



The Forum

January/February/March 2005

Death with Dignity: The Oregon Experience

By Susan Hedlund, LCSW

In recent years, the state of Oregon made national news by passing a referendum legalizing physician-assisted suicide under certain circumstances for terminally ill people. The referendum was blocked by a court injunction and referred back to the voters who again passed the measure by an even greater margin. The law has been in effect for six years, and a May 2004 decision in the Ninth US Circuit Court allows the law to remain a legal end of life option in Oregon. The data gathered thus far have revealed interesting variables about who chooses this option, and some of the early fears and assumptions regarding it have not been borne out in practice. This controversial issue, however, has had a much broader impact on end of life care in Oregon than the measure itself addressed.

Oregon History and Culture

In order to understand the Oregon experience at the end of life, one must understand a bit about the cultural and historical context of the state itself. Oregon has a long tradition of “rugged individualism,” as depicted in Ken Kesey’s (1997) novel *Sometimes a Great Notion* about Oregon logging families. Oregonians pride themselves on the natural beauty of the northwest—boasting glacier covered mountains, rainforests, deserts, and beaches with rugged, breathtaking shorelines. The urban areas are also unique, enjoying a quality of life that concerns itself with environmentalism, progressive thinking, and citizen involvement in community affairs. Conversely, Oregon’s version of the rural poor exists with families, many of whom have lived here for generations, making their livings in the massive timber and paper mill industries.

However, economic and environmental changes in recent years have resulted in many workers being displaced. Historically, people of color and diverse cultures have been underrepresented in Oregon, with the predominant culture being white (84.8%) (Dodd & Muckleston, 2004). Recent changes in national demographics are also evident in Oregon, with increases in Southeast Asian, Eastern European, and Hispanic/Latino people relocating to Oregon. Of note, Oregon is the “least churchd” state in the nation, with Oregonians referring to themselves as “deeply spiritual” but preferring to find their faith in nature.

History of the Death with Dignity Act

The Oregon Death with Dignity Act (DWDA) was a citizens' initiative first passed by Oregon voters in November 1994 by a 51% to 49% margin. Implementation was delayed by a legal injunction but, after proceedings that included a petition denied by the United States Supreme Court, the Ninth Circuit Court of Appeals lifted the injunction in 1997. In November 1997, a measure asking Oregon voters to repeal the Death with Dignity Act was placed on the general election ballot (Measure 51). Voters rejected this measure by a margin of 60% to 40%, retaining the Death with Dignity Act. After voters reaffirmed the DWDA in 1997, Oregon became the only state allowing physician-assisted suicide.

Although physician-assisted suicide has been legal in Oregon for six years, it remains highly controversial. In November 2001, US Attorney General John Ashcroft issued a new interpretation of the Controlled Substances Act that would prohibit doctors from prescribing controlled substances for use in physician-assisted suicide.

To date, all the medications prescribed under the Act have been barbiturates, which are controlled substances and therefore prohibited by this ruling for use in physician-assisted suicide. In May 2004, in *Ashcroft v. Oregon*, the US Court of Appeals decided that the Controlled Substances Act did not apply to Oregon's Death with Dignity Act. At this time, Oregon's law remains in effect. The enormous ebb and flow of legal issues over the last eight years has resulted in much media coverage, which also has functioned to educate and inform the broader citizenship about a host of issues and resources for care at the end of life, well beyond that of physician-assisted suicide.

Requirements of the DWDA

The Death with Dignity Act allows terminally ill Oregon residents to obtain and use prescriptions from their physicians for self-administered, lethal medications. Under the Act, ending one's life in accordance with the law does not constitute suicide. However, the term "physician-assisted suicide" is used because in the medical literature it is used to describe ending life through the voluntary self-administration of lethal medications prescribed by a physician for that purpose. The DWDA legalizes physician-assisted suicide,

but specifically *prohibits* euthanasia, where a physician or other person directly administers a medication to end another's life.

To request a legal prescription for lethal medications, the Oregon Death with Dignity Act (1998) requires that a patient must be:

- An adult (18 years of age or older);
- A resident of Oregon;
- Capable (defined as able to make and communicate health care decisions);
- Diagnosed with a terminal illness that will lead to death within six months, confirmed by two physicians.
- Patients meeting these requirements are eligible to request a prescription for lethal medication from a licensed Oregon physician.

To receive a prescription for lethal medication, the following steps must be fulfilled:

- The patient must make two oral requests to his or her physician, separated by at least 15 days;
- The patient must provide a written request to his or her physician, signed in the presence of two witnesses;
- The prescribing physician and a consulting physician must confirm the diagnosis and prognosis;
- If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological examination;
- The prescribing physician must inform the patient of feasible alternatives to assisted suicide including comfort care, hospice care, and pain control;
- The prescribing physician must request, but may not require, the patient to notify his or her next of kin of the prescription request.

Six Years of Data

The Oregon Death with Dignity Act has been in effect for six years. The following data indicate the number of people who requested, and followed through, in taking the prescription to hasten death.

- 1998 – 16 used
- 1999 – 27 used
- 2000 – 27 used
- 2001 – 21 used
- 2002 – 38 used
- 2003 – 42 used

Six-year total: 171

Although the number of Oregonians ingesting legally prescribed lethal medications has increased, the overall numbers of terminally ill patients ingesting lethal medications have remained small, with about one-seventh of one percent of Oregonians dying by physician-assisted suicide. The top two reasons that have consistently been stated by patients as justifying their requests for physician-assisted suicide are loss of autonomy and the desire to control the circumstances of dying.

Physician-assisted suicide is not disproportionately chosen by the poor, minorities, less educated, or the uninsured. Also, access to hospice or fear of pain are not associated factors. Rather, data indicate that, of those availing themselves of physician-assisted suicide, 90% were enrolled in hospice and 10% declined hospice. It is evident that the decision to pursue physician-assisted suicide is a complex decision influenced by autonomy, control of bodily functions, and desire to control the timing and manner of death (Oregon Department of Human Services, 2003).

Other Outcomes

There is no question that the Oregon initiative remains highly controversial and has challenged both citizens and health care providers alike to examine ethical, medical, and

legal challenges at professional and personal levels. Susan Tolle, MD, Director of the Center for Ethics at Oregon Health & Sciences University, is often quoted as referring to the Oregon vote as a “wake up call” for the medical community regarding care at the end of life. Oregon’s hospice penetration rate is among the top five states. Oregon’s cost of end of life care is the lowest in the nation, with high levels of patient/family satisfaction.

Studies indicate that most Americans (90%) prefer to die at home. However, greater than 50% die in hospitals. In 2001, only 22% of Oregonians died in hospitals, and Oregon continues to have the lowest in-hospital death rate in the nation. Oregon has one of the highest rates of Advanced Care planning. In 1997, 68% of those who died had Advance Directives and 97% of families felt their wishes were respected. Oregon’s morphine consumption, used as a crude predictor of physicians’ willingness to prescribe, has remained consistently high over recent years.

Conclusion

What happened in Oregon? Recently it was the legalization of physician-assisted suicide driven by the determination and strong will of Oregonians and their desire to have additional choices about dying. While physician-assisted suicide has been the most publicized and controversial issue, what has clearly resulted from the enormous visibility and debate is the sweeping change in how Oregonians are cared for at the end of life. These changes may exist in part *because* of, or in spite of, the legalization of the Death with Dignity Act. Professional and public awareness appears to be at an all time high, and progressive efforts will no doubt continue.

References

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About the Author

Susan Hedlund, LCSW, is Director of Counseling, Cancer CareResources and Instructor–School of Medicine–Oregon Health & Sciences University in Portland. She can be reached via e-mail: hedlund@cancerresources.org.