

What Are Two Days Worth? Facing Dilemmas Together at the End of Life

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Mr. J. was 35 years old when he died. He had loved the ocean, playing music, and joking with family and hospital staff alike. As an inpatient palliative care consultant, I took care of him during his last week. Mr. J. had all the makings of a “difficult case”: he was young with an invasive pelvic sarcoma and had developed a tolerance to opioids from years of slowly titrated analgesics. The cancer had bored through long bones and nerve plexuses without invading vital organs. When he was admitted for uncontrolled bone pain, I feared that the doses required for treatment of his pain were fast exceeding the standard amounts of pain medication, even for a patient with advanced cancer. I saw him first thing every morning, to catch the overnight nurses who told me about his excruciating crises that were unresponsive to whatever we’d ordered the day before.

The metaphors of medicine could not do justice to Mr. J.: I called in the cavalry; I threw in the kitchen sink; I searched for the secret sauce. I discussed his case with the best pain doctors I knew, my departmental leadership, and our interdisciplinary team. I checked and rechecked my arithmetic as my calculated doses climbed beyond the realm of the usual, even in the world of inpatient palliative care at a cancer center. As the week wore on, we discussed with Mr. J. the looming prospect of palliative sedation. Each day, we talked about the trade-offs between the sedating effects of the pain medicines and the escalating requirements driven by his explosive tumor growth. In 6 years of practice, I had never had a patient respond to such counseling with, “That’s okay, I brought a six-pack of Red Bull to counteract the meds.”

His wry wit was disarming and engaging. He adored his wife, brother, father, and friends, who were constantly at his bedside. Palliative sedation would lower the curtain on the events of the room, which held moments of joy, clarity, and profundity along with the suffering. Mr. J. was reluctant to miss out on a minute of connection, so I kept adding and adjusting, trying to find the right mixture. I told him that there might come a point where we had exhausted all options for pain control, where there was nothing left to relieve the pain except being asleep. He nodded, telling me, “We aren’t there yet.”

Friday morning arrived with a newfound equilibrium — his pain was finally at bay. I had never ordered such high doses of methadone for a patient-controlled analgesia machine, nor had Mr. J.’s intrepid bedside nurses pushed such large amounts of steroids and ketamine to achieve comfort. I had maximized the doses of every nonopioid pain medication to help him maintain lucidity. I was not on call for the weekend and wanted to arrange a workable plan to be carried out by one of my colleagues. We were way off the standard map, and we knew it. Given Mr. J.’s relative comfort that morning, I elected not to discuss palliative sedation further. I gave verbal pass-off to my colleague and signed out my pager that evening feeling deeply worried that this reprieve would be temporary.

Mr. J. died 3 hours before I returned to the hospital on Monday morning. His chart described his final days: Friday and Saturday were periods of relative stability and peace for him, even allowing out-of-town friends to gather and clink a glass of beer at his bedside. I wondered what these 2 days were like, what they meant to him, and what they were worth. When I clicked into the last few notes, it hurt to read his nurse’s narrative of the last 12 hours of Mr. J.’s life. He had spent his last moments in a pain crisis that gargantuan doses of potent opioids could not contain.

After his death, I questioned myself, my medical decision making, and my recommendations. He had trusted me, and I had trusted him to know what was right for this chapter of his life. **If I had pressed the issue of palliative sedation on Friday morning, maybe he would have accepted it, said his good-byes, and been enveloped in a phenobarbital haze for those last 2 days,** unaware of the friends and family at his bedside but free of the physical suffering that plagued him. What had held me back from strongly recommending that course? Was it just my wish to preserve his ability to interact with family and friends until the end?

I have sometimes found myself criticizing clinicians who request palliative care consultations while offering additional disease-directed treatment when patients are actively dying. In these situations of perceived nonbeneficial care, I have felt that such clinicians do patients a disservice while advancing an idealized vision of doctor as savior. Mr. J.'s case led me to wonder: Did I also buy into **an idea of a sanitized "good death"? What does such a thing look like? Or is the good death ultimately the one that unfolds on our own terms, according to our goals, values, and particularities?** Does it have to make sense to others, one's partner, or one's doctor?

I wonder whether we could have prepared Mr. J. better for the likely end, given what is known about his cancer. A recent investigation of decedents with musculoskeletal sarcoma found that 98% required opioids in the last 2 weeks of life and a staggering 39% needed to be sedated for refractory physical symptoms.¹ Perhaps if Mr. J. had had the opportunity to discuss the prospect of palliative sedation months before he found himself in the center of the storm, he and his doctors could have crafted a plan that respected his wish to live every moment to the fullest while accepting a difficult reality.

Palliative sedation holds unique meaning for clinicians, even those accustomed to providing care at the end of life. Although its goal is always control of refractory symptoms, we should all take pause when recommending it. In one national survey, **most palliative care providers said they believed that its use was ethically appropriate, but a substantial proportion reported feeling distressed when recommending it to patients.** It should be a treatment of last resort for a patient whose suffering cannot be relieved by any other means.² For many specialist-level palliative care providers, it is a procedure done only in extreme circumstances, and many clinicians don't endorse its use at all for existential suffering.³

Being honest with Mr. J. about the probability that when the end of his life came, **a sedated state would make him unable to interact with his loved ones would require his doctors to have difficult, frank conversations. Even with such informed consent, Mr. J. might still have chosen to stay lucid and relish those last 2 days — have that last beer with his family — despite the risk of uncontrolled symptoms. This type of choice has an existential element: it is not quite medical or scientific enough for our comfort. However, guiding patients in these crucial moments is the heart of our work.** It requires a certain amount of therapeutic courage for both patient and doctor and is essential to model and teach to our trainees.

What are 2 days worth? The answer is surely beyond the scope of medicine. In reflecting on Mr. J.'s fiery, love-filled, too-short life, I realize that if I faced the same decisions again, I would again defer to his wishes and again not be certain that my treatment plan was the right one. His last days were filled with the people he loved in a place where he knew he was safe. We were all living and working at the edge during his last week. His case was an extreme: I may never again prescribe methadone doses that high. **But the conflict that Mr. J. brought into sharp relief between the quality of life and its duration remains the daily focus of my career at the intersection of life and death.**