because death is not intended, hastened, or caused by TS. NHPCO's position rests on the assertion that PAS and euthanasia end a patient's life, but PTS does not end a patient's life. There is no problem with the claim that PAS and euthanasia are acts that end the lives of individuals. The problem is with the claim that acts of PTS do not end the lives of individuals.
Critical evaluation of NHPCO's position on PTS from common sense can be quite enlightening. That is, what is the common sense answer to the following two questions? (1) Which would you prefer - to be killed or to remain alive? The answer is simple and obvious -- to remain alive. The second question should have the same simple and obvious answer as the first, if NHPCO's argument is sound, because it merely substitutes NHPCO's concept of life into the question. (2) Which would you prefer - to be euthanized today or to remain alive (alive according to the NHPCO concept of being alive), that is, to be rendered totally unconscious for the next 15 years until death comes to you by heart/lung and kidney failure? The common sense reply to this question is, "Are you serious? Is this a joke? I do not want either done to me because they are both acts that end my life - one kills me outright and the other is just as good as being killed." The point, obvious to common sense, is that both euthanasia and PTS end one's life, even if there is a biological difference between the two resulting conditions. The biological difference is effectively irrelevant because it is nullified by the pharmacological intervention maintained on the PTS patient. Thus, PTS is existential euthanasia.

Put another way, PTS is a new, man-made, artificially induced and maintained form of living death, a drug-induced zombie-like condition. PTS relentlessly undermines any and all consciousness, rendering the brain's reticular activating system non-operational. Hence the "life" of a PTS individual is effectively reduced to a partially functioning, mindless human body. PTS is the ultimate suffering-stopper - short of standard euthanasia -- because PTS stops consciousness and neutralizes all five senses. In PTS there is no suffering experienced because there is no consciousness of self, others, or the world allowed to occur. One might point out that civil libertarians consider legalization of euthanasia the ultimate civil liberty. If this is the case, then PTS qualifies as the penultimate civil liberty.

Common sense might put all of this yet another way. There is a popular saying that it is a terrible thing to waste a mind -- to drug addiction. So too, it is a terrible thing (for a conscious, competent individual to autonomously request) to be rendered functionally mindless -- by drug induced PTS. So too, is it a terrible thing for third-parties to request and to render an incompetent adult or minor functionally mindless -- by drug-induced PTS. As far as the experience of the individual is concerned, the pharmacologically-induced and maintained PTS condition is little different than an intentionally induced PVS (persistent vegetative state) condition. Since PVS patients are commonly "let go," why would we expect anything different for PTS patients? This slippery slope feature of PTS policy is further greased by the fact that the patient, family, and health care team do not hold out any hope for recovery of consciousness, as is commonly the case for PVS patients. Also, the severity of the slippery slope incline is increased dramatically because the physicians and medical teams carrying out PTS are not restricted to anesthesiologists and ICU trained teams - e.g., PTS can be conducted in a hospice by the family physician or hospice director. The American Society of Anesthesiologists has highly refined guidelines for all levels of sedation, none of which are recognized by NHPCO policy. When a patient is under PTS, it is the volitional commitment of the physician and medical personnel to PTS that insures consciousness will never again be regained. So, when a PTS patient happens to get an infection that is treatable and reversible, how likely is it that it will be treated? What about the second time he or she gets an infection? Is it not more likely that the third parties involved will ask themselves, "Why should we treat this infection? Isn't death the objective here? The patient will never know the difference, and wouldn't he or she want us to desist treatment?"

The term "existential euthanasia" may appear to some to be an unusual application of euthanasia categories and terminology. This is true -- but PTS is a subtle and unusual form of terminating the life of a conscious human being by permanently undermining any and all consciousness without stopping the heart/lung function. New hospice and hospital offerings of such ways to manipulate and alter human life call for new terminology that is adequate to bring clarity to everyone so that ethical evaluation can be done in the open. Hence existential euthanasia is a term that emphasizes and spotlights fundamental features of PTS and frees it up from NHPCO's equivocations and soothing wordplay.
The prima facie ethic on PTS is this: If and when it is ethically wrong to kill an individual by PAS or euthanasia, so too it is wrong to end an individual's conscious, personal life by PTS. Given that PAS and euthanasia are ethically wrong, it follows that PTS is ethically wrong. For the same reasons that one ought not to choose suicide or euthanasia, one ought not to choose PTS. For the same reason that a physician ought not do PAS or euthanasia, a physician ought not to do PTS.

Therefore, the physician who induces PTS intentionally commits existential euthanasia -- because the embodied person (soul) is pharmacologically imprisoned, kept in embodied silence and solitary confinement from all consciousness and personal interaction with others and the world. Hence NHPCO's campaign of aggressively pushing agencies across the country to adopt PTS and make it "a comfortable addition to the palliative care repertoire" is seriously misguided.

Ducharme's Notes

2. Ibid.
4. Ibid., p. 9.
5. Ibid., p. 7.
6. Ibid., p. 9.
7. Ibid., p. 9.
8. Ibid., p. 7.
15. Ibid., p. 3.

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