Pain Medicine

Pain Medicine 2010; 11: 435–438
Wiley Periodicals, Inc.

ETHICS SECTION

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

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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.

Emotions are accompanied by a hormonal flux such as a discharge of catecholamine and those hormones produce effects throughout the body.

In thinking about this problem of palliative sedation, we must remember that we are speaking about very sick terminally ill patients. What is called existential distress arises from the impact of their sickness on their existence; helplessness, isolation, and loss of control that characterize severe illness, and which is brought on by symptoms as varied as pain or profound weakness. When these things are seen by the person as threatening their destruction as the persons they have known themselves to be, they start to suffer. Their suffering then becomes the problem. Their suffering, as suffering, is no different than the suffering that comes about because of pain. To see such suffering as somehow not as real as (say) vomiting or as "just emotional" is not true of severe illness as any clinician knows it to be.

The mind–body distinction continues to plague our understanding of sick persons and issues like palliative sedation for two reasons. The first is related to concepts in science and the second to religious beliefs. For science, all of nature is made up of forces operating in a random manner and without central purpose. Leaving behind the concept of teleology so central in religion was one of the hallmarks of the beginnings of science in the 17th century. The appearance of purpose results from the enormity of the whole of nature seen as a totality and the vastness of the expanse of time through which nature has come to its present point. On the other hand, persons and their minds clearly demonstrate purpose, so it appeared that persons or minds might be distinct from nature. It is also the case that animals, down to their lowest forms, have purpose, so the distinction from nature is false. The apparent lack of purpose in animals until the late 19th century was a circular argument arising from the Cartesian belief that only persons (having souls) could have purpose while animals (lacking souls) could not.

The other reason the mind–body dichotomy persists is the importance in some belief systems of seeing the body as the source of feelings, needs, or desires that are temptations that must be resisted in order to lead a life free of transgression. The place of such temptations and their resistance may play a vital part in many lives. Removing the mind–body distinction would threaten the beliefs of such persons. Nonetheless, for medicine and medical science there is no legitimate distinction between mind and body.

Conclusion

Suffering in patients in the terminal stage of illness deserves consideration for palliative sedation depending on the patient's needs and wishes without regard to what is believed to be the originating source of suffering. It is also important to note that whereas the AMA policy appears to preclude palliative sedation even when suffering has proven refractory to all other available measures, the Jansen and Sulmasy analysis at least acknowledges that in such cases resort to palliative sedation may be justified. In that regard, their less rigid and more nuanced position begins to approach the positions advocated in both the palliative medicine and psychiatric community [14–16]. These recognize some distinctions among physical, psychiatric, and existential suffering, but none that would preclude palliative sedation as an option of last resort. Lastly, we note with a sense of irony that when the issue of PAS came before the U.S. Supreme Court in 1997, many opponents from the palliative care community strenuously asserted that PAS was never necessary to insure that dying patients did not suffer, because when all other options failed, palliative sedation could be provided consistent with clinical, ethical, and legal standards of professional conduct [17]. Now, if the AMA policy becomes the standard of care, dying patients whose distress is genuinely intractable and has been labeled "existential" in nature will have no viable medical option of last resort except in those jurisdictions in which a lethal prescription is allowed.

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