

# Virtual Mentor

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## Clinical case

### Myths and misconceptions about palliative sedation

Commentary by Timothy E. Quill, MD

Mrs. Mancini was in the hospital for her third admission in three months. She required dialysis almost daily, but her worsening heart function was complicating the situation. On a few occasions her blood pressure dropped so low that she had to be given intravenous vasopressors in the intensive care unit. At 62 years old, Mrs. Mancini was well known to most of the critical care unit staff, who were familiar with her extended hospital stays and many comorbidities. New to the team was Dr. Hayden, a first-year resident, who had been monitoring Mrs. Mancini's case since her admission three months ago.

During that hospitalization the care team helped Mrs. Mancini document her advance directives and assisted her in choosing which medical procedures she would want in the event of a medical emergency. "I guess I don't want any life support, except for dialysis—if it would even make a difference. But no, no CPR—I don't want to just be some vegetable." The team was in agreement with this plan, and Mrs. Mancini was encouraged to share her wishes with her daughters and her brother. Several weeks later Mrs. Mancini called Dr. Hayden in a panic. "Ya know, I've been thinking, if I ever get really sick, I think that it would be best if I had CPR and a respirator. Who knows, these things might keep me alive long enough for them to find a cure for what ails me."

Now Mrs. Mancini was back. Her cardiomyopathy and severe peripheral arterial disease necessitated use of pressors that had to be administered in an inpatient setting. This medication was only a short-term intervention and did not resolve the long-term concerns related to her severe hypotension which compromised her ability to safely receive dialysis. The medical staff agreed that Mrs. Mancini's health was failing and that it was time to discuss the next steps with her. Her internist, Dr. Tyler, and Dr. Hayden called a team meeting. Dr. Hayden took the lead: "Mrs. Mancini, it's time to make some tough decisions. You can no longer receive dialysis effectively because of your failing heart. If you stop your heart medication, your blood pressure will not be regulated. We need to discuss where to go from here. Unfortunately, we don't have many options to offer. What we *can* do is assure you that we will make you comfortable, be honest with you, and make sure whatever questions you have are answered."

After a moment of silence, Mrs. Mancini began rapidly asking questions. “What’s going to happen to me? Am I going to be in pain? What am I going to do about my family? How long do I have before I *have* to make this decision?” She was teary-eyed, but after spending several hours with the social worker, nurses and the doctors, Mrs. Mancini concluded that she was ready to have DNR orders; instead of waiting to die from lack of dialysis, she would stop taking her heart pressors; and she would be given a sedative by her doctor when the time came, so that her death would be as painless as possible.

The next day Mrs. Mancini called her family to tell them the news. Her family was understandably distraught, but after meeting with members of Mrs. Mancini’s health care team and having their questions answered, they realized that this was their mother’s choice and that they were fortunate to be with her at the end.

The morning that Mrs. Mancini chose to have the pressors stopped she confessed to her doctor, “I’m not scared. All of the people I love are here, my spirits are high and I am sure that there is nothing more that can be done.”

Over the course of the morning the room began to overflow with friends and family and the sound of music, prayer, and tears filled the halls as nurses and other members of the hospital staff came to offer their condolences. Just before noon Dr. Tyler gave Mrs. Mancini a sedative and everyone felt as “ready” as they could be. The assembly, which included nurses, physicians, social workers and the clergy, congregated around her, held hands, prayed, cried and watched as Mrs. Mancini quietly, and peacefully, died.

### **Commentary**

This case presents a relatively common dilemma of a patient with end-stage renal disease on dialysis who subsequently developed advanced heart failure, so that she required intravenous vasopressors to maintain high enough blood pressure to tolerate dialysis. The initial question was whether to attempt cardiopulmonary resuscitation (CPR) in the future should she experience cardiac arrest. Mrs. Mancini initially declined, presumably based on the anticipated lack of efficacy of CPR given her multiple chronic diseases, but then she rescinded the decision in a moment of desperation. Her change of mind reflects the profound ambivalence frequently associated with making decisions of such critical import as the decision to have do-not-resuscitate orders (DNR), even when the treatment is harsh and without significant prospect of working. Rather than simply changing the order, the health care team should have scheduled a family meeting to try to understand Mrs. Mancini’s change of heart and perhaps deal more directly with some of her underlying fears and concerns.

A second question arose after Mrs. Mancini began to depend on intravenous vasopressors to sustain her blood pressure enough to support dialysis. At that point the team faced some tough decisions. They acknowledged that Mrs. Mancini’s medical options were limited and that the main thing they could offer was comfort,

honesty and an attempt to answer all of her questions. After several hours of discussion, Mrs. Mancini indicated that she wanted to stop not only dialysis but also vasopressors so she would “not have to wait to die from lack of dialysis.” Provided Mrs. Mancini was clear about the implications of her decisions, her desire to die sooner rather than later would not be a reason to deny her requests; she had a clear right to have treatments stopped based on her right to bodily integrity. The team’s obligation would be to ensure she understood all reasonable alternatives and that she was fully informed about the likely consequences. They then would be expected to palliate all symptoms that arose as the process unfolded. Since her decision consciously invites death, the medical team would want to be sure that Mrs. Mancini’s thoughts were clear and not distorted by depression, anxiety or delirium [1]. Close family should be centrally included in the decision-making process, rather than informed the next day as in this hypothetical case.

But the case crosses into more ambiguous ethical territory when we learn that Mrs. Mancini will be given a sedative so that death will be as painless as possible. I have difficulty with the terminology at this point. What is the purpose of the sedation? Is it intended to be *palliative* sedation or *terminal* sedation (also called *heavy* sedation or *sedation to unconsciousness*), which introduces the possibility of voluntary active euthanasia [2]. This is a time when ambiguity should be minimized and honesty and clarity about the purpose of the sedative maximized [3]. Clinicians administering *palliative* sedation, as usually construed under these circumstances, would be prepared to provide as much sedation as needed to relieve the suffering associated with discontinuing the vasopressors. The sedation would be proportionate to the level of Mrs. Mancini’s distress, which might be nonexistent, mild, moderate or severe. The dose would be increased progressively to provide relief from whatever degree of distress Mrs. Mancini experienced, but there would be no intent on the part of the clinicians to actively hasten her death [4].

*Terminal* sedation refers to sedation given for the purpose of rendering the patient unconscious as the only means for escaping otherwise intractable suffering at the very end of life. Hence terminal sedation is distinct from the more standard and relatively common practice of palliative sedation. Linguistically distinguishing this practice as terminal sedation is intended to put practitioners on alert and to make them think carefully and exercise caution. Terminal sedation is on the far edge of the spectrum of palliative sedation and should be reserved for the most severe physical symptoms and only when all other palliative measures including lesser levels of palliative sedation have been tried and failed. It should be used only as a last resort, because, while other palliative measures try to preserve consciousness as much as possible, terminal sedation causes the patient to lose the ability to interact with his or her family and environment. Furthermore, with terminal sedation, patients also lose the ability to eat and drink, and all other life-sustaining therapies including artificial hydration and nutrition are generally stopped. It has been argued that palliative sedation does not hasten death [5], but that argument is less credible when the practice crosses into terminal sedation. Terminal sedation is distinct from euthanasia in that the dose of the sedating medication is not increased once adequate sedation is

achieved, and no agent that actively induces death is added. But it borders on euthanasia [6], and should be reserved for the rare cases where less aggressive measures have been ineffective.

So what happened in this case? The patient accepted that it was her time to die, family and friends were assembled to say goodbye, and eventually she was given the sedative and died peacefully with everyone in attendance. It appears on the surface to have been a meaningful and comfortable process, yet the details of what was actually done are critically important. If Mrs. Mancini was given some mild sedation as the vasopressors were discontinued, and the dose of sedation was adjusted in proportion to the distress she was experiencing, then this would be an appropriate use of palliative sedation, and there would be nothing controversial about it [5]. If she was pharmacologically rendered unconscious at the outset to prevent awareness of any potential suffering that might have occurred as a result of stopping her vasopressors and her dialysis, then this would be a case of terminal sedation that would be controversial because of the absence of severe symptoms. Under this scenario, the sedation would have been given prophylactically to treat suffering that *might* occur rather than as a response to suffering that *was* occurring. This approach invites the question whether one has to wait for the onset of severe symptoms before providing the sedation. Careful presence and readiness to treat with a proportionate amount of sedation is probably a better approach.

We are not given a time course or sufficient medical detail about how Mrs. Mancini actually died. We learn that she died quietly, peacefully and, by implication, quickly, which raises the specter of euthanasia. Was the dosage of the sedative such that it intentionally sped up her death? Was the amount of sedation correct for achieving the desired level of sedation? My hunch is that some family and staff would also be left wondering what exactly happened and what the medical role was in the patient's death. This is why it is so important for medical personnel to be as clear as possible about what they are intending in such cases, what they are actually doing, and why.

If the clinicians believed that terminal sedation was indicated in this case because Mrs. Mancini's symptoms were going to be severe and because she was terrified about them, then they should have discussed this possibility explicitly with her, her family and the staff and sought second opinions from colleagues in ethics or palliative care because that treatment is irreversible and ethically controversial. It is also imperative that Mrs. Mancini's care team document their actions carefully and extensively in the medical record. If the clinicians were planning to provide sedation as needed to address symptoms aggressively as they arose, then this treatment would be much more standard, but still discussion and documentation would be critical. Because it is so easy to misinterpret what really happened and because there is potential to blur the boundaries between palliative sedation, terminal sedation and euthanasia [6] (as illustrated in this case report), it is paramount to assure complete informed consent from the patient and family, to document exactly what one is doing and to get help from experienced clinicians in ethically and clinically complex cases such as this.

## References

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