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Oregon's experience with aid in dying: findings from the death with dignity laboratory

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With passage of the Death with Dignity Act in 1994, Oregon became the first jurisdiction to authorize and regulate aid in dying. Data from that experience are comprehensive and bountiful, and answer a multitude of questions and concerns about whether the benefits of recognizing the medical practice of aid in dying justify the risks. An exhaustive description of findings from Oregon's aid-in-dying experience is beyond the scope of this or any single article on the subject. This article provides a summary of data highlights, gleaned from scientific investigations and governmental reporting. It organizes high-lighted reports along subjects so that readers may see what various sources have to teach on a number of questions important to policy makers.

Introduction

With passage of the Death with Dignity Act (DWDA) in 1994, Oregon became the first jurisdiction to authorize and regulate aid in dying. Data from that experience are abundant. The data answer a multitude of questions and concerns about whether the benefits of recognizing the medical practice of aid in dying justify the risks. A Medline search of English-language medical journals for keywords, "death with dignity" plus "Oregon" yields 255 articles, and exhaustive description of the findings from Oregon's aid-in-dying experience is beyond the scope of this or any single article on the subject. This article provides a summary of data highlights, gleaned from the most prominent scientific investigations and governmental reporting. It organizes the most comprehensive reports along subjects so readers may see the results of investigations about a number of questions important to policy makers.

History

In November 1994, Oregon voters approved a law recognizing the medical practice known as aid in dying. The new law authorized a request for life-ending medication when arising from a mentally competent, terminally ill adult seeking to avoid unnecessary suffering and achieve the means to end life "in a humane and dignified manner."[1] It established a civil, criminal, and disciplinary safe harbor for physicians and others who followed its eligibility criteria and procedural protocol.

Eligibility is restricted to Oregon residents with a prognosis of 6 months or less. Procedural requirements include attestations by two physicians that the patient is physically eligible and that his/her judgment is not impaired by depression or other psychopathology. The physicians must each counsel the patient on hospice and palliative interventions, attest to the absence of coercion or undue influence, and repeatedly tell the patient that any request is reversible. The patient makes three requests; two verbal requests separated by 15 days, and one

Ann. N.Y. Acad. Sci. July 2014 1–7 C 2014 New York Academy of Sciences.

written request before a witness that precedes the writing of a prescription by at least 48 hours. Both physicians and the dispensing pharmacist submit reports to the Oregon Public Health Division. State epidemiologists interview physicians when a patient who has received a prescription dies. Immunities apply to good-faith compliance with the law.

A legal challenge delayed implementation of the law, and the Oregon legislature placed its repeal on the 1997 ballot. The legal challenge failed for lack of standing to sue, and voters rejected the repeal by a supermajority. In November 1997, the Oregon DWDA went into effect. Legal challenges continued, but the law was never again enjoined. Eligible Oregonians have had uninterrupted access to aid in dying for almost 17 years.

Data sources

Data on the experience arise from three chief sources. First, the Public Health Division of the Oregon Health Authority publishes annual reports that include the number of death with dignity prescriptions written each year, the numbers who die by ingestion of this medication, and demographic variables. Second, clinical investigators from Oregon Health and Sciences University (OHSU), the Portland Veterans Affairs Medical Center, Oregon State University, Portland State University, and other institutions have conducted a number of comprehensive studies and published their findings in academic, peer-reviewed journals of medicine and bioethics. Third, the press, both in Oregon and nationally, has been vigilant in its investigation and publication of empiric evidence and the experiences of Oregon patients, families, and physicians.

These sources combine to form a data set both deep and broad on one particular end-of-life decision. No similar data set exists for any other end-of-life decision. For example, this data set is considerably more comprehensive than that related to choosing to discontinue life-sustaining treatments, choosing palliative sedation to die in a sedated state, or voluntarily abstaining from nutrition and hydration.

Who asks for access to aid in dying?

Most demographic data come from the sixteen annual state reports of the Oregon Public Health Division, which receives its information from the documents filed by physicians and pharmacists, death certificates, and interviews with each attending physician. In the first year of implementation (1998), division investigators also performed a matched case-control study comparing persons who took life-ending medication prescribed under the act with up to three control patients who died from similar illnesses without accessing the new law. In the second year, division investigators added family member interviews to augment data on physical suffering, finances, and hospice care. These studies appeared as "Special Reports" in *The New England Journal of Medicine (NEJM)*.[2] The third year's investigation did not include a matched control component or family interviews and appeared in the *NEJM* as a letter.[3] Some data from years four and five also appeared as letters in the *NEJM*.[4] All reports reside permanently at http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct.

In total, 1173 people have received prescriptions for life-ending medication under the DWDA and 752 have died from ingesting that medication. Studies reveal some important differences between those who request aid in dying and those who eventually ingest lie-ending medication under the law.

Those who request aid in dying

Public health officials report information only on completed requests, as that is the event that triggers the reporting requirement. Population studies reveal the law's impact reaches beyond the small numbers of the state's annual reports. A 2004 large-population study of dying Oregonians by researchers at Oregon Health and Science University revealed one in six dying Oregonians (17%) personally considered aid in dying seriously enough to discuss it with their families.[5] Among whites, the figure was 18%, and among Asian Americans, 24%.[6] Of the 1384 decedents studied, one had received a DWDA prescription and did not take the medication. Being younger than 65, low religiosity and greater symptom

Ann. N.Y. Acad. Sci. July 2014 1–7 C 2014 New York Academy of Sciences.

distress were the only independent predictors of aid-in-dying consideration. Two percent (1 in 50) formally requested life-ending medication from their physician under the law. One in 25 requests were completed and resulted in a prescription being written.[5] Consideration of aid in dying is higher among patients with cancer and amyotrophic lateral sclerosis (ALS). Investigators concentrating on Oregon and Washington ALS patients found one-third discussed a desire for aid in dying during the last month of their lives.[7]

Those who ingest aid-in-dying medication

Approximately 32,000 Oregon residents die each year, and this number of aid-in-dying deaths represents 2.19 deaths per 1000 or 0.2%. Absolute numbers of DWDA deaths increased from year 1 to year 2 (16–27), remained at 27 for year 3, and fell to 21 in year 4. For 6 years, they hovered between 38 and 49, and then trended up to 85 in 2012. In 2013, they fell to 71. The number of people who die from ingesting the medication as a proportion of those who receive a prescription ranged from 47.7% to 82%, with the median at 62%. The remainder died of disease progression, leaving their life-ending medication unused.

Of the total 752 who died as a result of the medication, slightly more were men (52.7%). Over half fell into the age ranges of 65–74 (28.9%) and 75–84 (27.4%). The overwhelming majority was white (97.3%). Asian-Americans and Hispanics, each made up around 1% of the total. Most were either married (46.2%) or widowed (22.8%). Seventy two percent had some college education, 45.6% of which were baccalaureate or higher.[8]

Ninety percent were enrolled in hospice at the time of their death, and more than 98% were covered by Medicare, Medicaid, or private insurance. People dying of cancer dominated the group at 78.9%. ALS was the next most common terminal illness at 7.6%, but given the relatively low incidence of the disease, it is overrepresented among DWDA deaths. Median duration between the first request and death was 47 days.

As educational attainment increases, so too does the likelihood of obtaining and ingesting aid-in-dying medication. College graduates are 6.5 times more likely to die by aid in dying than those without a high school diploma.[9] In contrast, the study of those considering aid in dying found those with a high school education just as likely to consider it as those with more education. The authors postulated that more education enables some to navigate the bureaucratic request process.[7]

What motivates those who request aid in dying and ingest life-ending medication?

Within 10 calendar days of the death of a patient who received a prescription under the law, the physician files a report with the Public Health Division. Among the data fields are seven factors the physician may believe contributed to the patient's request. Most reports include more than one concern, usually two to three. Consistently, the three most frequently cited concerns are loss of autonomy (93%), decreasing ability to participate in activities making life enjoyable (88.7%), and loss of dignity (73.2%). The doctors cite losing control of bodily functions next most frequently (50.3%), followed by being a burden on caregivers (40%), inadequate pain control (23.7%), and financial implications of treatment (2.9%).

These concerns differ from those reported among people who considered, but did not pursue, aid in dying. The latter were reported to experience a higher number of symptoms, with pain and sadness most strongly associated with aid-in-dying consideration.[5] Another team of investigators studied a cohort of 83 decedents who had made explicit and documented requests, including 52 who received prescriptions and 32 who died after ingesting the medication. From a list of 28 potential reasons, family members identified the most important at the time of the request as wanting to control the circumstances of death, wanting to die at home, loss of dignity, fear of poor quality of life, loss of independence, and inability to care for self in the future. Family members described those who pursued aid in dying as "individuals for whom being independent and in control is important, who anticipate the negative aspects of dying, and who believe that the impending loss of self, abilities, and quality of life will be intolerable."[10]

Two years later, the authors validated their findings by gathering data directly from 56

Ann. N.Y. Acad. Sci. July 2014 1–7 C 2014 New York Academy of Sciences.

Oregonians interested in aid in dying. Of 29 potential reasons, those ranked as "very important" were wanting to control the circumstances of death, wanting to die at home, loss of independence, and fear of future poor quality of life, future pain, and future inability to care for self. The authors commented, "Their desire to die is not strong, and they do not believe that their life is poor in quality, meaningless, or worthless. Rather, they appear to be protecting against the risk of future experiences they do not believe they can endure."[11]

The same authors designed a study to determine the prevalence and severity of psychological distress, including major depressive disorder, among 58 Oregonians who had requested aid in dying. A competence-assessment tool confirmed the participants' abilities to make medical decisions and consent to research. A battery of psychological tests indicated 15 with depression and 13 with anxiety. The study generated public scrutiny, as the authors used an inclusive approach in diagnosing depression. They attributed all physical symptoms such as sleeplessness, weight loss, fatigue, and lack of appetite to depression, even when related to terminal cancer.[12,a]

Formal psychiatric examinations occurred in 6% of all patients who completed the qualification process over the past 16 years. The percentage has diminished over the years, as in the early years some providers referred every requesting patient for a psychological evaluation as a matter of policy.[14] Psychosocial assessments upon admission and psychosocial monitoring by the hospice team occur as part of the mental health services integral to hospice care, which 90% of those completing requests receive.[15] Physicians decline 24 of 25 aid-in-dying requests they receive. This figure suggests that when physicians suspect that a psychological disorder is impairing judgment, they are likely to decline the request rather than order a psychiatric evaluation.[5]

Who participates: what are the characteristics of physicians and hospices who accept a request for aid in dying?

An anonymous physician survey published in 2000 revealed that, in the first 21 months after the law went into effect, 5% of Oregon physicians received formal requests. The strongest predictor of whether a physician would receive a request was treating a large number of terminally ill patients per year. Other significant predictors included willingness to write a prescription, finding care of the dying patient intellectually satisfying, and having sought to improve knowledge of pain medications since the law's passage in 1994.[16]

Of the 144 physicians who received aid-in-dying requests, 69 were internists and 24 were subspecialists, including 11 oncologists and 6 pulmonologists. Eighty-one percent were in private or group practice, and 72% reported either supporting the DWDA or being neutral. Thirty-seven percent said they were unwilling to prescribe medication under the act for a qualifying patient. Eighty-eight percent made efforts to improve their skill in end-of-life pain management, and 76% had sought to improve their ability to recognize psychiatric illness in the terminally ill.[17]

This report of data gathered from physicians indicated they granted one in six requests for aid in dying. This contrasts sharply with findings of 1 in 25 requests being granted when the investigators asked family members of decedents.[5] This suggests that patients and families may believe a request has been made, but usually physicians have not heard, understood, or acknowledged that intention.

Semi-structured interviews of 35 Oregon doctors who received requests indicated that these requests had a powerful impact. Doctors were concerned about adequately managing symptoms and suffering and not wanting to abandon patients. Physicians reported that their participation was emotionally intense and required a significant time investment. Physicians reported no regrets and felt the experience

[a] Dr. Timothy Quill anticipated this problem several years earlier. "Depression scales need to be adjusted when they are applied to seriously ill, potentially dying patients. Thinking about death and preparing for it are essential parts of this phase of life, and symptoms such as fatigue, anorexia, sleep disturbance, and poor concentration are common in the terminally ill, yet in unadjusted depression scales designed for physically healthy persons such features may over diagnosis deprrssion."[13]

Ann. N.Y. Acad. Sci. July 2014 1–7 C 2014 New York Academy of Sciences.

increased their confidence in dealing with other dying patients. They tended to discuss emotional aspects of the experience with their spouses but not their colleagues.[18]

In 2010, the Hastings Center published an examination of 55 Oregon hospices and their policies toward aid in dying. Degree of participation varied widely, with 16% participating fully, 32% participating moderately, 27% allowing limited participation, and 25% barring participation. Despite wide policy differences, two policy positions were universal. The first was a promise to provide customary hospice services irrespective of a patient's aid-in-dying request status. The second was a policy to refrain from paying for, providing, or assisting in the self-administration of medication.[19] The latter may arise from federal constraints on Medicare funding.[20]

What is the experience of aid in dying; how does it differ from other deaths?

State reports yield the most comprehensive information about the character of assisted deaths. Medical professionals at the bedside report standard information to state epidemiologists. Almost all patients die at home (95%). Only one has died in the hospital. Unconsciousness and death usually occur rapidly after ingestion of the medication, which is a large dose of fast-acting barbiturates. The time for goodbyes and final words must precede ingestion. Time between self-administration of medication and unconsciousness ranged from 1 to 38 minutes, with a median of 5 minutes. Respiration slows and death follows ingestion by between 1 minute and an extreme of 104 h, with a median of 25 minutes. Regurgitation occurred in 22 of the 752 assisted deaths. Six patients regained consciousness after ingesting aid-in-dying medication and died some days later of their underlying illness. They are not included in the 752 assisted deaths.[b]

Between 2004 and 2007, a research team from the OHSU School of Nursing and the Department of Psychiatry administered the 33-item Quality of Death and Dying Questionnaire to 52 Oregonians who received life-ending prescriptions, 34 who requested a prescription but did not receive it, and 63 who did not pursue aid in dying. They found that those receiving aid-in-dying prescriptions had higher quality ratings on items measuring symptom control and higher ratings on items related to preparedness for death than those who did not pursue aid in dying, or who began but did not complete a request. The authors report that aid in dying may meet the goal of relieving worries about future discomfort, pain, and loss of control, and a request was not a reflection of poor care.[21]

Hospice nurses and social workers have provided important insights into the experience of patients who use aid in dying compared to other hospice patients. A survey mailed to every hospice nurse and social worker in the state yielded 179 who had cared for at least one patient who had requested aid in dying. They confirmed the motivations identified in other studies. Respondents also reported fears of loss of control of the circumstances and location of death and fear of loss of independence as more dominant than in other hospice patients. Conversely, they reported that symptoms of pain, depression, anxiety, dyspnea, and fear of the process of dying were more pronounced among non-requesting hospice patients. Respondents reported family caregivers of aid-in-dying patients were more likely to find positive meaning in caring for the patient and were more prepared for and accepting of the patient's death than family caregivers of non-requesting patients. They reported families of requesters as less likely to be burdened by caring for the patient and the cost of doing so than families of non-requesting patients.[22]

Investigators examined the mental health impact on family members with a survey of the families of 95 decedent Oregonians who requested aid in dying and a control group of family members of patients who did not. The study revealed no difference in family members' primary mental health outcomes of depression, grief, or use of mental health services. However, aid-in-dying families felt, on average, more prepared for the death and more accepting of it.[23]

[b] Cumulative data appears in the Year 16 report. (http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf).

Ann. N.Y. Acad. Sci. July 2014 1–7 C 2014 New York Academy of Sciences.

A less formal social worker pilot project explored conversations between the authors and patients, families, team members, and health systems. Themes that emerged included mental health, the role of choices, team concerns, family issues, and the values and ethics of restricted conversations and professional struggles. One uniform observation was that the current bereavement literature as applied to suicide in an otherwise healthy person "does not fit" families of aid-in-dying patients. Another was that, while the median hospice stay in Oregon hovered at 16 days for several years, the median length of stay for hospice patients who accessed aid in dying was 49 days.[24]

How does aid in dying affect vulnerable populations?

Before the existence of scientific data from a U.S. jurisdiction, important public-policy authorities predicted that aid in dying would have an adverse impact on vulnerable populations. In 1994, the New York Task Force on Life and the Law opined that risks "would be most severe for those whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, advanced age or membership in a stigmatized social group."[25] The data set from a variety of sources confirms that those who complete an aid-in-dying request are equally divided between genders and mostly white, well-educated, insured, and receiving hospice services. Several commentators who articulated concerns about the DWDA have publicly stated that their fears about abuse of the vulnerable have not materialized.[26] One commented, "I was worried about people being pressured to do this. But these data confirm that the policy in Oregon is working. There is no evidence of abuse or coercion or misuse of the policy."[27] Similarly, the small numbers of aid-in-dying cases and the stability of these numbers over 16 years have alleviated concerns that providers would coerce patients into assisted dying. Careful financial analysis of the cost of care at the end of life and savings attributable to assisted dying do not indicate that institutional self-interest would encourage premature death.[28]

Investigators from the University of Utah examined Oregon data in 2007 and found no evidence of heightened risk for the elderly, women, the uninsured, people with little education, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses, or racial or ethnic minorities. The only group disproportionately represented among aid-in-dying patients was people with AIDS.[29] The executive director of the disability advocacy group Disability Rights Oregon testified before the American Public Health Association in 2007 that he had no knowledge of any cases in Oregon to contradict the findings of that report.[30]

Conclusion

Today's dialogue about aid in dying takes place in an environment rich with 16 years of data from a variety of independent investigators, published as peer-reviewed research in respected medical journals. There is no need to shape public policy with unsubstantiated speculation or fears. It is appropriate for influential policy institutions to consider their recommendations regarding authorization of aid in dying in the context of the scientific record. That record has made clear that the risk of harm is small when the law authorizes terminally ill, mentally competent adults to access medication they may self-administer for peaceful dying.

Conflicts of interest

The author declares no conflicts of interest.

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