Oregon Data: Sense of Control Key at End of Life

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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 cited in the political debate over the law were significant in determining who chose assisted suicide. Patients who requested lethal prescriptions were no more likely to be depressed, poor, poorly educated, from minority groups, or in worse physical condition than patients who opted not to make such a request.

"These were individuals who wanted to control their lives," Dr. Ganzini said. Relatively few people go through with assisted suicide, but those who do are determined to remain self-reliant until the end.

Many who requested assisted suicide had highly successful professional careers. Overcoming adversity early in life was another common experience.

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."

Compared with other patients, those with amyotrophic lateral sclerosis (ALS) in Oregon have an odds ratio above 20 for dying by assisted suicide. A sense of hopelessness was an important predictor of interest in obtaining a lethal prescription, Dr. Ganzini and her associates found in a study of 100 ALS patients.

Dr. Ganzini is now studying patients 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," she said. Patients feared worsening of symptoms, but at the time of their requests, none complained of physical symptoms worse than 2 on a scale of 1-5.

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.

In her current study, 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: "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 was that the Death with Dignity 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.

The Oregon experience highlights "a very rarefied group" of people whose needs are not generalizable but should not be ignored, Dr. Ganzini concluded. ■