

# All Palliative Care Is Local

## An Interview with Dr. Steve Pantilat

Dr. Steve Pantilat started up and leads one of the first hospital-based palliative care programs in the country. He is a professor of clinical medicine at UCSF, where he holds the Alan M. Kates and John M. Burnard Endowed Chair in Palliative Care. Also, he is director of the UCSF Palliative Care Leadership Center. In April 2013 Pantilat spoke with CHCF's Emma Dugas about [new data](#) on end-of-life care in California.

**CHCF:** New research shows that Medicare beneficiaries at the end of life are being referred to hospice in greater numbers, but there's also been a significant increase in the number of hospice patients whose stay is very short. In fact, the length of stay for a third of hospice patients is now three days or less.<sup>1</sup> What is your thinking about that?

**Pantilat:** The data doesn't tell us enough about whether that's good news or bad news. In my mind, the question is, "Is a very short time in hospice care so terrible?" If the other choice would have been keeping these folks in the hospital for those three days and instead, they got to be at home, which is where most people want to be, then it's a good thing. They would probably say that their care was of better quality and it's almost certainly going to cost less than staying in the hospital. What the data don't tell us is how many of these people *should and could* have been enrolled in hospice months earlier, but were referred so late that they received it for less than three days.



**CHCF:** Why do you think referrals to palliative care and hospice come so late?

**Pantilat:** I find that there are different reasons in different hospitals, but my experience is that it's often about physicians. Patients are not usually the barrier. Surveys have found that patients really don't know what palliative care is, so if you just ask them, "Do you want palliative care?," they might say "Yes" and they might say "No." So at UCSF we don't ask about palliative care but rather say to people, "We're going to give you an extra layer of support to help you with your pain and symptoms and the stress of being sick," and they say, "That sounds good to me. I want that."

The American Society of Clinical Oncology recommends this approach for patients with advanced cancer. You can assure patients that along with providing them with the best medical treatment directed at their cancer, they can also receive palliative care services that have been found to be really helpful. The goal in some ways is to get doctors away from having to worry about, "Is this the right timing?"

**CHCF:** How well is UCSF doing in terms of length of stay with hospice?

**Pantilat:** It's better than three days. And our palliative team is reaching a lot more patients in the hospital. But our hospice length of stay has shortened, and I don't have a definitive explanation for that. The mortality rate for palliative care patients seen in the hospital has also gone up, so it's possible that as we're growing we're seeing sicker patients. There is more we can do to keep people alive longer but that means that many people are also sicker when they are referred to palliative care. With sicker patients the palliative care is more complex and getting them out of the hospital is much more difficult. We're doing a good job of getting people out of the hospital; it's just that we're getting more patients who are a lot closer to the end of life.

**CHCF:** Is this a change from when you started the palliative care service?

**Pantilat:** In the first few years, we were primarily seeing people who were very close to death. Eighty percent of the people we saw died in the hospital. After a few years that changed—all our growth was with people we were sending out of the hospital. We were seeing people earlier in the course of illness.

Now the work seems to be in a kind of second wave. We are expanding to seeing more patients with a wider variety of conditions, such as liver transplant and leukemia, and a lot of those people are very, very sick. Sometimes by the time we are asked to see these patients they are very late in the course of illness and close to the end.

On one hand, this is good news because we're starting to see patient populations who really do need our services. And it may be that the patients we are asked to see *first* are the ones who are the sickest and therefore hardest to get out of the hospital. That may be just part of the natural evolution of bringing in different groups of specialists to refer to palliative care.

**CHCF:** How are you coping with growth in the service?

**Pantilat:** We're very busy—which isn't unusual for palliative care services. The data from a CHCF-funded survey in California shows that over half of palliative care services say that they are struggling to cope with the amount of work they have. And, over half say they believe that they are seeing fewer than half of the patients who need to be seen.

The good news is that there are lots of people doing really good palliative care in many places. It tends to be like many things—it's all local. LaCrosse, Wisconsin, has a program called Respecting Choices. As a community they took it upon themselves to make advance care planning a priority. And they did. Many people in that community have an advance directive. There are many other places that have adopted a similar approach. So it's possible to change the culture of a hospital, a community, a state, and a nation.

**CHCF:** And in your experience, how can a hospital increase physician interest in palliative care referrals?

**Pantilat:** There are lots of ways that are being tried. At the VA in West Los Angeles, they put reminders in the electronic medical record for doctors, and it really worked. They just asked a simple question, "How likely do you think it is the patient's going to die in the next six months?" The follow-up question was, "Do you want a palliative care consult?" It increased the number of consults they received.

However, what I find nowadays is that once a hospital starts a palliative team, they are incredibly busy. While new services worry that they're not going to get patients, and they're going to just sit there like the Maytag repairman, it's not likely. By the end of the first year, they're bursting at the seams. Then the challenge is whether they can get the additional resources to care for the additional patients who are being referred.

So, while there are pockets of physician resistance, that's changing, particularly among younger physicians. And then, if you do a good job, the word gets out.

**CHCF:** So the opportunities are out there?

**Pantilat:** The palliative care teams are always identifying more opportunities: "Oh, we need palliative care in the outpatient clinic. There are more people in the ICU to see. There are people in the ER to see." Sometimes you see a patient who's been in the hospital for five days, and probably could have avoided being admitted altogether if we'd seen them in the ER and talked to them at that point. We



might have been able to arrange for them to have services at home.

Unfortunately, the palliative care teams don't have the bandwidth. And we don't have enough experts. We don't have enough nurse practitioners; we don't have enough doctor experts in palliative care. So the challenge is that there's often a disconnect between the available resources for palliative care and the amount of need there is.

**CHCF:** How big is your palliative team at UCSF and how do you go about expanding to additional patient populations?

**Pantilat:** Every day of the year there's a doctor on service 24/7. Four days a week we have our social worker; three days a week we have a chaplain. There's also a nurse, a resident, and medical students. In terms of our expansion, we don't do advertising or marketing, although we give lectures and do some outreach with colleagues. We don't market our services very actively, partly because we're afraid of what will happen if it works!

**CHCF:** Where do patients usually go when you get them out of the hospital?

**Pantilat:** Some of them go to hospice, but not all of them do. The patients may not want or be ready for hospice for whatever reason. What these patients really need is to be able to see palliative care doctors and nurses and social workers and chaplains in the clinic, or at home. But it's very hard to find that. In fact, only about 8% of all hospitals in California offer clinic-based palliative care.

Even in a big city like San Francisco, if I have a patient with emphysema who's really having a lot of symptoms and stress and wants to receive palliative care, where can that patient be seen? It's not clear to me at all that there's any place, and that's a shame. At UCSF we are embarking on a project to develop outpatient palliative care services to serve patients like this.

**CHCF:** Many hospitals do not have palliative care despite the need. What do you expect to see going forward?

**Pantilat:** There's a lot happening. The Center to Advance Palliative Care has a State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals.<sup>2</sup> The Let's Get Healthy California task force is focused on metrics to improve end-of-life care. Also, this year OSHPD is including questions on palliative care in their mandatory statewide survey of hospitals. Because of this survey we will now know which local hospitals have a palliative care program, and whether it's interdisciplinary, and whether it's board certified. So in the near future, patients will be able to look up this information for themselves. Put together, this information helps identify which hospitals don't offer palliative care and helps us reach out to them.

**CHCF:** Do you see momentum building among your colleagues outside of UC medical centers?

**Pantilat:** Yes, it's so interesting to talk to people at large systems that are looking ahead toward accountable care organizations under health reform. They recognize that if you want to provide high quality care to really sick people and help them stay out of the hospital, and enable them to be at home at the end of their lives, you need palliative care services. You need them in the home, in the outpatient setting, and in the hospital. And many systems are busy building their palliative care departments in order to address those concerns. That's the future of health care.

**CHCF:** Do you think that's going to offer a more consistent experience for patients regardless of their insurance or where they live?

**Pantilat:** I think the big systems' interest in access to palliative care is part of the solution to widespread consistency. Organizations like Kaiser and the VA are thinking about taking the best possible care of populations of 100,000 or 200,000 or 500,000 people, and doing it in a way that's financially responsible.



**CHCF:** Will their ideas become the new benchmark?

**Pantilat:** I think so. Typically in health care there is dissemination of good ideas because people share what they're doing. For example, at UCSF we have trained teams from over 200 hospitals to develop palliative care services. And what you find is that each team is a little bit different. Their staffing is different, their model is different, their populations are different, their community resources are a little different. So, even though the issues are global, the solutions are local.

But there's a lot we can learn from each other. We have a Palliative Care Quality Network, which right now includes 20 hospitals that share information about the best way to take care of people in a hospital palliative care program. In addition there are many national forums where we share information about our program.

**CHCF:** Will spreading the word about palliative care programs impact the health care market?

**Pantilat:** Well, hopefully one day people will select their health insurance and their providers with this kind of service in mind. This is what many pregnant women do today by asking providers: "What does the birthing suite look like? Who is on call? What's your C-section rate?" Those are legitimate questions when you anticipate having a baby.

So I can imagine a world in which the same thing is true with palliative care services. People will ask: "How many patients die in the ICU? I don't want that. How many people end up using hospice? How many hospices do you work with? Do you have a palliative care team? Who's on the team? Can I get palliative care in the clinic as well?" I don't think anybody chooses that way right now, but I can imagine it.

When the general public comes to understand that palliative care helps people to live better and longer, patients and families will say: "We need that. We need you to provide this service." In rural hospitals, for example, the community has a lot of input and members of the hospital board live right up the street. A lot of those hospitals don't have palliative care programs now, but pressure could build up from the community.

**CHCF:** We know that small hospitals—many of which are in rural areas—are less likely to offer palliative care. Why is that?

**Pantilat:** There are a number of reasons, but partly it has to do with scale. Scaling up palliative care is not that hard. If you're going to see 500 patients, you get one doctor, one nurse, one social worker, one chaplain. If you're going to see 1,000, you get two of each. If you're going to see 1,500, you get three. But scaling down is not as easy. If you have a 50-bed hospital where 100 patients a year might need palliative care, how are you going to make your service available when it's needed?

You can't say, "We'll be here on Tuesdays and Thursdays." What if a patient on Friday needs palliative care? That system doesn't work. So, maybe what you need would be two hours a day of a nurse, and an hour a day of a doctor. But that should be available every day, and it's not that easy. Often it's a doctor or nurse who's got something else already going on, and this is just added on to their job. So, it's logistically a little harder. But that's not a reason that it can't happen; it's just a reason why it takes a little bit more time.

**CHCF:** The other group of hospitals that don't typically offer palliative care services is for-profit hospitals. Why do you suppose that is?

**Pantilat:** I've been trying to figure this out for a long time. What I've been told is that the quarterly earnings reports show the costs right away, but the benefits take a while to accrue. So it may look like a new program is operating at a loss. That may be true, but you have to keep in mind that palliative care services tend to pay for themselves within the first year. I would have thought that the for-profit hospitals would be the first to adopt it. I've also heard that they are having a hard time finding qualified doctors, nurses, social workers, and chaplains. That is certainly a challenge, but one that is surmountable.

**CHCF:** A recent *JAMA* article questions whether increasing hospice access actually leads to lower resource use or higher.<sup>3</sup>

**Pantilat:** Yes, but if we keep our focus just on cost, we're missing the essential question, which is really about value—how do we produce the best quality for cost? If we could improve quality a lot and the cost goes up a little, that's actually not a problem because we get a lot more value. Palliative care is a place where patient choices result in what people really want—which is care that is focused on quality of life. Very often that care is, in fact, less invasive, and therefore less costly.

An article in *Health Affairs* by my colleague Alex Smith supports this argument. He found that over half of Medicare patients who died (55%) had an ER admission in the last six months of life. Of those people, almost 70% were admitted to the hospital. And those admitted had more than a 70% chance of dying in a hospital. By contrast, those who had hospice services for more than a month had only a 15% chance of going to the ER in the last six months.<sup>4</sup> My guess is that a month of hospice care costs less than a single ED visit.

There are also supply data showing that whether you die in a hospital or not has to do with how many hospital beds there are in your community. Available beds tend to get filled, including when patients are dying.

**CHCF:** To sum up, what would you say is the most important thing to be learned from the data on end-of-life care in California?

**Pantilat:** There is great variation from place to place and time to time, and that tells a lot of little stories. But there is one big story in the data: People still die in hospitals, which is not where they want to be, and they die in ICUs, which is *really* not where they want to be.<sup>5</sup>

The geographic details will not be very compelling to the public. People aren't going to move to Humboldt because the numbers there are better on a particular measure that they care about. But, exposing variation publicly may help drive hospitals in a region to try and improve their numbers and provide the palliative care services that matter to their patients.

Ultimately, the fact that there *is* variation may be as important as *where* it is. The truth is that we should be seeing that 100% of hospitals have a palliative care program.

1. Teno, Joan M., et al. "Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009." *JAMA*, February 6, 2013, vol 309, No. 5, pps 470-477.
2. Center to Advance Palliative Care. State Report Card on Access to Palliative Care in Our Nation's Hospitals, 2012. [www.capc.org/reportcard/home/CA/RC/California](http://www.capc.org/reportcard/home/CA/RC/California)
3. See note 1.
4. Smith, Alexander K., et al. "Half of Older Americans Seen in Emergency Department in Last Month of Life; Most Admitted to Hospital, and Many Die There." *Health Affairs*, June 2012, vol. 31 No. 6, pps 1277-1285.
5. Dartmouth Atlas Project. "End-of-Life Care in California: You Don't Always Get What You Want." [www.chcf.org/publications/2013/04/eol-what-you-want](http://www.chcf.org/publications/2013/04/eol-what-you-want)



**CALIFORNIA  
HEALTHCARE  
FOUNDATION**