

Need for Control Drives Assisted Suicide Requests

Patients who went through with assisted suicide wanted to be self-reliant until the end, studies show.

BY JANE SALODOF MACNEIL
Southwest Bureau

SANTA ANA PUEBLO, N.M. — The key factor motivating the terminally ill to seek assisted suicide under Oregon's Death with Dignity Act—a sense of control—should prompt a rethinking of end-of-life care, Dr. Linda Ganzini said at the annual meeting of the Academy of Psychosomatic Medicine.

Studies of terminally ill patients in Oregon showed that “some people want to leave this world in the driver's seat. That's their major goal,” said Dr. Ganzini, director of the geriatric psychiatry fellowship program at Oregon Health and Science University, Portland. “And we need to let this goal start driving how they should be cared for—whether they get assisted suicide or not.”

The findings gained new currency last month, when the U.S. Supreme Court ruled that the Bush administration improperly tried to use a federal drug law to stop physicians from prescribing lethal drugs to terminally ill patients under the Oregon law.

The studies, which also included physicians, nurses, hospice chaplains, and family members, showed that few of the factors anticipated in the political debate over the law were significant to the terminally ill in determining who chose assisted suicide. Most patients who requested lethal prescriptions were no more depressed, poor, poorly educated, from minority groups, or in worse physical condition than were those who opted not to make such a request.

“These were individuals who wanted to control their lives,” Dr. Ganzini said. Rel-

atively few people go through with assisted suicide, but those who do are determined to remain self-reliant until the end.

Often, those who requested assisted suicide had highly successful careers and worked as school superintendents, teachers, lawyers, and dentists, Dr. Ganzini said. Overcoming adversity early in life was another common experience for many who requested assisted suicide.

“Many had parents who were neglectful or incompetent,” she said. “They learned to be very self-sufficient and to prize their independence.”

Oregon's voters passed its Death with Dignity Act by a slim majority in 1994, making Oregon the first and only state to approve assisted suicide. The act was delayed by a legal injunction until 1997, when 60% of voters refused to repeal it.

Since 1997, Oregon has had 208 deaths by assisted suicide, said Dr. Ganzini, also a senior scholar at the university's center for ethics in health care. “For every 1,000 patients in Oregon who die, 100 will seriously consider assisted suicide, 10 will make an explicit request, and 1 will die by it,” she said.

Amyotrophic lateral sclerosis (ALS) is the disease tied to the highest number of assisted suicide requests, Dr. Ganzini said. Compared with other patients, ALS patients in Oregon have an odds ratio above 20 for dying by assisted suicide.

A study she and her associates conducted with 100 ALS patients showed that a sense of hopelessness was an important predictor of interest in obtaining a lethal prescription.

Dr. Ganzini is now studying patients who are in the process of making legal requests. “They are really focused on what

is coming down the road, how intolerable it will be, and how it will make their lives not worth living when it happens,” she said. She noted that no patient complained of physical symptoms worse than 2 on a scale of 1-5 when they made their requests, but that they feared worsening symptoms as the disease progressed.

In another study with cancer patients, growing dissatisfaction with medical care was a leading predictor of interest in assisted suicide, and perhaps the interest reflected hopelessness, she added.

Depression was expected to be the biggest risk factor for assisted suicide requests, Dr. Ganzini said. In addition to the patient having to provide two oral requests and one written request, Oregon's law requires that patients be screened by a psychiatrist or psychologist if depression is suspected.

Yet physicians surveyed by Dr. Ganzini ranked the prevalence of depression at about 20% of patients making a request (N. Engl. J. Med. 2000;342:557-63). Hospice social workers and nurses also put depression among the least important reasons for requests (N. Engl. J. Med. 2002; 347:582-8).

In her current study, she reported that only 6 of 46 patients requesting assisted suicide met criteria for a major depressive disorder in structured clinical interviews. Even patients who felt hopeless were not depressed.

“I remain very perplexed. I still don't know why there are not more depressed people making a request,” Dr. Ganzini said. But she has a few theories that might explain why investigators don't find more

depression. “I have no empirical data to support it, but people who go through this process have to be very physically fit, determined, convincing, and articulate. I think depressed people, particularly if they are physically ill people, may get left behind in this process.”

Another concern that arose before the passage of the Death with Dignity Act was that the act might undermine efforts to improve hospice or palliative care. Instead, 86% of assisted suicides occurred in hospice patients, Dr. Ganzini said.

Opposition to the law remains fairly strong. About 42% of hospice chaplains and a third of hospice nurses oppose the law, she said. Yet few said they would actively oppose it with a patient, and no chaplain would seek transfer of a patient who requested assisted suicide.

“Even though they oppose suicide, their moral feelings about abandoning the patient are stronger,” she said, adding that the chaplains said providing nonjudgmental support was the most effective way to help change a person's mind.

The Oregon experience highlights “a very rarified group” of people whose needs are not generalizable but should not be ignored, Dr. Ganzini concluded. As an example, she cited Annie, who stopped hospice services after 13 days, saying, “They [the staff] are really nice, but I just hate it when other people tell me what to do.”

The one-size-fits-all hospice care model actually does not fit everyone, Dr. Ganzini said. “I think hospice and palliative care have to change to individualize the treatment they offer.” ■



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Physician-Rating Game Fraught With Difficulty

BY JOYCE FRIEDEN
Associate Editor, Practice Trends

WASHINGTON — The lists of “best doctors” published in magazines may not be all they're cracked up to be, several speakers said at a health care competition conference sponsored by Health Affairs journal and the Center for Studying Health System Change.

“Outcomes are much more difficult to measure in health care” than in other industries like auto repair or roofing, said Robert Krughoff, president and founder of the Center for the Study of Services, which publishes the service-rating magazine “Consumers' Checkbook” in several cities nationwide. “Consumers know right away if [the plumber is good]. With a health care provider, they may not know until 5 or 10 years out.”

Further, an outcome cannot always be attributed to the intervention of the health care provider, he said. And because of health insurance, consumers often are insulated from the true costs of care, so it's

hard to talk about who provides the best value for the money.

Taking a regional approach to physician rating could have value, Mr. Krughoff suggested. “Patients would report their experience with physicians—they would tell how well the physician listens, how well he or she coordinates care, and whether they are good at working with patients to devise acceptable prevention behaviors,” he said.

The cost of doing such a survey would be a concern, but Mr. Krughoff said he thought it could be done for less than \$200 per physician and it wouldn't have to be done annually, although a physician should be able to pay for a re-survey if he or she made improvements to the practice.

Tom Scully, former administrator of the Centers for Medicare and Medicaid Services, agreed that information is key to getting patients involved as consumers.

“The health care system is pitiful when it comes to public information,” said Mr. Scully, now senior counsel at Alston & Bird LLP, a Washington law firm. “As much as

people avoid it and fight it, it works to change behavior. I've never run across any instance where providers, as much as they didn't like it when they were forced to share information, didn't come back a year or two later and say, ‘You know what? It's worked out pretty well, it's changed my behavior, and it wasn't that hard after all.’”

Although health care in this country will never be a pure market economy, “in some sense supply and demand will help, and there is no way to have supply and demand if you don't send consumers information and give them some understanding of what they're buying and what the relative price and quality is,” Mr. Scully said. The problem is getting providers to provide the information, and the best way to do that is with monetary incentives.

For example, when CMS wanted hospitals to voluntarily report on 10 quality measures, “we put through a little teeny thing [into the Medicare budget legislation] that said, ‘It's totally voluntary; you don't have to give us the 10 measures, but if you don't, we'll volunteer to pay four-

tenths of a percent less of the market-basket rate” for hospital costs, he said. “We went from zero compliance to 99% compliance in a year. I personally believe as a Republican that you shouldn't mandate anything—just voluntarily pay people less if they don't behave right.”

That may work for health care providers, but the health care industry alone can't make patients better consumers, said Bernard Tyson, senior vice president for brand strategy and management for Kaiser Foundation Health Plan. “There isn't a health care system in place today that can support that kind of consumer interaction and behavior,” he said. “It will take forces outside the industry itself to enforce that change. Two outside forces that can really help move this are government and employers.”

One thing that must be done is to “demystify” the health care industry, Mr. Tyson continued. “The average consumer does not know how to measure [health care] and really doesn't know how to define [its] value.” ■