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Column: After my mother's disastrous hospice experience, we filed a state complaint. It came to nothing

By Steve Lopez
Columnist | Follow

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My mother did not die well.

She was discharged in January from a Bay Area hospital and transported to a residential care home in distress, writhing in agony at times.

Her pain and sedation medication did not arrive with her, as the hospice agency had told us it would, nor did the hospice nurse assigned to her case. We were told the nurse was tied up at a different location with another patient. After our repeated pleas, a backup nurse arrived several hours later with medication.

My mother improved slightly but still suffered through the next two days. We fired the hospice agency, signed on with another, and finally my mother rested peacefully and mostly pain-free until her death several days later, in mid-January.

Incensed by her poor treatment, I filed a complaint against the hospice agency with the Licensing and Certification Program of the California Department of Public Health. I've now received a letter detailing the agency's findings.

"L&C was not able to validate the complaint allegation through direct observation, interviews, and/or review of documents."

This was not a surprise. I had spoken to the investigator several times. She told me she believed the accounts given to her by my sister and me, but the hospice agency presented a different story. It argued that we were told to get the medication ourselves (not true), and that my mother was fine after the nurse finally arrived several hours late (demonstrably not true).

The hospice agency also argued that we should have known from the contract we signed that the first visit by a hospice staffer could take up to 48 hours. OK, the contract did say that, but we were verbally promised that someone would be there upon her arrival at the care facility.

When my mother was still suffering, a supervisor apologized and told me her hospice agency had failed us. She said that Friday discharges from a hospital are often a problem because limited staff is available. Then either hire more staff, I said in response, or don't discharge on Fridays.

The state said it would also investigate into the hospital's handling of my mother's discharge, but I've heard nothing on that one yet.

My purpose in writing about this is not to air a personal grievance, so I'm not naming the hospice agency involved. My objective is to use what I've learned to inform the public as to what's right and wrong with a fast-growing industry that has evolved from a small nonprofit movement to a corporatized, for-profit behemoth.

We are aging rapidly in this nation; about 1.5 million people enter hospice care each year, and it is generally a great end-of-life service. Most of the nurses and medical assistants I met during the hospice care of my father and mother were admirably caring, professional, and devoted.

And yet the regulation and oversight of hospice care are sorely lacking, and too little information is available to family members on how to make a smart choice for the best

care.

Unsurprisingly, there's a price to pay.

In a study of the nation's hospices between 2012 and 2016, "over 80% had at least one deficiency; 20% had a serious deficiency," according to the federal Health and Human Services' Office of Inspector General, which published its findings last month. The problems included poor care planning, mismanagement of services and inadequate assessment of patients.

A serious deficiency "means that the hospice's capacity to furnish adequate care was substantially limited, or the health and safety of [patients] was severely limited," the authors explained.

In a separate report from the same federal agency, a dozen examples of harm to patients were presented in gruesome detail. In one case, the hospice didn't treat ulcers on a patient's heels, and an amputation was required after gangrene set in.

For another patient, "the hospice allowed maggots to develop around a beneficiary's feeding tube." In another case, which sounds all too familiar, "a hospice mismanaged a grievance a family filed over poor pain control."

Another key finding: For-profit hospice agencies were more likely to have deficiencies than nonprofit agencies. No surprise there. Keeping staffs as thin as possible can maximize profits. In my mother's case, the agency that admitted to failing her was for-profit. The one that did a better job was nonprofit.

And yet for all of this, consumers are pretty much left in the dark, and the federal government has limited tools for disciplining substandard hospice agencies — whether they're for-profit or nonprofit — and no authority to fine them.

"Hospice oversight is fairly minimal," said David Stevenson, director of health policy education at Vanderbilt University's School of Public Health Policy. Stevenson said the federal Centers for Medicare and Medicaid Services "does not have any immediate sanctions at its disposal — like fines … or installing temporary management."

Hospice agencies have been sued for Medicare billing fraud. They ought to be slapped with financial penalties not just for cheating but for failing their patients.

Stevenson said I'm not alone in making a complaint that was not substantiated by investigators. In his review, he found that only about one-third of complaints are substantiated. And even when they are, it's not easy for consumers to get access to that information.

That's a point that Charlene Harrington, a UC San Francisco professor and former state public health official, finds appalling. She says you can get limited information at the federal government's Hospice Compare website, and if you're relentless and diligent, you can find a bit more on California websites.

But no comprehensive consumer resource is available.

Harrington filled that void for years by gathering all available information on a site called calqualitycare.org, but her funding from a healthcare nonprofit dried up. She rang me last week to say the state had kicked aside her bid for money to get the site firing at full force again. She said she was told to sit tight for 18 months, while the state considers a master plan for aging.

It shouldn't take 18 days, let alone months, for California to figure out how to better serve patients and their families. Hospice agencies have to be reviewed and recertified every several years, but in California about 80% of the roughly 1,000 hospice agencies pay private companies to do that certification, and the results are not made public.

The fox is guarding the henhouse at a time when there are billions of dollars to be made in Medicare reimbursements, said Michael Connors of California Advocates for Nursing Home Reform.

“What should legislators be asked to do? Take hospices off the honor system,” Connors said. “California should strengthen hospice standards, inspect hospices at least annually, make it easy to file complaints and investigate them promptly, hold hospices accountable when they mistreat patients and provide consumer-friendly information online that makes it easy for the public to distinguish good hospices from bad ones.”

The CMS Inspector General report made similar recommendations at the federal level. In California, Connors is calling on Gov. Gavin Newsom to take the high road and turn the Department of Public Health into more of a consumer protection industry, and less of a tool for care providers.

The late Grace Lopez, rest her soul, would greatly appreciate that.

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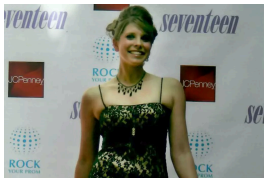

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Steve Lopez is a California native who has been a Los Angeles Times columnist since 2001. He has won more than a dozen national journalism awards and is a four-time Pulitzer finalist. Lopez is the author most recently of “Independence Day: What I Learned About Retirement, From Some Who’ve Done It and Some Who Never Will.” His book “The Soloist,” inspired by his columns on his relationship with a Juilliard-trained homeless person, was a Los Angeles Times and New York Times best-seller, winner of the PEN USA Literary Award for Non-Fiction, and the subject of a Dream Works movie by the same name. He has also written three novels and two column collections.