Oregon's Death with Dignity Act: 1998—2007

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Introduction

Oregon is the only state in the United States where physician-assisted suicide is legal. The Death with Dignity Act (DWDA) allows terminally-ill Oregon residents to obtain and use a prescription from their physician for a self-administered, lethal dose of medications. Under the Act, ending one's life in accordance with the law does not constitute suicide. The Death with Dignity Act specifically prohibits euthanasia, where a physician or other person directly administers a medication to end another's life. The DWDA was a citizen's initiative, put on the ballot in response to a petition from the public, and was first passed by Oregon voters in November 1994 with 51% in favor. Implementation was delayed by a legal injunction for 3 years. In November 1997, a measure asking Oregon voters to repeal the Death with Dignity Act was placed on the general election ballot. Voters rejected this measure by a margin of 60% to 40%, retaining the Death with Dignity Act.

During the decade that the Death with Dignity Act has been in effect in Oregon, there have been additional legal challenges to the law. On November 6, 2001, US Attorney General John Ashcroft issued a new interpretation of the Controlled Substances Act, which would have prohibited doctors from prescribing medications such as barbiturates for use in DWDA. In response to the lawsuit filed by the State of Oregon, the US Supreme Court affirmed decisions made by lower courts upholding Oregon's law. At this time, the Oregon Death with Dignity Act remains in effect.

The first DWDA death occurred in 1998. From 1998-2007, 341 terminally ill Oregonians died by ingesting legally prescribed lethal doses of medication under the DWDA. This paper describes the characteristics of those participating in the DWDA.

Requirements

To request a prescription for lethal medications, the Death with Dignity Act requires that a patient must be: an adult (18 years of age or older); a resident of Oregon; capable of making and communicating health care decisions; and diagnosed with a terminal illness that will lead to death within six months.

Patients meeting these requirements are eligible to request a prescription for lethal medication from a licensed Oregon physician. To receive a prescription for 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; and the prescribing physician and a consulting physician must determine whether the patient is capable. 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, including comfort care, hospice care, and pain control. Physicians and patients who adhere to the requirements of the Act are protected from criminal prosecution. Physicians, pharmacists, and other health care providers are under no obligation to participate in the DWDA.

The Reporting System

The Oregon Department of Human Services (DHS) is required by the DWDA to develop and maintain a reporting system for monitoring and collecting information on DWDA. To fulfill this mandate, DHS uses a system involving physician and pharmacist compliance reports, death certificate reviews, and follow-up questionnaires.

When a prescription for medication is written under the DWDA, the physician must submit to DHS information that documents compliance with the law. Reporting is not required if patients begin the request process but never receive a prescription. These reports are then linked to death certificates, which allow us to confirm patients' deaths, and provide patient demographic data (e.g., age, place of residence, level of education). In addition, using our authority to conduct special studies of morbidity and mortality, DHS collects information from prescribing physicians after the patient dies. Each physician is asked to confirm whether the patient took the medications. If the patient had taken the medications, we ask physicians for additional information, including hospice enrollment, patients' motivating factors for the request, and the DWDA process, including time to unconsciousness and death, and any adverse reactions. Because physicians are not legally required to be present when a patient

ingests the medication, not all have information about what happened when the patient ingested the medication. When available, we include information from other health care providers or volunteers who may have been present at the death. We do not interview or collect any information from patients prior to their death.

Patient Characteristics

During 1998-2007, 341 terminally-ill Oregonians died by ingesting legally prescribed lethal doses of medication. The 341 patients who used the DWDA represent an estimated rate of 11.3 per 10,000 deaths (range 6-15 annually). The number and rate of DWDA deaths has increased during the decade that the law has been in effect (figure).

Although year-to-year variations occurred, certain demographic patterns have become evident over the past 10 years (Table 1). Males are slightly more likely than females to use the DWDA. Most deaths (57 percent) were among residents 65-84 years of age, but DWDA rates were highest among younger patients and lowest among the elderly, ranging from 63 per 10,000 population in 18-34 year-olds to 15 in patients 85 or older. Nearly all patients were white. By marital status, divorced/never married Oregonians were 1.8 times more likely than married/widowed residents to participate. An increasing level of educational attainment was associated with an increasing likelihood of using DWDA; those with an advanced degree were 9.5 times more likely to do so than those lacking a high school education.

Patients with cancer accounted for 82 percent of the cases, with amyotrophic lateral sclerosis and chronic lower respiratory disease accounting for 8 percent and 4 percent, respectively (Table 1). The DWDA participation rate for patients with ALS was 67 times higher than that for patients with heart disease. Rate ratios were also elevated for persons with HIV/AIDS.

Physicians were asked if, based on discussions with patients, any of seven end-of-life concerns might have contributed to the patients' requests for lethal medication. In nearly all cases, physicians reported multiple concerns contributing to the request. The most frequently reported concerns included losing autonomy (89%), a decreasing

ability to participate in activities that make life enjoyable (97%), and loss of dignity (82%). More than 27% of patients expressed concern about current or future pain control.

The majority of DWDA patients (86%) were enrolled in hospice at the time of death and most patients died at home (94%). During 1998-2007, secobarbital was prescribed for 51% of patients, and pentobarbital for 47%. Physicians reported that 19 patients experienced complications, primarily emesis. One of the patients regained consciousness after ingesting the medications, and died later of their underlying disease.

Comment

During the decade since legalization, the number of prescriptions written for DWDA and the number of terminally ill patients taking lethal medication has increased. The number has remained small compared to the total number of deaths in Oregon, with about 1/7 of one percent of Oregonians dying by the DWDA. Overall, smaller numbers of patients appear to use the DWDA in Oregon compared to the Netherlands.

Physicians have consistently reported that concerns about loss of autonomy, decreased ability to participate in activities that make life enjoyable, and loss of dignity are important motivating factors in patient requests for lethal medication across all six years. These findings are consistent with those of previous studies based on family member interviews that examine Oregon patients' motivations for using the DWDA, which include wanting control over the circumstances surrounding death, and concerns about loss of dignity and independence. Reported concerns about inadequate (current or future) pain control are troubling. The Act specifically requires the prescribing physician to review alternatives to DWDA, including comfort care, hospice care, and pain control. During the 10-year study period, enrollment in hospice among patients remained consistently high, with an average of 86% of patients receiving hospice care at the time of death.

The availability of the DWDA may have led to efforts to improve end-of-life care through other modalities. While it may be common for patients with a terminal illness to

consider the DWDA, a request for the DWDA can be an opportunity for a medical provider to explore with patients their fears and wishes around end-of-life care, and to make patients aware of other options. Often once the provider has addressed a patient's concerns, he or she may choose not to pursue the DWDA. The availability of the DWDA as an option in Oregon also may have spurred Oregon doctors to address other end-of life care options more effectively. In one study, Oregon physicians reported that, since the passage of the Death with Dignity Act in 1994, they had made efforts to improve their knowledge of the use of pain medications in the terminally ill, to improve their recognition of psychiatric disorders such as depression, and to refer patients more frequently to hospice.

REFERENCES

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