

What not to do in palliative care

*Some things physicians thought they were doing to help patients at the end of life are actually ineffective and even potentially harmful.

[By Stacey Butterfield](#)

There's an art to practicing palliative care, but there's also quite a lot of science, palliative care specialist and hospitalist Steven Pantilat, MD, told attendees at the University of California San Francisco (UCSF)'s Management of the Hospitalized Patient conference in October.

“As palliative care grows as an academic field and grows as a board-certified specialty, we're seeing increasing science in our practice,” said Dr. Pantilat. In particular, recent research has shown that some of the things physicians thought they were doing to help patients at the end of life are actually ineffective and even potentially harmful.

Dr. Pantilat, who is a professor of medicine and director of the palliative care program at UCSF, focused his talk on 5 such things that hospitalists should stop doing routinely, and some alternative actions that could provide more palliative care benefit to patients.

Oxygen

“If you walk through the hospital, you'll see so many people getting supplemental oxygen for shortness of breath,” said Dr. Pantilat. That's a good idea if patients are hypoxemic, but randomized, controlled evidence shows oxygen isn't doing anything for patients who have dyspnea without hypoxia.

“If you're not hypoxemic, oxygen doesn't help you any more than air does,” he said. And there are numerous disadvantages to patients being on oxygen. “Even with nasal cannula, they get pretty uncomfortable. Their ears start to hurt, their noses dry out. What we see at the end of life is oxygen often gets in the way of people getting close to their loved ones. They don't want to get in and caress their face or give them a kiss, because they're afraid that the oxygen is going to fall.”

Oxygen is also a hassle for patients leaving the hospital, who have to worry about the tank running out or carrying it around with them. For patients at the very end of life, it can unnecessarily prolong the dying process. “There's some point at which that the oxygen level gets so low that it's no longer compatible with life. If you're providing supplemental oxygen, that might just take longer,” said Dr. Pantilat.

Discontinuing unnecessary oxygen requires good communication with the patient and family. “Explain to families that ‘You know what, this is really not helping. He really doesn't need it. I think he'll be just as comfortable without it.’ . . . On rounds, we'll bring this up at the beginning of the visit, take the oxygen off and say, ‘Let's just watch what happens.’ Very often if the patient is not hypoxemic, what we'll see is that nothing changes,” Dr. Pantilat said.

He offered a number of alternative methods to treat dyspnea. “Draining a pleural effusion often makes people feel so much better when they are short of breath from it. Often they feel better just from the decompression of the lung, long before their oxygenation improves,” he said. If it's a continuing problem, patients may benefit from placement of a drainage catheter. “Patients can go home with them. They actually work really well. You can put them in the abdomen for management of refractory ascites as well,” said Dr. Pantilat.

Treatment of pneumonia or a pulmonary embolism, if present, can also make an end-of-life patient feel better. So can opioids.

“There are really good randomized trials of opioids for management of dyspnea. You can use a very low dose, like morphine 2 mg orally. Nobody stops breathing with 2 mg of morphine, although some of your specialty consultants might be very worried about that,” said Dr. Pantilat. Research has shown

that even 20 mg of long-acting morphine a day can be safe for patients for chronic obstructive pulmonary disease, he reported.

Then there are the very simplest measures, which family members can also provide. "They are often looking for ways to be helpful, things to do that are beneficial, nonharmful, and easy," he said. One option: Moving a patient to a more upright position can reduce shortness of breath. "We just get them to sit up, maybe put pillows on either side," said Dr. Pantilat.

Fresh air can also make patients feel better, but since it's often not available in the hospital, a fan is a good substitute. "There is something about cool air blowing across the face that actually physiologically relieves the dyspnea," Dr. Pantilat said. Similarly, a cool cloth to the face has been proven to reduce shortness of breath.

Death rattle and IVs

If you, contrary to current evidence, prescribe atropine to treat rattle, your error is understandable. "Maybe I taught you about this and recommended it. If I did, I'm sorry," said Dr. Pantilat. "Atropine sublingual does not reduce rattle, and neither do any other medications."

The good thing about rattle is that it doesn't appear to bother patients, since they are typically not very cognizant when it occurs. "It's the oral secretions, the phlegm that gathers in the back of the throat as you're breathing, and it makes a sound that can be really unpleasant," explained Dr. Pantilat.

Family members often find rattle quite disturbing to witness, and it is a sign that patients are near death (although not a very specific one, Dr. Pantilat noted: "hours to days"). Explaining the phenomenon to families may help some. "The more they hear from us that we understand what the symptoms are, that we can explain to them what's going on, the better they feel and the more confident they are that we're not only understanding what's happening, we can normalize it for them," he said.

Giving atropine probably doesn't cause harm, but since it also doesn't work, there's no reason to do it. Don't use suction, either, because that actually is likely to be uncomfortable for patients.

Instead, try turning them. "It takes a while for everything to collect again on the other side," said Dr. Pantilat. He also recommends limiting IV fluids. "There is no study that has looked at IV fluids and death rattle, but it certainly makes some physiologic sense that that [an association] would be the case."

The use of IV fluids is a topic of debate among palliative care experts. "I come from the 'limit IV fluids' camp in that debate, having seen lots of people who develop edema near the end of life," said Dr. Pantilat.

Some experts believe that fluids can make dying patients more comfortable, but they can also cause effusions and ascites. And ceasing to eat and drink is a normal part of the dying process. "Why should we go against what is happening normally physiologically?" Dr. Pantilat asked.

He mentioned a trial published in the *Journal of Clinical Oncology* in January 2013 that found no improvement in symptoms, quality of life, or survival when end-of-life patients were randomized to 1,000 mL of fluid a day versus 100 mL.

IV fluids don't even reduce thirst, which is a common symptom among ICU patients, Dr. Pantilat reported. If patients are thirsty, better solutions may be to drink water or suck on ice chips.

Constipation and chemotherapy

Docusate is a standard part of many physicians' admission orders for patients on opioids. "We do it, too," said Dr. Pantilat. "But here is evidence that docusate is not helpful."

A randomized trial, published in the *Journal of Palliative Medicine* in May 2008, compared senna with docusate plus senna. "The patients getting senna alone did better. They had more bowel movements more frequently than those on [docusate]," said Dr. Pantilat.

And in case you need more reason not to prescribe it: "The other thing is [docusate] tastes horrible. . . Only a few drops ruins an entire bowl of applesauce and makes it taste disgusting," Dr. Pantilat said. (Want evidence? Check out this taste-test [video](#).)

"Why make someone miserable? Start with senna," said Dr. Pantilat. If senna, which can be taken up to 4 times a day, isn't working, the next step should be polyethylene glycol, lactulose, or sorbitol. Still nothing? Consider methylnaltrexone. It's given subcutaneously, with weight-based dosing, starting with 12 mg for patients over 60 kg and down to less than 8 mg for those under 30 kg.

"When it works, it's not quite magic, but close. In the studies, most people for whom it works, it worked within an hour," he said. "If your patient is 3 days, 4 days, no bowel movement, you've given a lot of medicines and things aren't moving, and the patient's not obstructed, obviously, then definitely give it a try."

Cancer patients may be tempted to give chemotherapy a try, even toward the end of life, but Dr. Pantilat presented new evidence on that front. Palliative chemotherapy is offered with the goals of improving quality of life and extending survival. However, a recent cohort study finding that half of patients were receiving chemotherapy 4 months prior to death also discovered that those patients had the same survival rate as those who didn't do chemo.

"Patients with good functional status were more likely to receive chemo. That's not surprising," he said. However, for those patients who had better functional status at baseline, getting chemo was associated with worse quality of life. "Exactly the opposite of what you would have thought and told your patients," said Dr. Pantilat.

This evidence, published in *JAMA Oncology* in September, should inform hospitalists' conversations with patients and oncology colleagues. "We have a role in at least advising our patients and also talking with the oncologist about what might be appropriate for the patient," said Dr. Pantilat. "If you discuss this with the oncologist, you really have to push them a little bit: Is this really going to be beneficial?"

The oncologist may point out that this study was based on data from 2002 to 2008 and that oncology drugs have improved substantially since then. That may be valid, Dr. Pantilat said, but, "It really does make me raise the question about whether it's going to be effective."

Decisions about chemotherapy should be based in part on patients' life expectancy (chemo in the last weeks of life is a marker of poor care, he noted). Of course, it's usually difficult to come up with that prognosis. Dr. Pantilat recommends the Karnofsky scale, which uses markers like whether a patient spends more than half of his or her waking hours in bed, to predict life expectancy.

Closer to the end of life, useful prognostic markers are abnormal breathing, particularly pauses in breathing, and a thready or absent radial pulse. Those suggest that a patient will die within a day, and the latter is evidenced by mottling of fingers and toes. "I always mention that to families because they do notice it and it's weird and it's unpleasant to look at," said Dr. Pantilat.

Communication

In contrast to the interventions that have been proven not to work, good communication with families continues to be a definitive way to improve end-of-life care.

“A major source of family dissatisfaction is communication with us. Poor, infrequent communication is in fact the norm, and insufficient information on what to expect. People don't know what's going to happen and they're very unhappy. They don't get enough time with us and when they do get time, they're unhappy with what happens,” said Dr. Pantilat.

To make families feel better about their loved ones' care, encourage them to talk. “It feels inefficient, but it turns out to be very efficient to ask those open-ended questions,” said Dr. Pantilat. Ask what the patient was like before his or her illness, and invite the family to bring in photos. “It's a simple thing we can do, even when we're busy. Any of us will only have 1 or 2 patients at a time where this is really essential, where they have important decisions to make or are facing end of life.”

Talk to the patient, too, even if he or she is unconscious. “You don't know what to say to unconscious people,” said Dr. Pantilat. “I say, ‘We're going to take really good care of you.’ They don't have to respond. I say that to the family as well. It's amazing the response that you get.”

Also, have a response ready for when the family says one of those common but not very helpful lines like, “Our mom is a fighter.” Of course, no one's mom is a quitter, said Dr. Pantilat. “They're saying, ‘Don't give up on her.’ . . . This is not meant to direct care. What I like to say is, ‘Yes, she has been very strong. I worry that this time the illness is stronger.’”

The same applies when a family says their father wants to live. “I try not to ignore it. I just say, ‘Of course he does, we all want to live, but would he want to live like this?’ People imagine they're going to live the way they did before they got sick, but that's not our choice right now, unfortunately,” Dr. Pantilat said. When a family is making a care decision and you disagree, it's important to find a way to still say something supportive, such as, “I can see that you are doing what you think is best for him.”

It's a small step that a physician can take to help make patients and families more comfortable, which is, after all, the goal of end-of-life care. “Take away their burdens by not adding treatments that aren't going to be helpful. Do the things that do work, and provide good and frequent communication,” Dr. Pantilat summarized