

## ***Ethical Issues in Palliative Care***

Series Editors: Muriel Gillick, MD, and Gregg K. VandeKieft, MD, MA

# Preemptive Use of Palliative Sedation and Amyotrophic Lateral Sclerosis

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### **Abstract**

*Patients in the advanced stages of amyotrophic lateral sclerosis often are faced with the dilemma of whether to use or continue to use mechanical ventilation. Patients who elect to terminate ventilatory support may be subject to significant and even extreme respiratory symptoms. Severe dyspnea and other symptoms are sometimes treated with palliative sedation, which is generally recommended as a last resort approach to refractory symptoms. However, the preemptive use of palliative sedation is sometimes appropriate. The preemptive use of palliative sedation is examined through a case-based analysis of a patient with advanced amyotrophic lateral sclerosis. J Pain Symptom Manage 2012;43:802–805. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

### **Key Words**

*Ethics, palliative sedation, amyotrophic lateral sclerosis*

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## **Introduction**

Patients who suffer from advanced amyotrophic lateral sclerosis (ALS) often have particularly challenging palliative care needs. Compared with some other patients who are ventilator dependent, these patients generally are cognitively unimpaired. They are able to reflect on their condition and prognosis quite clearly and deliberate about their treatment options without the urgency or clinical instability coexistent with some other causes of respiratory failure such as pneumonia or sepsis. Such patients who elect to discontinue mechanical ventilation can anticipate their symptoms, their

process of dying, and their death well in advance of treatment withdrawal. Palliative sedation can be a powerful tool for these patients, who may request it preemptively. Yet, guidelines for this type of palliative sedation do not always account for the particular needs of ALS patients. The following case illustrates some of these challenges.

## **Case**

L. R. is a 38-year-old man diagnosed with ALS four years before this final hospital admission. Eight months ago, he was hospitalized for treatment of pneumonia. Although L. R. had always intended to avoid mechanical ventilation, he agreed to be intubated because his pulmonologist, Dr. J., expected that respiratory independence would return once the pneumonia fully resolved. L. R. agreed to the placement of a tracheostomy and returned home with

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a mechanical ventilator to continue weaning trials. Unfortunately, he has remained ventilator dependent. Two months ago, after six months on the ventilator, L. R. began to contemplate its withdrawal. He was aware that he could live for months or longer on the ventilator and was aware that he would most likely die within minutes to hours after disconnection from the ventilator. L. R. also was mindful of his diminishing ability to communicate, which was now limited to eye blinking and facial expressions. L. R. involved his wife intimately in these deliberations and met numerous times with Dr. J., his pastor, and his attorney.

L. R. wanted to come off life support before he became totally locked in and thus unable to direct his care. He wished to be admitted to the hospital to die because he believed that dying at home would burden his wife and leave her surrounded with memories of his demise. Moreover, his greatest fears were to feel suffocation and to be aware of his dying. L. R. wanted Dr. J., his trusted physician, to manage his death—to sedate him to unconsciousness and to guarantee his comfort.

Dr. J. agreed to fully sedate L. R. before removing him from the ventilator to ensure total control of the anticipated dyspnea. Dr. J. consulted various guidelines on palliative sedation to better understand its use as a preemptive measure but found little direct guidance. Nevertheless, Dr. J. sedated L. R. with a lorazepam infusion and removed the ventilator. Surprisingly, 12 hours later, L. R. continued to breathe. At this juncture, Dr. J. thought L. R. could possibly survive up to several days, and having just read guidelines on palliative sedation, he believed that lightening L. R.'s sedation to the target symptom of dyspnea was required. The patient's family objected to this plan, stating that it would be cruel to wake up a person who thought he had died only to face death again. L. R. remained sedated and died several hours later.

## Discussion

Palliative sedation is the pharmacological sedation of patients for the purpose of symptom relief. Guidelines for palliative sedation require that the patient suffer from intolerable and refractory symptoms, that the degree of

sedation be proportionate to the target symptom (up to and including full sedation if necessary), and that palliative sedation be reserved as a treatment of last resort.<sup>1-6</sup> Guidelines also require that patients have a terminal prognosis, but vary on how close to death patients must be for palliative sedation to be permissible, and range from hours or days to simply any terminal prognosis. Guidelines also differ on whether palliative sedation for existential distress is permissible.

With these considerations in mind, how did Dr. J.'s use of palliative sedation square with current guidelines? L. R. did not complain of pain or dyspnea, let alone any particular symptom that was demonstrably intolerable. Because he had not yet been treated for symptoms, a determination of symptom refractoriness could not be made. Finally, Dr. J. used palliative sedation as a first resort treatment, not as a last resort. Is assessing Dr. J.'s management of symptoms against guidelines for palliative sedation even appropriate because the case of L. R. is, in some ways, a simple case of withdrawing burdensome treatment? Certainly, the patient's well-informed and considered basis for doing so met established ethical requirements. However, guidelines for ventilator withdrawal recommend controlling symptoms before extubation and reserve medically induced unconsciousness for refractory situations.<sup>7-9</sup> The preemptive use of full palliative sedation, whether for ventilator withdrawal or the termination of other treatments, presents a somewhat different clinical challenge. This case illustrates this issue and others pertaining to palliative sedation.

Perhaps, on the one hand, one could presume that L. R.'s symptoms would be severe, intolerable, and refractory, and if so, guidelines do not require first trialing less intensive measures that are expected to be inadequate. On the other hand, many patients who are terminally extubated do not require total sedation to achieve adequate symptom control. Regardless, once L. R. was fully sedated and the ventilator withdrawn, guidelines seemed to require that proportionate sedation be pursued. Should Dr. J. have attempted to down-titrate the lorazepam infusion to a minimal level of sedation necessary for symptom control? Was L. R.'s fear of being aware of his demise an appropriate target symptom for palliative sedation?

Rather than assess whether Dr. J.'s use of palliative sedation was consistent with current guidelines, I will discuss whether guidelines accommodate clinically sound and ethically supportable practices as they pertain to the care of patients with ALS in particular. Should symptom refractoriness always be a criterion for the use of palliative sedation? Is reserving palliative sedation as a last resort necessary or appropriate? Should preservation of consciousness always be a priority?

Guidelines for palliative sedation are restrictive and overly so for the vast majority of patients who potentially would benefit from this intervention.<sup>10</sup> These criteria for its use reflect, in part, caution in distinguishing palliative sedation from active euthanasia because the interface between the two activities often raises moral disconcertion.<sup>11–13</sup> Restrictions on some applications of palliative sedation could be eased by more clearly distinguishing between situations in which palliative sedation is likely to hasten death from ones where it has a purely palliative effect with negligible impact on the timing of death.

Again, consider the case of L. R. His request to remove a medical impediment to his lethal disease process was well informed and deeply considered. His death was clearly a case of ethically justified "allowing to die." If L. R. was expected to die shortly after ventilator withdrawal from frank respiratory failure, sedation should not measurably shorten his life. In fact, the ways in which full palliative sedation could measurably shorten one's life do not apply to this case. One way would be through an excessive dose of a sedative that depresses respiration, a rare phenomenon indeed and one not realized in L. R.'s case. Another way for full and continuous palliative sedation to accelerate a patient's demise is by preventing an otherwise capable patient from self-hydrating. Patients without any source of hydration typically die within two weeks,<sup>14–17</sup> and if dehydration causes death sooner than would the disease process, it too would be a case of killing. Concerns about terminal dehydration were not pertinent to L. R.'s situation, given his expected brief survival after the removal of life support.

Therefore, in situations like that of L. R. where full palliative sedation is purely palliative, that is, it does not accelerate time to death

beyond the trajectory of disease, what is the relevance and purpose of the criteria of refractoriness and last resort use? What is to be gained by requiring patients such as L. R. to demonstrate the intolerability and refractoriness of symptoms before receiving the most effective palliative measure? Particularly for patients near the end of life, where time is of the essence, does it make sense to first trial other palliative interventions to see if they are adequate?

Additionally, how does the criterion of proportionality in sedation serve this subset of patients? Although proportionality is a sound approach to care generally, its relevance to all palliative situations is not so clear. For patients seeking complete symptom control without delay and who do not value preservation of consciousness, what is the purpose of proportionality? These patients are not likely to be harmed by direct full sedation and may be harmed without it. Shouldn't these end-of-life patients be free to make their own assessment of relative priorities? Our patient, knowing that he will die shortly once disconnected from the ventilator regardless of how his symptoms are treated, does not value consciousness. In fact, he values unconsciousness for its definitive palliative effect on dyspnea and its amelioration of his existential distress.

Palliative sedation for existential distress finds no consensus among various published guidelines. Some prohibit it, some permit it, and other guidelines merely note that this is an area of controversy. Certainly there are many legitimate questions about existential distress such as defining it, diagnosing it, and determining a level of distress for purposes of selecting treatment.<sup>17</sup> These concerns notwithstanding, if palliative sedation is used so it does not accelerate time to death, and psychic distress can be unbearable, then palliative sedation for existential distress ought not to be prohibited.

For patients whose death from disease is expected to occur in days to a couple of weeks, palliative sedation often does not actively shorten life, and in these cases, it should not necessarily be restricted as a treatment of last resort. Patients who may want total symptom relief above all else may elect palliative sedation first. The assessment of whether preservation of consciousness is a prime goal is best left

to patients, not to physicians. Preservation of consciousness is a value judgment for which current guidelines offer no ethical justification for its imposition on patients.

In conclusion, palliative sedation used as a first resort intervention and without proportionality can serve selected patients in a manner that is medically appropriate and ethically supportable.

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