

## ETHICS SECTION

# Intractable End-of-Life Suffering and the Ethics of Palliative Sedation

Eric J. Cassell, MD,\* and Ben A. Rich, JD, PhD†

\*Weill Cornell Medical College, New York, NY

†School of Medicine Alumni Association Endowed Chair of Bioethics, University of California, Davis School of Medicine, Sacramento, CA

Reprint requests to: Ben A. Rich, JD, PhD, UC Davis Medical Center, 4150 V Street, Suite 2500, Sacramento, CA 95817, USA. Tel: 916-734-6010; Fax: 916-734-1531; E-mail: barich@ucdavis.edu.

### Abstract

Palliative sedation (sedation to unconsciousness) as an option of last resort for intractable end-of-life distress has been the subject of ongoing discussion and debate as well as policy formulation. A particularly contentious issue has been whether some dying patients experience a form of intractable suffering not marked by physical symptoms that can reasonably be characterized as “existential” in nature and therefore not an acceptable indication for palliative sedation. Such is the position recently taken by the American Medical Association. In this essay we argue that such a stance reflects a fundamental misunderstanding of the nature of human suffering, particularly at the end of life, and may deprive some dying patients of an effective means of relieving their intractable terminal distress.

**Key Words.** End-of-Life Care; Ethics; Sedation; Palliative Treatment

In 2008, the House of Delegates of the American Medical Association (AMA) adopted a report by its Council on Ethical and Judicial Affairs (CEJA) entitled “Sedation to Unconsciousness in End-of-Life Care” [1]. The report lays out the clinical and ethical parameters for providing palliative sedation to the point of unconsciousness for dying patients whose pain and symptom distress have proven refractory to standard palliative measures. The critical language is the following:

Palliative sedation to unconsciousness is only appropriate for terminally ill patients “as an intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that have not been relieved by symptom-specific palliation.” Specifically, such clinical symptoms include pain,

nausea and vomiting, shortness of breath, agitated delirium, and dyspnea . . . Severe psychological distress may also warrant palliative sedation to unconsciousness when potentially treatable mental health conditions have been excluded. Purely existential suffering may be defined as the experience of agony and distress that results from living in an unbearable state of existence including . . . death anxiety, isolation, and loss of control . . . The Council concurs with those who argue that existential suffering, distinct from previously listed clinical symptoms, is not an appropriate indication for treatment with palliative sedation to unconsciousness, because the causes of this type of suffering are better addressed by other interventions [1].

Interestingly, the source cited by the CEJA for the argument that palliative sedation is inappropriate for existential end-of-life suffering is a case discussion that simply notes that the use of sedation for purely existential suffering is controversial, citing articles on both sides of the issue; the authors do not take a position on the controversy itself [2]. The CEJA report provides no further analysis or authority for its distinction between types of suffering and the acceptable means of relieving it. There is, however, another article in the literature, authored by bioethicists Lynn Jansen and Daniel Sulmasy, that does appear to provide the missing analysis and argumentation for the AMA policy position [3]. Shortly, we will return to and directly engage with that analysis.

### Professional Organization Policies on Palliative Sedation

The AMA is certainly not the first major health professional organization to adopt a policy on palliative sedation. Indeed, the American College of Physicians Ethics and Human Rights Committee published a position paper on physician-assisted suicide (PAS) in 2001, which in the process of distinguishing palliative sedation from PAS, set out practice parameters quite similar to the recent AMA policy. Both create a critical distinction between two types of suffering at the end of life: 1) clinical suffering of a physiological or psychiatric nature and 2) existential suffering that cannot be directly linked to either form of suffering captured in the first category. A similar distinction was made by the National Ethics Committee of the Veterans Health Administration, and that committee’s failure to reach a consensus resulted in a policy position resembling that of the AMA [4].

Organizations such as the American Academy of Hospice and Palliative Medicine have formulated policies on palliative sedation that make no distinction between clinical and “nonclinical” suffering at the end of life [5]. Other guidelines

for palliative sedation in the medical literature specifically include intractable existential end-of-life suffering [6]. In doing so, they specify that reasonable efforts to provide adequate relief of suffering short of sedation to unconsciousness should be undertaken and only when they prove inadequate and the patient is in the advanced stages of terminal illness should resort to palliative sedation be clinically and ethically indicated [7]. The validity and defensibility of the distinction between types of end-of-life suffering and the range of clinical interventions that may be provided to address them warrants a more extensive articulation and analysis than its proponents have thus far offered. First, however, a brief review of the recent history of palliative sedation in the continuum of end-of-life care is indicated.

#### The Confused Semantic History of Palliative Sedation

One reason why palliative sedation generates a level of controversy that is disproportionate to its stated goal of alleviating otherwise intractable suffering in dying patients may be that early on it was saddled with the unfortunate and misleading label of "terminal sedation." That characterization was hopelessly ambiguous in that it failed to indicate whether the patient's underlying condition, the sedation process itself, or the ultimate consequence of the withholding or withdrawing of artificial nutrition and hydration that often (but not necessarily) followed the total sedation of the patient was that to which the word "terminal" referred. The controversy was further heightened by the introduction of yet another unfortunate term—"slow euthanasia"—to describe the hanging of a morphine drip as a form of terminal sedation [8]. As the many critiques of the "slow euthanasia" characterization pointed out, the purpose of and the usual intent in providing pharmacological sedation to dying patients is not to hasten their inevitable and often imminent death, but rather to ensure that they do not suffer in the process [9]. Despite diligent efforts on the part of the hospice and palliative care professional community, the use of the term "terminal sedation" continues unabated in some quarters [10]. The semantic problems also increase the challenge of assessing the frequency with which sedation to unconsciousness is provided to patients with intractable suffering in the final stages of terminal illness as well as the incidence and prevalence of the varieties of intractable end-of-life suffering [11].

#### The Problem with the AMA Position and the Jansen-Sulmasy Paper

These policy positions and arguments concerning palliative sedation make a distinction between physical and existential sources of distress. For both, palliative sedation is deemed to be an appropriate response to physical symptoms (or, as Jansen and Sulmasy refer to them, physiologic or pathophysiologic sources of suffering) or suffering from unremitting mental disorders. In both there

are the same two difficulties: the failure to define suffering and a continuation of the ancient and discredited distinction in medicine between mind and body. First, neither the AMA nor Jansen and Sulmasy define suffering. Especially with regard to the Jansen and Sulmasy analysis, it is as if suffering occurs when pain or other pathophysiologic symptoms such as nausea or dyspnea are very severe. Suffering is equated with the severity of the symptom—another synonym for very bad. This is a controversial use of the term that is not adequate for medical purposes. We and many others accept that suffering is a specific distress that occurs when an impending destruction of the person is perceived and continues until the threat is gone or the integrity of the person can be restored. A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational human individual existing through time in a narrative sense. Generally, all of these parts are consistent and are harmoniously accordant. Suffering, in which all of these parts are affected, variously destroys the coherence, cohesiveness, and consistency of the whole. It is in this sense that the integrity of the person is threatened or destroyed.

The origins of suffering can be found in the meanings attached to the source of distress and beliefs about what can be expected if the distress continues. Bodies do not construct meaning and do not have a sense of the future, only persons do. Suffering is an affliction of persons, not bodies [12]. Suffering is personal, individual, lonely, and marked by self-conflict. When a source of distress, like pain, produces suffering, it is the suffering that becomes the central distress not the pain. It is not valid to make a distinction between suffering whose source may be physical, such as pain, and suffering coming from the threat to the integrity of the person from the very nature of the person's existence. This is underlined by reviewing the three reasons most frequently given by persons requesting assistance in dying under Oregon's Death with Dignity Act: loss of autonomy (95%), loss of dignity (92%), and decreasing ability to participate in activities that make life enjoyable (92%) [13].

It is no longer valid to make a medical distinction between the body and the mind or the person and the mind. The mind-body dichotomy goes back to antiquity, but is perhaps best known in the form described by Rene Descartes, where the body is part of nature and the material world, and the mind is the place of the soul and part of the spiritual world of God. The dichotomy has been discredited for more than a century but is persistent. For medicine and science persons are of a piece, whatever happens to one part happens to all and whatever takes place in the whole person has an impact on every single part. There is no such thing as a pain or nausea, vomiting, or dyspnea that solely occurs in the body without having an impact on the conscious person. If for no other reason, everything of which a person is aware is given meaning and every meaning has an effect from the molecular to the spiritual. It is, for example, inconceivable that severe pain would not produce an emotional reaction in the person with the pain.

