THE INEVITABLE—DEATH: OREGON'S END-OF-LIFE CHOICES

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HOSPICE AND ODDA: INTRODUCTION

Hospice professionals have taken their role seriously in Oregon's "laboratory" of the states,[1] adding experience-based information to the discussion of physician-assisted death (PAD) and closing the data void that existed prior to 1997—the year when PAD became legal in the United States for the first time in the modern world.[2] The perspective of hospice workers is significant because (1) they visit patients and families frequently in the last weeks and months of life; and (2) they are able to compare hospice patients who hasten death with hospice patients who do not. Their experience is important because 86% of persons who have used the Oregon Death with Dignity Act (ODDA) were enrolled in hospice.[3]

The purpose of this paper is to discuss openly and honest end-of-life option, especially to hospices. Dying Oregonians are eligible for both hospice and PAD.

All hospices operating in Oregon provide care to persons who consider a prescription to end life and to persons who actually do use a prescription to end life. One explanation for the very low number of people who use the ODDA is the high quality of hospice care in Oregon.[4]

This paper intends to focus, from the hospice experience with the ODDA, both on the practical implications of medical science on legal decision-making and on the law of making end-of-life medical decisions.

HOSPICE AND ODDA: HISTORY

The membership of the Oregon Hospice Association (OHA), against the advice of its board chair, declared an intent to formally participate in any public debate over euthanasia or physician-assisted suicide at its annual meeting in January 1992.[5] The board chair's concern was about involvement in a controversial legal issue; the membership's concern was about the social irresponsibility of noninvolvement. Hospice workers, the membership knew, were uniquely qualified as end-of-life experts. The role the members chose was one of education. Their goals would be (1) to ensure that well-informed voters marked ballots, if there was an election, and (2) to improve quality of care at the end of life, regardless of an election's outcome.[6] Their naive assumption, as it turned out, was that the public—and the media—would demand hospice input. If faced with such a demand, the membership would be ready.

A multi-disciplinary,s thaddSiz3 demskntencd), OHA and Oregon Health Decisions (OHD), a member of the ethics task force, hosted nineteen simultaneous community meetings in August 1994, via Ed-Net.[8] Participants from throughout Oregon identified and discussed end-of-life wishes and fears, in the context of Ballot Measure 16. To ensure an unbiased process, neither organization had taken a position. At its September meeting, using input from the community meetings, OHA's board voted to oppose the measure. The decision was deliberately made late in the campaign, and was not unanimous. The organization was aware that, by taking a position, it risked alienating Oregonians who did not agree. Three years later, OHA's board voted to support the repeal effort of Measure 16, again shortly before the election. The following information , in an effort to reassure all voters, was included in statements issued by the board to the media immediately after the elections in both 1994 and 1997:

> The Oregon Hospice Association respects Oregonians' right to choose from among all legal end-of-life options, including the Death With Dignity Act. Dying Oregonians may choose both hospice and physician-assisted suicide. OHA recommends hospice referrals for patients who seek a prescription, if not already enrolled. Hospice care successfully addresses the fears and needs that are often behind a request.[9]

ODDA: LEGAL CHALLENGES

The ODDA was a citizen's initiative that first passed by a margin of 51% to 49% in November 1994.[10] An injunction filed in December 1994 was lifted in October 1997, a few days before the repeal referendum was defeated by a margin of 60% to 40% that November.[11] Implementation of the Act was effectively delayed until April 1998, when then U.S. Attorney General Janet Reno reversed an

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[8] OR. HOSPICE ASS'N & OR. HEALTH DECISIONS, PHYSICIAN-ASSISTED DEATH: HOW WILL YOU VOTE? 1 (Aug. 2004) (on file with author).

[9] OR. HOSPICE ASS'N, ORGANIZATIONAL POLICIES RELATED TO PAD Nos. 9, 10, 15 (last updated 2006), *in* Press Release, Or. Hospice Ass'n (Nov. 2, 1994) (on file with author). *See also* Press Release, Or. Hospice Ass'n (Nov. 5, 1997) (on file with author); Or. Hospice Ass'n, *Choosing Among Oregon's Legal End-of-Life Options*, June 1, 2007, http://oregonhospice.org/endoflifecare_legal.htm.

[10] OR. DEP'T OF HUMAN SERV., FAQ ABOUT THE DEATH WITH DIGNITY ACT, *available at*

opinion issued by the U.S. Drug Enforcement Agency (DEA).[12] The DEA had overstepped its authority, in November 1997, when it threatened to sanction Oregon physicians who wrote prescriptions under the Act.

The Lethal Drug Abuse Prevention Act (LDAPA) of 1998[13] would have permitted the DEA to revoke the registrations of physicians or pharmacists who intentionally dispensed or distributed a controlled substance for the purpose of "physician-assisted suicide," but it faced widespread opposition.[14] In 1999, the LDAPA was replaced by the Pain Relief Promotion Act (PRPA),[15] which won the support of the American Medical Association (AMA) and the National Hospice Organization (NHO).[16]

OHA strongly opposed both the LDAPA and the PRPA.[17] The PRPA would have legally acknowledged the double effect of pain medications and formally encouraged palliative care. The PRPA would also have allowed the DEA and federal prosecutors to effectively judge a physician's intent in prescribing controlled substances after the fact.[18]

Challenges to the ODDA resumed in November 2001,[19] when U.S. Attorney General John Ashcroft reinterpreted the Controlled Substances Act to prohibit physicians from prescribing controlled substances under the ODDA. A temporary restraining order issued in response to a lawsuit filed by the State of Oregon was made permanent in April 2002, and appealed by Ashcroft.[20] The appeal was denied by a Ninth Circuit Court of Appeals panel in May 2004.[21] An appeal in July to rehear Ashcroft's previous motion was declined

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[12] Death with Dignity Nat'l Ctr., *Legal and Political Timeline in Oregon*, http://www.deathwithdignity.org/historyfacts/oregontimeline.asp (last visited Oct. 24, 2008).

[13] Lethal Drug Abuse Prevention Act of 1998, H.R.4006, 105th Cong. (1998).

[14] Jack P. Freer, Op-Ed., *Congress and the Pain Relief Promotion Act*, 172 WEST. J. MED. 5, 5 (2000), *available at* http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1070704&blobtype=pdf.

[15] Pain Relief Promotion Act of 1999, H.R. 2260, 106th Cong. (1999).

[16] Freer, *supra* note 14, at 6.

[17] OR. HOSPICE ASS'N, ORGANIZATIONAL POLICIES RELATED TO PAD No. 16 (June 1998) (last updated 2006); OR. HOSPICE ASS'N, ORGANIZATIONAL POLICIES RELATED TO PAD No. 18 (April 1999) (last updated 2006).

[18] Freer, *supra* note 14, at 5.

[19] OR. DEP'T OF HUMAN SERV., FAQ, *supra* note 10.

[20] *Id.*

[21] *Id.*

by the Ninth Circuit en banc in August 2004.[22] Ashcroft then appealed to the U.S. Supreme Court to review the decision in November 2004.[23] Finally, in February 2005, the U.S. Supreme Court agreed to hear *Gonzales v. Oregon* (formerly *Ashcroft v. Oregon*).[24] Oral arguments were heard in October 2005, and the U.S. Supreme Court affirmed the Ninth Circuit Court's decision in January 2006.[25]

The ODDA has remained in effect since April 1998, with few other legal challenges. Senator Sam Brownback introduced the Assisted Suicide Prevention Act in August 2006, but it generated very little interest.[26]

The challenges to the ODDA all have one thing in common: effectively increasing an already chilling impact of regulatory scrutiny on physician willingness to provide aggressive pain relief. Uncontrolled pain is recognized as epidemic in the United States, despite efforts to improve pain management.[27] Researchers at the Center for Ethics at Oregon Health Sciences University (OHSU), who began monitoring reported pain in November 1996, observed a significant increase in pain in the last quarter of 1997, coinciding with the election.[28] The purpose of the study had been to measure pain, not to identify causes of pain. However, the study's authors did suggest two possibilities for the initial increase in pain. First, increased publicity about pain, before and after the election, may have raised expectations about pain management in patients and their families.[29] Second, physicians and their prescribing methods also may have been affected by the DEA threat of sanctions.[30] Reports of pain remained at the increased level between 2000 and 2002, when the study was

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[22] *Id.*

[23] *Id.*

[24] *Id.*

[25] OR. DEP'T OF HUMAN SERV., FAQ, *supra* note 10; *see also* Gonzales v. Oregon, 546 U.S. 243 (2006).

[26] Assisted Suicide Prevention Act of 2006, S. 3788, 109th Cong. (2006).

[27] Christina Guest, *The Pain Game: Advances in Pain Management Gives Hope to Many Sufferers*, KANSAS CITY BUS. J., Aug. 20, 1999, *available at* http://www.bizjournals.com/kansascity/stories/1999/08/23/focus1.html?jst=s_rs_hl.

[28] Erik K. Fromme et al., *Increased Family Reports of Pain or Distress in Dying Oregonians: 1996 to 2002,* 7 J. PALLIATIVE MED. 431, 437 (2004).

[29] *Id.* at 438.

[30] *Id.* at 439.

several other states has been defeated.[36] Additionally, citizen initiatives to legalize physician-assisted suicide and euthanasia were defeated by voters in Washington in 1991 and California in 1992.[37]

ODDA: PROVISIONS

The ODDA allows a terminally-ill adult to make a request for a prescription of self-administered, life-ending medication.[38] The ODDA prohibits euthanasia.[39] "Physician-assisted suicide" was the term adopted by the State of Oregon to describe measures taken under the Act. The Task Force to Improve the Care of Terminally-Ill Oregonians, convened by OHSU in 1995, agreed to use the term physician-assisted suicide because that term was the most consistent with descriptions in medical literature.[40] However, a provision within the Act states that ending life, within the Act's confines, is *not* suicide or assisted suicide.[41] In 2006, the State of Oregon stopped using the term "physician assisted suicide" when legal action against the State by authors of the ODDA became a possibility.[42] The terms generally used in this paper are "physician-assisted death" or "physician-assisted dying" (PAD).

ODDA: PATIENT REQUIREMENTS

A person who makes a request must be eighteen years of age or older[43] and show evidence of Oregon residency.[44] He or she must be capable of making and communicating health care decisions.[45] The request must be voluntary;[46] coercion or undue influence on a person

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[36] Kathi Hamlon, Int'l Task Force on Euthanasia and Assisted Suicide, *Failed Attempts to Legalize Euthanasia/Assisted-Suicide in the United States*, http://www.internationaltaskforce.org/usa.htm (last visited Oct. 26, 2008).

[37] *Id.*

[38] OR. REV. STAT. §§ 127.800-127.895 (2007).

[39] *Id.* § 127.880.

[40] *See* ARTHUR CHIN ET AL., OR. DEP'T OF HUMAN RES., OR. HEALTH DIV., OREGON'S DEATH WITH DIGNITY ACT: THE FIRST YEAR'S EXPERIENCE 1 (1999), http://egov.oregon.gov/DHS/ph/pas/docs/year1.pdf.

[41] OR. REV. STAT. § 127.880.

[42] Kevin B. O'Reilly, *Oregon Nixes Use of Term "Physician-Assisted Suicide,"* AM. MED. NEWS, Nov. 6, 2006, http://www.ama-assn.org/amednews/2006/11/06/prsc1106.htm.

[43] OR. REV. STAT. § 127.800 (1) (2007).

[44] *Id.* § 127.860.

[45] *Id.* § 127.800(3).

[46] *Id.* § 127.805(1).

to use the ODDA is considered a Class A felony.[47] He or she must have a terminal disease,[48] defined as a disease with a prognosis of six months or less,[49] an eligibility requirement similar to that of hospice benefits.

The person must make two verbal requests, separated by at least fifteen days, and one written and witnessed request to his or her physician.[50] The prescribing[51] and consulting[52] physicians must confirm the diagnosis and prognosis; determine that the person is "capable;" and consider a psychiatric or psychological referral if the person's judgment may be compromised by depression or another mental condition.[53] The person must be informed of alternatives that include hospice, comfort care, and pain management.[54]

ODDA: PRESCRIPTION RECIPIENTS

In the first ten years, 341 Oregonians died as a result of ingesting medication under the ODDA,[55] a rate of 11 ODDA deaths per 10,000 total deaths.[56] In 2007, 49 persons used medication, including three with earlier prescriptions.[57] The rate of ODDA deaths per 10,000 deaths was 15.6.[58] In 2007, 85 prescriptions were written.[59] In 1998, 24 prescriptions were written, and 16 persons ingested medication.[60] The rate was approximately five ODDA deaths per 10,000 total deaths.[61] The Ninth Circuit Court of Appeals lifted the injunction on October 27, 1997, but the law was not effectively implemented until

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[47] *Id.* § 127.890.

[48] *Id.* § 127.805.

[49] *Id.* § 127.800.

[50] *Id.* § 127.840.

[51] *Id.* § 127.815.

[52] *Id.* § 127.820.

[53] *Id.* § 127.825.

[54] *Id.* § 127.815.

[55] OR. DEP'T OF HUMAN SERV., TENTH ANNUAL REPORT ON OREGON'S DEATH WITH DIGNITY ACT 2 (2008), *available at* http://oregon.gov/DHS/ph/pas/docs/year10.pdf [hereinafter TENTH ANNUAL REPORT ON ODDA].

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April 1998, when Janet Reno reversed the opinion of the DEA.[62]

Although the rate of utilization has increased slightly, the numbers remain very low. During the public debates in 1994 and 1997, when many were making predictions as to the Act's potential impact, it was estimated that the utilization rate could be as high as 10 percent of all deaths.[63] Approximately 30,000 people die in Oregon annually.[64] Thus, in the first ten years the ODDA was in effect, approximately 300,000 Oregonians died from all causes.[65] Only 341 Oregonians died as a result of ingesting medication under the ODDA.[66] This is a rate of just over 0.1 of 1 percent.

The data collection responsibilities of Oregon's Public Health Division begin at the time a doctor writes the prescription under the ODDA: 540 prescriptions were recorded between 1998 and 2007.[67] It is not known how many prescriptions have been filled or how many persons have qualified for a prescription. That some prescriptions are not written until a person is ready to use the medication is consistent with the experience of Oregon's hospices.[68] A study by Susan Tolle, and colleagues at OHSU's Center for Ethics, of the caregivers of more than 1,400 persons who died in the previous months revealed that one of twenty-five individuals who make a formal request for a prescription will ingest medication.[69] The study further reveals that dying Oregonians are 100 times more likely to request a prescription than to follow through and use the prescription.[70] Hospice workers often describe the qualification for a prescription as a kind of insurance policy: a patient will ask for a prescription on day one, and on day fifteen, with a plan for the worst case scenario in hand, will get on with life.

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[62] DEATH WITH DIGNITY ACT HISTORY, *supra* note 1.

[63] This information is based on the author's own personal recollections during public debates in 1994 and 1997.

[64] *See, e.g.*, OR. DEP'T OF HUMAN SERV., CTR. FOR HEALTH STATISTICS, OREGON RESIDENT DEATHS BY AGE GROUP AND COUNTY OF RESIDENCE: 2005 FINAL DATA (2005), *available at* http://www.dhs.state.or.us/dhs/ph/chs/data/finalabd/05/deathage.pdf.

[65] *See id.*

[66] TENTH ANNUAL REPORT ON ODDA, *supra* note 55, at 2.

[67] PRESCRIPTION HISTORY, *supra* note 60.

[68] This information was collected during fo

ODDA: PATIENT DEMOGRAPHICS

The Public Health Division compared 341 persons (ODDA) who died as a result of ingesting medication under provisions of the ODDA with 98,942 persons (cohort) who died with the same diseases, between 1998 and 2007.[71] Hospice nurses identified 102 persons who stopped eating and drinking for the purpose of hastening death (VRFF),[72] as reported in a 2003 study published in the *New England Journal of Medicine*.[73] In many respects, the three groups are similar. In others, they are very different.

A. Sex, Age, and Race

Persons who used the ODDA were more likely to be male (54%) than female (46%),[74] and the median age was 69.[75] In the cohort of persons with the same diseases, the percentages of males and females was nearly equal (50.4% and 49.6%), and the median age was 76.

B. Residence

During the public debates, many were concerned that people who lived in rural areas would be more likely to use the ODDA because of less access to hospice and comfort care. All Oregonians have access to hospice, including those living in the frontier areas of the state. Access to the ODDA, however, may be compromised by physician willingness to participate, and in some geographic areas, fewer physicians will write a prescription. Patient choices are often restricted by the rights of others to make different choices, and patients are often reluctant to change doctors.[81] In some geographic areas, the opposition to the ODDA by religious organizations effectively restricts choices.

The majority of persons who used the ODDA in its first ten years have been residents of metropolitan area and other western counties. People who lived east of the Cascade Mountains were the least likely to use the ODDA.[82] Of those persons who stopped eating and drinking, 18% were residents of the Portland metropolitan area.[83] Research currently in progress, related to hospice social workers' experiences with hastening death, indicates that 45% of patients have considered or used VRFF or, when appropriate, palliative sedation as an alternative to the ODDA.[84] Personal conversations with hospice workers suggest that VRFF and palliative sedation are offered and used as alternatives in geographic areas where access to physician-assisted dying is compromised.

C. Marital Status

It was predicted during the public debates that people who lacked social support would be more likely to use the ODDA than other Oregonians. The Health Division data appears to support this assumption. Persons who were divorced (25% v. 15%) or never married (8% v, 4%) are disproportionately represented among persons

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[81] Teri Robert, *Patient as Consumer*, HELP FOR HEADACHES & MIGRAINE, May 16, 2006, http://www.helpforheadaches.com/articles/patient-consumer.htm.

[82] *Comparison*, *supra* note 71.

[83] *See* Ganzini et al., *Nurses' Experiences with Hospice Patients*, *supra* note 73, at 361 tbl.1.

[84] P. Miller, *Communication at the End-of-Life: Social Work, Hospice and Oregon's Death With Dignity Act*, Slide No. 30, Or. Hospice Ass'n Professional Practices Exchange, Redmond, Oregon, Oct. 3, 2008, *forthcoming* http://oregonhospice.org/handout_downloads.htm.

who used a prescription.[85] Marriage rates are similar for both people using the ODDA and those with the same diseases.[86] Widowed persons are less represented among those using the ODDA.[87]

Hospice workers, however, described persons using the ODDA as having as strong or stronger social support networks than those hospice patients who did not use the ODDA. In a list of twenty-one reasons for using the ODDA, "lack of social support" was ranked twentieth in importance by hospice nurses and last by hospice social workers.[88]

D. Education

During the public debates in Oregon, the lack of an education was identified as a predictor for a greater likelihood of using the reported by the Health Division.[93] Physicians, hospice nurses, hospice social workers, and hospice chaplains have all described people who consider a prescription under the ODDA as more likely to assume control and responsibility for all aspects of their care. [94]

E. Underlying Diseases

Most persons who used a prescription to end their lives had malignant or nonmalignant neoplasms or tumors.[95] Diseases most disproportionately represented among those who used the ODDA included ALS, HIV/AIDS, and cancer of the oral cavity, all of which are uncommon.[96] "Other" diseases include scleroderma, which is rare. Lung cancer represented the diagnosis with the highest number of ODDA users.[97] Fears of suffocation, choking, being unable to breathe are common among these diseases. [98] ALS illustrates well the implications of medical science on legal decision-making and of law on end-of-life decision-making. Self-administration of medication is a safeguard within the ODDA to protect physicians against accusations of unlawfully offering mercy killing, euthanasia, and assisted suicide. Some disability rights groups see the provision as discriminatory against people who are unable to use a prescription without assistance.[99]

Twenty-six persons with ALS used the law in the past ten years.[100] Hospices describe some of these persons as having done so

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[93] OR. DEP'T OF HUMAN SERV., CTR. FOR HEALTH STATISTICS,

before they were ready to die, but while they could still swallow.[101] Oregon's Health Care Decisions Act (Chapter 127)[102] provides a right to comfort measures, including medication, for people who are dying. Palliative or terminal sedation to the point of coma is an appropriate option to keep patients unaware of distressing symptoms, but in personal discussions with ALS support groups, it appeared that very few were aware of this right. A case study presented to hospitalists at Grand Rounds revealed that fewer than 1% included terminal sedation as an option for patients with severe obstructive lung disease, although 98% would have wanted terminal sedation for themselves, under those circumstances.[103] In addition, in these meetings with ALS support groups, few seemed aware that they could refuse food and fluids[104] or that a feeding tube could be a plausible route for self-administration under the ODDA.[105] People with ALS are generally aware of their ultimate death from the outset. That does not translate into actual knowledge about making informed end-of-life care decisions.[106]

F. Insurance

Another prediction during the public debates was that people who lacked financial resources or health insurance would more likely use physician-assisted death. Of 341 persons who used the ODDA, 334 were insured and 3 were not. The insurance status of 4 persons is not known. The federal government prohibits federal dollars from being used to support the ODDA.[107] The ODDA is covered by the Oregon Health Plan, using state funds only. Hospice is a covered benefit under the Oregon Health Plan and there is no waiting period

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[101] This information regarding the experience of hospice workers with the ODDA was learned through conversations between the author and hospice employees, occurring at Oregon Hospice Association Professional Practices Exchanges between 1998 and 2007.

[102] OR. REV. STAT. § 127.642 (1993).

[103] Joanne Lynn & Nathan Goldstein, *Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering,* 138 ANNALS OF INTERNAL MED. 812 (2003).

[104] Or. Hospice Ass'n, *Choosing Among Oregon's Legal End-of-Life Options*, June 1, 2007, http://oregonhospice.org/endoflifecare_legal.htm.

for eligibility for admission to hospice.[108] In addition, Oregon's hospices offer their services on a sliding fee scale, ensuring that dying Oregonians without insurance will not fall through the cracks of a flawed health care system.

It was also predicted that people would use the ODDA to protect their families from financial and other burdens.[109] On a list of twenty-one reasons for using the ODDA, hospice nurses reported "fear of being a financial drain" to loved ones near the bottom.[110]

MENTAL HEALTH CONCERNS

Depression is generally considered a major predictor for the desire to die, and many expressed concern during the public debates that people with depression and other mental conditions would more likely ask for and use a prescription.[111] On the list of twenty-one reasons, however, depression is ranked nineteenth in importance by hospice nurses and hospice social workers,[112] and fourteenth on a list of fifteen reasons by chaplains.[113] Only 36 persons (11%) of those who used the ODDA were referred for a psychiatric or psychological evaluation as required by the Act—when a patient's judgment to make health care decisions is questioned.[114]

Hospice social workers assess the mental health of every person admitted to hospice care, and with the hospice team, routinely monitor the psychosocial status and needs of all hospice patients and family members. The hospice care plan is reviewed and updated at least every two weeks, or as a patient's condition changes.[115] Eighty-

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[108] OR. ADMIN. R. 410-142-0040 (2007); OR. ADMIN. R. 410-142-0100 (2007).

[109] *See, e.g.*, Or. State Council of Senior Citizens, Argument in Favor of Measure No. 51, Statewide Special Election Online Voters' Guide, Nov. 4, 1997, *available at* http://www.sos.state.or.us/elections/nov497/voters.guide/M51/M51arf.htm (if passed, Measure No. 51 would have repealed the ODDA).

[110] Ganzini et. al, *Experiences of Oregon Nurses and Social Workers with Hospice Patients*, *supra* note 4, at 584; Ganzini et al., *Nurses' Experiences with Hospice Patients*, *supra* note 73, at 362.

[111] *See*, *e.g.*, David A. Abbott, Argument in Favor of Measure No. 51, Statewide Special Election Online Voters' Guide, Nov. 4, 1997, *available at* http://www.sos.state.or.us/elections/nov497/voters.guide/M51/M51arf.htm.

[112] Ganzini et al., *Nurses' Experiences with Hospice Patients*, *supra* note 73, at 362

six percent of persons who have used the ODDA were enrolled in hospice at the time medication was ingested.[116] Hospice provides support to approximately fifty percent of dying Oregonians annually.[117] As a result, hospice social workers are more experienced at assessing mental health and addressing psychosocial needs of people who are dying than are other mental health professionals.[118]

Oregon's experience in this regard is being discounted, however, as other states consider similar legislation or initiatives. Proposed legislation and ballot measures in California, Hawaii, Vermont, Arizona, and Maine have included the additional "safeguard" of a mandatory requirement for a psychiatric or psychological evaluation.[119] Washington's Measure No. 1000, to be decided in November 2008, does not.[120] Oregon's hospice workers[121] and other health care professionals[122] generally agree that the bar is already high enough to protect persons who are clinically depressed. A new study, however, suggests that the current practice under the ODDA may not protect all patients with mental illness and recommends more systematic examination for depression among those asking about PAD.[123]

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[116] *Comparison*, *supra* note 71.

[117] Ctr. for Medicare Medicaid Serv., Medicare Hospice Data, 1994–2007 (reports prepared by Jay Cushman and Cordt Kassner are on file with author)

[118] Ganzini et al., *Experiences of Oregon Nurses and Social Workers with Hospice Patients*, *supra* note 4, at 582, 586.

[119] *See e.g.*, California Compassionate Choices Act, A.B. 374 (Cal. 2007); Death with Dignity Act, H.B. 2487, 21st Leg., Reg. Sess. (Haw. 2002); Maine Death with Dignity Act, Question 1 (2000).

[120] Wash. Death with Dignity Act, Initiative Measure No. 1000 (2008), *available at* http://www.secstate.wa.gov/elections/initiatives/text/i1000.pdf ("If, in the opinion of the attending physician or the consulting physician, a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, either physician shall refer the patient for counseling.").

[121] This information regarding the experience of hospice workers with the ODDA was learned through conversations between the author and hospice employees, occurring at Oregon Hospice Association Professional Practices Exchanges between 1998 and 2007.

[122] Brief for Coalition of Mental Health Professionals as Amicus Curiae Supporting Respondents at 9, Gonzales v. State of Oregon, 546 U.S. 243 (2006) (No. 04-623), *available at* http://www.compassionandchoices.org/documents/mental_health_pro.pdf.

[123] Linda Ganzini et al, *Prevalence of Depression and Anxiety in Patients Requesting Physicians' Aid in Dying: Cross Sectional Survey*, 337 BRIT. MED. J. 973, 975 (2008).

PRESENCE OF HEALTH CARE PROVIDER WHEN MEDICINE INGESTED

Many presumed that persons would use prescriptions when they were alone, involving innocent bystanders in some instances, suffering "botched"[124] deaths when "pills didn't work,"[125] and creating additional expenses to taxpayers. Of special concern were persons who rented a hotel room, perhaps at a resort, and who were found by the hotel housekeepers. An amendment to the Act provides for the estate to pay for costs which "[a]ny governmental entity . . . incurs . . . resulting from a person terminating his or her life pursuant to the provisions of [the Act] in a public place."[126]

Some persons exercise their right to ingest medication without the presence of others, but they are in the minority. Compassion & Choices reports that family members and friends were present 90% of the time with their clients, who represent approximately 75% of the 341 persons who have used the ODDA.[127] Health Division data indicates that the person's prescribing physician or another provider or both were present in 80% of the situations where medication was ingested.[128] A majority of hospices have policies that prohibit hospice personnel from being present when the medication is taken. Hospice workers generally step out of the room or the building, then return to provide support to family members and caregivers.[129]

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[124] *See, e.g.*, Or. Med. Ass'n, Argument in Favor of Measure No. 51, Statewide Special Election Online Voters' Guide, Nov. 4, 1997, *available at* http://www.sos.state.or.us/elections/nov497/voters.guide/M51/M51arf.htm.

[125] *See, e.g.*, David Lodzinski, Argument in Favor of Measure No. 51, Statewide Special Election Online Voters' Guide, Nov. 4, 1997, *available at* http://www.sos.state.or.us/elections/nov497/voters.guide/M51/M51arf.htm.

[126] OR. REV. STAT. § 127.892 (2008).

[127] State Representative George Eighmey, Remarks at 10 Years: The Data, Seminar on End of Life Options, Including Oregon's Death with Dignity Act, Compassion & Choices of Oregon, and the Oregon Hospice Association, Or. Med. Ass'n Medical Educ. Conference Ctr. (June 21, 2008).

[128] *Comparison*, *supra* note 71.

[129] P. Miller, *Communication at the End-of-Life: Social Work, Hospice and Oregon's Death With Dignity Act*, Slide No. 16, Or. Hospice Ass'n Professional Practices Exchange, Redmond, Oregon, Oct. 3, 2008, *forthcoming* http://oregonhospice.org/handout_downloads.htm.

COMPLICATIONS

It was predicted that pills would not work and that botched cases would repeatedly result in permanent brain damage.[130] In 2005, one person awoke after ingesting medication and died a natural death two weeks later.[131]

END-OF-LIFE CONCERNS

The loss of autonomy or control has consistently been the major

QUALITY OF DEATH: VRFF AND ODDA

Hospice nurses rated and compared the quality of deaths experienced by hospice patients who ingested medication under the provisions of the ODDA and those who stopped eating and drinking.[150] Prior to the publication of the *New England Journal of Medicine* article in 2003, only a few cases had been reported in the literature about persons who stopped eating and drinking for the purpose of hastening death. Preliminary surveys of hospice workers suggested that the practice was more widespread than expected, and so it was decided to include VRFF in the research questionnaire.[151] Nearly twice as many hospice nurses reported on VRFF cases than reported on ODDA cases, adding information about 102 individuals who stopped eating and drinking.[152] Publishing this information was potentially opening the proverbial can of worms. The median length of time of death from stopping eating and drinking was fifteen days; the mandatory waiting period before a prescription could be written under the ODDA was also fifteen days.[153] No laws prohibited capable people from stopping eating and drinking; it was a legal option in all states. Hospice nurses rated the quality of death for both as very high, with VRFF deaths having less pain and suffering and being more peaceful.[154]

The implications of these studies on both legal and medical decision-making became dramatically apparent in March 2005, when Terri Schiavo's feeding tube was removed.[155] IRB-approved research offered convincing evidence that Terri Schiavo's death by starvation would not be the same as staking her out in the desert to die.[156]

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[150] *See* Ganzini et. al., *Nurses' Experiences with Hospice Patients*, *supra* note 71.

[151] Sandra Jacobs, *Death by Voluntary Dehydration—What the Caregivers Say*, 349 NEW ENG. J. MED. 325, 359 (2003).

[152] Ganzini et al., *Nurses' Experiences with Hospice Patients*, *supra* note 73, at 361 tbl.1.

[153] *Id.* at 364.

[154] *See id.* at 363.

[155] Ryan Bowley, *Controvery Ends in Peaceful Death*, THE COWL, April 7, 2005, *available at* http://media.www.thecowl.com/media/storage/paper493/news

Results of the autopsy in June showed that Schiavo "suffered severe, irreversible brain damage . . . in nearly all its regions."[157]

QUALITY OF END-OF-LIFE CARE IN OREGON

Between 1998 and 2007, 341 Oregonians died within the provisions of the ODDA.[158] Approximately 300,000 Oregonians died of other causes.[159] In April 1998, when the law was publicly used for the first time, Oregon was being recognized outside of the state's borders as a leader in end-of-life care.[160] This honor created an excellent benchmark. In 2002, the Robert Wood Johnson Foundation issued "Means to a Better End," a national report card on end-of-life care.[161] OHA statisticians used grades awarded in the report to rank all states.[162] The report clearly indicated a need for improvement in the care of dying Americans throughout the country.[163] Oregon, ranking second, had a grade of only a B-. Grades in this report have been incorrectly reported—and often repeated—by opponents of physician-assisted dying as evidence of the ODDA's negative impact.[164] Forbes Magazine ranked Oregon second in 2005 on its "Best Places to Die" in America.[165]

End-of-life care in Oregon ranks high in almost all indicators. Nine of ten Americans want to die at home.[166] Oregon's hospital

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[157] David Brown & Shailagh Murray, *Schiavo Autopsy Released*, WASH. POST, June 16, 2005, at A1.

[158] *See supra* note 55 and accompanying text.

[159] *See supra* note 65 and accompanying text.

[160] *See* The Nat'l Program Office for Cmty-State P'ships to Improve End-of-Life Care, *Using Qualitative and Quantitative Data to Shape Policy Change*, STATE INITIATIVES IN END-OF-LIFE CARE, FOCUS: OREGON, June 1998, at 3, *available at* http://www.rwjf.org/files/publications/other/State_Initiatives_EOL1.pdf.

[161] *See generally,* LAST ACTS, MEANS TO A BETTER END: A REPORT ON DYING IN AMERICA TODAY (2002), *available at* http://www.rwjf.org/files/publications/other/means betterend.pdf.

[162] *See id.* at 9–44.

[163] *Id 8 1 2 . 3 3 1 0 T D - 0 . 0 0 1 4 T j 7 o h i 2 6 (f f i c e f o r v - 3 . 4 1 55*

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death rate is among the lowest;[167] its home death rate among the highest.[168] The cost of end-of-life care in Oregon is among the lowest,[169] but patient/family satisfaction with care is equal to or better than in states were the cost of end-of-life care is highest.[170]

Oregon's advanced planning rate is highest by a wide margin. In 2002, nearly 80% of dying Oregonians had an advance directive, and the likelihood that an advance directive would be respected was high.[171] When a POLST was in place, wishes were respected virtually 100% of the time.[172]

Morphine consumption in Oregon, a crude indicator of physician willingness to prescribe controlled substances, is consistently among the top ten and nearly double the national average.[173] Oregon's laws on prescribing medication are among the least restrictive in the nation. Those states with the most restrictive laws rank at the bottom, at approximately half the national average.[174] The U.S. DEA and the U.S. Department of Justice support a national prescription monitoring system. Efforts to pre-empt the DEA by adopting a prescription monitoring system modeled after one that has had a positive effect on state physician prescribing practices, have so far failed in Oregon.

Oregon is ranked fourth in hospice penetration for those 65 and over (Medicare hospice deaths/total Medicare deaths).[175] Medicare's

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[167] Ctr. for Gerontology and Health Care Research, Facts On Dying: Policy Relevant Data on Care at the End of Life, Oregon State Profile, http://www.chcr.brown.edu/dying/orprofile.htm (last visited Oct. 26, 2008).

[168] *Id.*

[169] *See* Press Release, Dartmouth Med. Sch., New Study Shows Need for a Major Overhaul of How United States Manages Chronic Illness (May 16, 2006), *available at* http://dms.dartmouth.edu/news/2006_h1/16may2006_overhaul.shtml (discussing Dartmouth Atlas Project).

[170] *See id*.

[171] *See id*.

[172] *See* Susan W. Tolle, et al., *A Prospective Study of the Efficacy of the PO(L)ST: Physician Order Form for Life-Sustaining Treatment*, 46 J. Am. Geriatrics Soc'y 1097 (1998); Susan Hickman, et al., *Use of the POLST (Physician Orders for Life-Sustaining Treatment) Paradigm Program in the Hospice Setting*, J. Palliative Med. (forthcoming 2008).

[173] Office of Diversion Control, Dep't of Justice Drug Enforcement Admin., Retail Drug Summary: Rep. 4—Cumulative Distribution in Grams per 100K Population, 26 (1996), *available at* http://www.deadiversion.usdoj.gov/arcos/retail_drug_summary/2006/06_rpt4.pdf.

[174] Pain & Policy Studies Group, Univ. of Wis. S

data base is the only one to reflect hospice utilization for all states. Oregon, through OHA, is one of a handful of states that collects comprehensive and statistically significant data about hospice utilization.[176] Oregon is the only state to require accreditation and certification for hospices.[177] OHA is recognized as an accrediting body for hospices.[178]

Hospice utilization has increased in Oregon since the ODDA was passed, but hospice utilization in Oregon has been among the highest in the nation since at least 1992.[179] Hospice utilization has increased throughout the country in the past ten years, alarmingly so in some areas.[180]

The ODDA has been a catalyst, however, in efforts to improve Oregon's end-of-life care.[181] Whether Oregon's health care professionals personally support or oppose the ODDA or the concept behind it, they do not want Oregonians to use it because end-of-life care is inadequate. It is one thing for people to use the ODDA because they are concerned about pain, and another for people to use needs of hospice patients. And hospice workers are unanimous in agreement that the ODDA facilitates meaningful and important conversations about the end of life.