IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV-2015-485-235

UNDER	**The Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990**
BETWEEN	**LECRETIA SEALES**
	Plaintiff
AND	**ATTORNEY-GENERAL**
	Defendant

AFFIDAVIT OF LINDA KAY GANZINI
AFFIRMED 16 APRIL 2015

RUSSELL McVEAGH

A S Butler | C J Curran | C M Marks
Phone +64 4 499 9555
Fax +64 4 499 9556
PO Box 10-214
DX SX11189
Wellington

I, **LINDA KAY GANZINI**, psychiatrist of Portland, Oregon, the United States of America affirm:

Introduction

1. I am a Professor of Psychiatry and Medicine at the Oregon Health & Sciences University ("**OHSU**"). I am a practising geriatric psychiatrist.

2. I have been asked to make this affidavit in relation to Lecretia Seales' statement of claim dated 20 March 2015. The purpose of this affidavit is to provide the court with research that I have authored in relation to the risk to vulnerable groups following the legalisation of various forms of physician assisted death.

3. I obtained my BA from Yale University in 1978 and my Doctor of Medicine in 1983 from OHSU. Between 1984 and 1987 I was a Psychiatry Resident at OHSU (including Chief Resident from 1986 to 1987), and from 1987 to 1989 I was a Gerontology Fellow at the Portland Veterans Affairs Medical Center. In 2003 I obtained a Masters of Public Health with an emphasis in epidemiology and biostatistics from OHSU. I received my Diploma from the American Board of Psychiatry and Neurology in 1989, and Certification in Geriatric Psychiatry in 1991, 2000 and 2010. I have authored over 120 peer reviewed articles in the medical literature on such topics as decision making capacity, end of life care and physician assisted death.

4. I currently hold the following positions:

   (a) Professor of Psychiatry and Medicine, OHSU;

   (b) Director of Geriatric Psychiatry Fellowship Programme, OHSU;

   (c) Director of the Division of Geriatric Psychiatry, OHSU; and

   (d) Senior Scholar, Center on Ethics in Health Care, OHSU.

5. I annex a copy of my curriculum vitae at page 1 of the annexure "**LKG-1**".

6. I have read the Code of Conduct for Expert Witnesses and agree to comply with it.

Research into impact of physician assisted dying on vulnerable groups

2007 Study

7. In 2007, I was part of an international cross-disciplinary team that published "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups", *J Med Ethics* 2007; 33:591-597 ("**2007 Study**"), page 20 of annexure "LKG-1". The Journal of Medical Ethics is a leading international journal with a double blind peer review process.

8. The purpose of the study was to empirically investigate the very serious concerns raised about whether legal physician assisted dying can put at risk those who are members of vulnerable groups. We approached the task by investigating the data by reference to groups that are commonly described as vulnerable. We assessed 10 groups. They were:

(a) the elderly;

(b) women;

(c) those without health insurance;

(d) people with AIDS;

(e) people with low educational status;

(f) the poor;

(g) racial and ethnic minorities;

(h) people with non-terminal physical disabilities or chronic non-terminal conditions;

(i) minors and mature minors; and

(j) people with psychiatric illness (including depression and Alzheimer disease).

9. Those groups corresponded, in our view, with the groups commonly described as "vulnerable" by those concerned about the potential effects of legalised physician assisted dying (in box one of our study at page 592 we set out the concerns expressed by bodies such as the New York State Task Force on Life and the Law, the joint opinion in the US Supreme Court decision of *Washington v Glucksberg* and other eminent groups referring to such vulnerable populations).

10. We chose the jurisdictions of Oregon and the Netherlands in which physician assisted dying is legal and in which data was collected pertaining to the conduct of physician assisted dying. Our methodology and the data available to us are set out in our report, as is a summary of the legal regimes in those two jurisdictions (see box 2 at page 593).

11. Risk is a statistical and epidemiological term. In summary, we were unable to find any evidence of a heightened risk in that sense to people within nine of the vulnerable groups. However, we did identify a heightened risk in that sense in relation to people with AIDS. In Oregon, however, the number of persons with AIDS/HIV who access the law is very low, comprising eight deaths since the law's enactment in 1997, representing 1.1% of all deaths under the law.

12. We concluded overall that the data does not support concerns that death in this way would be practised more frequently on persons who are considered vulnerable in terms of demography or illness, excepting the possibility of persons with AIDS.

Criticism of the 2007 Study

13. Ilora Finlay and Robert George published a critique of our study making four criticisms ("Legal physician-assisted suicide in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups - another perspective on Oregon's data", *J Med Ethics*, published online on 11 November 2010 (doi.10.1136)), page 28 of annexure "LKG-1". Our reply is at page 32 of annexure "LKG-1".

14. The principal objection made was that vulnerability is not necessarily defined by socioeconomic groups (page 172 of the paper). I agree with that.

15. Indeed, the point and focus of the 2007 Study, as described in the article itself, was to identify whether members of groups, which respected commentators on legalised physician assisted dying had identified as being vulnerable, were at risk. We found that they were not, subject to the caveat around patients with AIDS. I am not aware of any other study that established that the groups we researched are at risk from legalising physician assisted dying.

16. In addition to the principal criticism of the 2007 Study, other criticisms were raised. Those criticisms and why they were not well made are:

    (a) The sample available does not introduce a systematic error into the assessment of the risk to the elderly. Our data showed that in Oregon those over 85 had the lowest ratio of assisted dying, followed by those aged between 65 and 84. In the Netherlands, there was no difference in the rate between those younger than 65 and those aged 65 or older.

    (b) It is true, as we noted, that some who received prescriptions in Oregon survived more than six months. That reflects the fact that prognosis is not perfect. But survival for more than six months does not mean that the patient is not suffering from terminal illness. Nor is it evidence that assisted dying in Oregon is used in cases of chronic illness.

17. That is not to say that the jurisdictions that we studied (and indeed other jurisdictions) cannot improve on the practices we observed in Oregon and the Netherlands. For example, in a subsequent study (L Ganzini, E Goy and S Dobscha "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey", *British Medical Journal* 2008: 337: A1682), page 34 of annexure "LKG-1", which was relied on by Ilora Finlay and Robert George, we tried to understand the prevalence of depression in those seeking aid in dying. Although our sample was small, we concluded that while most patients who request aid in dying do not have a depressive disorder, the Oregon system may not adequately protect all mentally ill patients and increased vigilance and systematic examination for depression were needed. I emphasise that the most we were able to conclude was "may not"; that was because we were unable to determine if depression was influencing the request for physician assisted death. In addition, I note that the measures we identified would be reasonably straightforward to implement. Again, to be clear, the issue we identified is not a reason, in my opinion, to oppose physician assisted dying.

Developments since the 2007 Study

18. Oregon ceased publishing the detailed data on which this study was based in 2006, and to my knowledge there has been no further research published in relation to the situation in Oregon that allows comparison of persons who die from lethal prescriptions to those who die from other causes. I am not aware of any equivalent study attempting to identify the impact of legal physician assisted dying on any of the 10 groups in the 2007 Study.

19. Since the 2007 Study was published, similar laws to those in Oregon have been passed in Washington and Vermont. I am not aware of any study addressed at vulnerable groups in those jurisdictions.

20. To my knowledge, none of the North American jurisdictions have had difficulty with physicians adapting to the law changes. For example, following the law change in Oregon (which came into force in 1997), ethical guidance was provided by the professional bodies (page 39 of annexure "LKG-1"). An article describing the experience of one hospital in Washington, following legalisation of physician assisted dying in that state in 2008 is at page 166 of annexure "LKG-1". Importantly, all of the US jurisdictions allow any physician to opt out of participating in the law for any reason.

Conclusion

21. To the best of my knowledge, the 2007 Study remains the most comprehensive and authoritative study into the potential for legalised physician assisted dying to disproportionately affect the vulnerable. I am aware of no research that contradicts or invalidates the conclusions drawn in that study.

AFFIRMED at Portland, Oregon this 16th day of April 2015 before me:

Robert LeChevallier

Linda Kay Ganzini

A person duly authorised to administer oaths in Oregon Attorney-at-law OSB 782818

Notary Public for State of Oregon
Subscribed and Sworn to before me
this 16th day April. 2015

State of Oregon)
County of Clackamas)

OFFICIAL STAMP
ROBERT T LE CHEVALLIER
NOTARY PUBLIC-OREGON
COMMISSION NO. 933812
MY COMMISSION EXPIRES NOVEMBER 09, 2018

"LKG-1"

CURRICULUM VITAE
LINDA GANZINI, MD, MPH
03/19/2015

WORK ADDRESS:	VA Portland Health Care System (VAPORHCS) Mental Health Division (R&D 66) 3710 SW U.S. Veterans Hospital Road P.O. Box 1034, Portland, Oregon 97207
WORK PHONE:	(503) 220-8262, Ext. 56492
FAX:	(503) 402-2952
EMAIL:	Linda.Ganzini@va.gov

CURRENT POSITIONS

1989 - Present	Staff Psychiatrist, Consult-Liaison Psychiatry Service and Outpatient Mental Health, VAPORHCS
1990 - Present	Director of Geriatric Psychiatry Fellowship Program, VAPORHCS
1995 - Present	Senior Scholar, Center on Ethics in Health Care, Oregon Health & Science University (OHSU), Portland, OR
2001 - Present	Professor of Psychiatry, OHSU
2003 - Present	Professor of Medicine, OHSU
2005 - Present	Director, Division of Geriatric Psychiatry, OHSU
2013 - Present	Associate Director, HSR&D Center to Improve Veteran Involvement in Care (CIVIC)

EDUCATION

1974 - 1978	BA, Yale University, New Haven, Connecticut
1979 - 1983	MD, OHSU
1998 - 2003	MPH with emphasis in epidemiology and biostatistics

MAJOR PROFESSIONAL TRAINING AND EXPERIENCE

1983 - 1984	Internal Medicine Resident, OHSU
1984 - 1987	Psychiatry Resident, OHSU
1986 - 1987	Chief Resident in Psychiatry, OHSU
1987 - 1989	Gerontology Fellow, VAPORHCS
1989 - 1994	Assistant Professor of Psychiatry, OHSU
1989 - 1998	Director of Consult-Liaison Psychiatry, VAPORHCS
1993 - 1995	Co-Director VAPORHCS demonstration project, "Enhancing the Management and Continuity of Mental Health Care of Older Veterans in the Acute Psychiatry and Nursing Home Care Unit Settings"
1994 - 1997	Director, Medical Student Clerkship in Psychiatry, OHSU
1994 - 2001	Associate Professor of Psychiatry, OHSU
1996 - 2001	Associate Director, Psychiatry Residency Training Program, OHSU
1998 - 2000	Project on Death in America Faculty Scholar, Open Society Institute
2001 - 2013	Director, Interprofessional Fellowship Program in Palliative Care, VAPORHCS
2006 - 2013	Director, Portland Center for the Study of Chronic, Comorbid Mental and Physical Disorders, VA HSR&D Research Enhancement Award Program

This is the annexure marked **"LKG-1"** referred to in the affidavit of **Linda Kay Ganzini** affirmed at Portland, Oregon this day of April 2015 before me

Signature Robert LeChevallier atty-at-law

A person duly authorised to administer oaths in Oregon OSB 782818

PROFESSIONAL EXPERIENCE

1989	Visiting Fellowship in Psychogeriatrics, Guy's-Hithergreen Hospital, London (April 1 - May 1)
1989 - 1994	Examiner, American Board of Psychiatry and Neurology, Part II "Oral Exams"

MEDICAL LICENSURE

1984	Oregon (MD14026)

SPECIALTY CERTIFICATION

1989	Diplomate in Psychiatry, American Board of Psychiatry and Neurology
1991	Added-qualification in Geriatric Psychiatry, American Board of Psychiatry and Neurology
2000	Added-qualification recertification in Geriatric Psychiatry, American Board of Psychiatry and Neurology
2010	Added-qualification recertification in Geriatric Psychiatry, American Board of Psychiatry and Neurology - through 2020

HONORS AND AWARDS

1983	Cum Laude - OHSU
1983	Alpha Omega Alpha
1983	Lange Book Award
1983	American Women's Medical Association Award for Scholastic Achievement
1985 - 1987	APA Mead-Johnson Fellowship in Public Psychiatry
1987	Resident Research Award, North Pacific Society for Psychiatry and Neurology
1991	National Institute of Mental Health - International Congress on Schizophrenia Research, Young Investigator Award
1991	Psychiatry Residency Teaching Award - OHSU
1993	American College of Neuropsychopharmacology, Young Investigator Award
1994	Portland Veterans Affairs Health Care Research Award
1996	Distinguished Service Award, Psychiatry Residency Training Program, OHSU
1996	Best Doctors in America, Pacific Region, Geriatric Psychiatry
1997	Nancy C.A. Roeske, M.D., Certificate of Recognition for Excellence in Medical Student Education, American Psychiatric Association
1998	Best Doctors in America, Geriatric Psychiatry
2003	Faculty Development Award, Department of Psychiatry, OHSU
2003	Second Place Award, Poster Session, Academy of Psychosomatic Medicine Annual Meeting, San Diego, CA
2004	Best Doctors in America, Psychiatry
2005	Research Award, Academy of Psychosomatic Medicine
2005 - 2009	Best Doctors in America
2010	Finalist, Dlin-Fisher Award, Best paper submission, Academy of Psychosomatic Medicine

PROFESSIONAL COMMITTEES (selected)

1989 - 2005	Ethics Committee, VAPORHCS
1989 - 2005	Ethics Clinical Consultation Subcommittee, VAPORHCS (Chair, 1994-2005)

1996 - 2004	Task Force to Improve the Care of Terminally-Ill Oregonians
1997 - 2003	Research and Development Committee, VAPORHCS (Chair, 2001-2003)
1998 - 2005	Board Member, Oregon Hospice Association
1999 - 2002	VA National Bioethics Committee
2005 - 2007	Research and Development Committee, VAPORHCS
2006 - 2008	Academy of Psychosomatic Medicine, Annual Meeting, Program Committee
2006 - Present	Department of Psychiatry Executive Committee, OHSU
2006 - 2011	Promotion and Tenure Committee, School of Medicine, OHSU
2006 - 2011	Medical Student Award Committee, OHSU
2007 - 2011	School of Medicine Faculty Council, OHSU
2007 - Present	Academy of Psychosomatic Medicine, Council
2008 - Present	OHSU Department of Psychiatry Promotion and Tenure Committee
2008 - Present	Member, Northwest Parkinson's Disease Research, Education and Clinical Center, VAPORHCS
2008 - 2011	Lake Oswego School District Foundation Northside Campaign Chair, 2008-2009—Raised $1.6 million for Lake Oswego Schools President, 2009-2010 Campaign Chair, 2010-2011—Raised $2.2 million for Lake Oswego Schools
2008 - 2010	Academy of Psychosomatic Medicine, Chair, Research Committee
2009 - 2012	Member, Northwest HSR&D Steering Committee
2010 - 2011	Alternate Chair, Research & Development Committee, VAPORHCS
2011 - 2012	Academy of Psychosomatic Medicine, Program Chair
2011 - Present	Ad Hoc Reviewer, HSR&D NRI Scientific Merit Review Board
2012 - 2013	Academy of Psychosomatic Medicine, Secretary
2013 - Present	OHSU Research Committee
2013 - Present	President, Portland VA Research Foundation

TEACHING, EDUCATION AND MENTORING (last decade)

Courses

1990 - Present	Introduction to Geriatric Psychiatry, MS3 (2 hours every six weeks)
1990 - 2013	Introduction to Geriatrics for PGY 2 and PGY 3 Psychiatry Residents (8 hours biannually)
1991 - Present	Coordinator for weekly Geriatric Psychiatry Journal Club
1994 - 1997	Course Director, Medical Student Clerkship in Psychiatry
1998 - 2009	Lecturer and Small Group Leader, MS2 Aging Section, Growth and Development (3 hours)
2003 - 2012	Coordinator, All City Palliative Care Conferences
2002 - Present	Palliative Care Fellowship, Didactics (6 hours annually)
2006 - Present	"Decision-making Capacity." Yearly to Forensic Psychiatry Fellows
2007 - 2009	Principles of Clinical Medicine, MS1 course, spring, small group leader (24 in-class hours)

Clinical Supervision (last decade)

1989 - Present	PGY2 Psychiatry Resident, Psychiatry Consultation Service
1991 - Present	PGY5 Geriatric Psychiatry Fellows in Outpatient Clinic
2005 - Present	Geriatric Medicine Fellow, Psychiatry Consultation Service
2007 - Present	MS3 Psychiatry Clerkship, Psychiatry Consultation Service
2010 - Present	PGY1 Neurology Resident, Psychiatry Consultation Service

Research Supervision

1992 - 1994	Kathleen Farrell, MD, Geriatric Medicine Fellow, "Misidentification of delirium as depression."
1993 - 1994	Pam Edwards, MD, Psychiatry Resident, "Violent elderly in emergency care."
1994 - 1996	Susan Levitte, MD, Psychiatry Junior Faculty, "Geriatric training in adult psychiatry resident training programs."
1995 - 1997	Beverly Kay Young, MD, Geriatric Psychiatry Fellow, "Neuropsychiatric adverse effects of antiparkinsonian drugs."
1998 - 1999	Maria Silveira, MD, Medicine Resident, "Caregivers' assessment of a good death for ALS patients."
1999 - 2004	Richard Mularski, MD, Pulmonary Fellow, "Concordance among family caregivers on quality of death" and "Pain as a 5th vital sign."
2001 - 2012	Sahana Misra, MD, Psychiatry Junior Faculty, "Capacity to consent to research participation in bipolar patients." VA Career Development Award, 2004-2007
2003 - 2012	Elizabeth Goy, PhD, "Last month of life in patients with Parkinson's disease: caregiver perspectives." VA Career Development Award, 2006-2009
2003 - 2012	Suzanne Watnick, MD, "Depression and mortality in dialysis patients."
2004 - 2009	Steven Dobscha, MD, "Treatment of depression in primary care." VA Advanced Career Development Award, 2005-2008
2005 - 2009	Kristen (Snyder) Dunaway, MD, "Effect of Oregon motor vehicle reporting changes on elderly drivers."
2010 - Present	Christopher Slatore, MD, MS, "Lung Cancer Evaluation Process: Understanding Risks Along the Continuum."

PROFESSIONAL PRESENTATIONS (last decade)

April, 2005	"Update on Depression and Behavioral Disorders in the Elderly." Department of Medicine 12th Annual Internal Medicine Review, OHSU, Portland, OR
September, 2005	"Physician-Assisted Suicide." Pain and Palliative Care Conference, Stanford University Medical Center, Stanford, CA
October, 2005	"The Lessons of Terri Schiavo." Keynote speaker, "Artificial Nutrition and Hydration at the End of Life: Ethics and Evidence." Smith College, MA
October, 2005	Ernest Becker Society, Annual Meeting. Keynote speaker, Seattle, WA
November, 2005	"Oregon's Death with Dignity Act: Who Requests Assisted Suicide?" Academy of Psychosomatic Medicine, Research Award and Plenary Lecture, Albuquerque, NM
February, 2006	"Behavioral Problems in Dementia." OHSU Family Medicine Review Course, Portland, OR

February, 2006	“Oregon’s Death with Dignity Act: Who Chooses Physician-Assisted Suicide?” American Academy of Hospice and Palliative Medicine Annual Assembly, Nashville, TN
February, 2006	“Care of Patients with Posttraumatic Stress Disorder and Schizophrenia at the End of Life.” American Academy of Hospice and Palliative Medicine Annual Assembly, Nashville, TN
March, 2006	“Controversies in Artificial Food and Hydration at the End of Life.” American Medical Directors Association, Dallas, TX
March, 2006	“The Oregon Death with Dignity Act: Eight Years Experience.” Canadian Palliative Care Association, Victoria, BC
May, 2006	“The Effect of the Pharmaceutical Industry on Medical Education.” Federal Pharmacy Conference, Tacoma, WA
May, 2006	“Artificial Nutrition and Hydration at the End of Life: Ethics and Evidence.” Oregon Geriatric Education Center, Annual Conference, Portland, OR
June, 2006	“Care of Patients with Chronic Mental Disorders at the End of Life.” Statewide Palliative Care Conference, Beaverton, OR
September, 2006	“The Disappearing Patient.” Morbidity and Mortality, Department of Medicine, Portland, OR
November, 2006	“When Does a Feeding Tube Prolong Life or Increase Comfort?” Academy of Psychosomatic Medicine Annual Meeting, Tucson, AZ
November, 2007	“Accusations of Euthanasia in End of Life Care.” Academy of Psychosomatic Medicine Annual Meeting, Amelia Island, FL
March, 2008	“Update on Delirium.” OHSU Family Medicine Review Course, Portland, OR
September, 2008	“Medical Decision Making and Palliative Care for People Who are Chronically Mentally Ill.” Legacy Department of Medicine Grand Rounds, Portland, OR
September, 2008	“Caring for People With Mental Illness at the End of Life.” OHSU Department of Psychiatry Grand Rounds, Portland, OR
November, 2008	“The Oregon Death With Dignity Act: A Decade of Experience.” Academy of Psychosomatic Medicine Annual Meeting, Miami, FL
April, 2009	“Medical Decision Making and Palliative Care for People Who are Chronically Mentally Ill.” Update on Gerontology, Oregon State University, Corvallis, OR
April, 2009	“Washington’s Initiative 1000: Lessons from Oregon’s Death With Dignity Act.” Fred Hutchinson Cancer Center, Seattle, WA
May, 2009	“The Oregon Death with Dignity Act: Who Chooses Assisted Suicide.” Symposium, APA, San Francisco, CA
June, 2010	“Medical Decision Making and Palliative Care for People Who are Chronically Mentally Ill.” 2010 Statewide Palliative Care Conference presented by Hospice and Palliative Care of Washington County and the Center for Ethics in Health Care, Portland, OR
June, 2010	“Testamentary Capacity: Views of an Psychiatrist Expert.” Basic Estate Planning and Administration, Oregon State Bar CLE, Portland, OR
September, 2010	“End of Life Assistance (Scotland) Bill Committee - Papers for 4th Meeting 2010.”

	Teleconference with Parliament, Edinburgh, Scotland, from OHSU, Portland, OR
December, 2010	"The Oregon Death with Dignity Act: Why Do Patients Request Physician Assisted Death?" 21st Annual Symposium on ALS/MND, invited speaker, Orlando, FL
December, 2010	"Testamentary, Contractual, and Financial Capacity: Views of a Psychiatrist." Northwestern School of Law of Lewis & Clark College, Portland, OR
May, 2011	"Refusal of Life-Sustaining Treatment." 164th Annual Meeting of the American Psychiatric Association, Honolulu, HI
June, 2011	"Capacity." VA Mental Health Integration in Palliative Care Conference, Phoenix, AZ
June, 2011	"Ethics Vignettes." VA Mental Health Integration in Palliative Care Conference, Phoenix, AZ
August, 2011	"Capacity – Medical and Psychiatric Considerations." Oregon Law Institute of Lewis & Clark Law School, Portland, OR
September, 2011	"The Death with Dignity Act: Why Do Individuals Pursue Hastened Death?" 24th Annual Fall CME Conference of the Oregon Psychiatric Association, Ashland, OR
November, 2011	"The Management of Suicidal Ideation in the Terminally Ill and Disenfranchised Patient." Academy of Psychosomatic Medicine, Phoenix, AZ
November, 2011	"Elopement Risk." Academy of Psychosomatic Medicine, Phoenix, AZ
December, 2011	"Financial Capacity." Oregon Law Institute CLE, Portland, OR
September, 2012	"Why Do Patients Request Physician Aid in Dying?" San Diego Hospice and Grand Rounds University of San Diego, CA
September, 2012	"Case Studies in Decision Making Capacity at the End of Life." San Diego Hospice and Grand Rounds University of San Diego
November, 2012	"Delirium and End of Life Care in Patients with Schizophrenia." Academy of Psychosomatic Medicine, Atlanta, GA
May, 2013	"Advances in Medical Care for Patients with Schizophrenia." American Psychiatric Association Annual meeting, San Francisco, CA
November, 2013	"A Focused Review of Suicide for the Consultation-Liaison Psychiatrist." Academy of Psychosomatic Medicine, Phoenix, AZ
November, 2013	"Assessment and Management of Suicide Risk in Nonpsychiatric Settings." Academy of Psychosomatic Medicine, Phoenix, AZ
November, 2013	"Advances in Medical Care for Patients with Serious Mental Illness." Academy of Psychosomatic Medicine, Phoenix, AZ
December 2013	"Financial Capacity." OHSU Department of Psychiatry Grand Rounds, Portland, OR
August, 2014	"The Oregon Death with Dignity Act." Invited presentation, International Conference on End of Life: Law, Ethics, Policy and Practice 2014, Queensland University of Technology, Brisbane Australia
August 2014	"Financial Capacity." Oregon Guardians and Conservators Association, Portland, OR
September 2014	"Decision making capacity." VISN 20 Rural Dementia, Portland, OR

February, 2015	"Oregon's Death with Dignity Law: How's it Working?" OHSU Primary Care Review, Portland, OR
February, 2015	"Financial Capacity in the Elderly." VISN 2O Northwest Mental Illness Research, Education, and Clinical Center, Portland, OR
March, 2015	"Death with Dignity: Why Do Patients Request Hastened Death?" Webinar, Association of Professional Chaplains, Portland, OR

<u>EDITORIAL BOARD</u>

Palliative and Supportive Care (2003-2012)
General Hospital Psychiatry (2012-current)

<u>REFEREED PUBLICATIONS</u>

1. **Ganzini L**, McFarland B, Bloom J: Victims of fraud: A comparison of victims of white collar and violent crimes. <u>Bulletin of the American Academy of Psychiatry and the Law</u> 18:55-63, 1990
2. **Ganzini L**, McFarland B, Cutler D: Prevalence of mental disorders after catastrophic financial loss. <u>Journal of Nervous and Mental Disease</u> 178:680-685, 1990
3. **Ganzini L**, Heintz RT, Hoffman WF, Casey DE: The prevalence of tardive dyskinesia in neuroleptic-treated diabetics: A controlled study. <u>Archives of General Psychiatry</u> 48:259-263, 1991
4. **Ganzini L**, Heintz RT, Hoffman WF, Keepers GA, Casey D: Acute extrapyramidal syndromes in neuroleptic-treated elders: A pilot study. <u>Journal of Geriatric Psychiatry and Neurology</u> 4:222-225, 1991
5. **Ganzini L**, Lee MA, Heintz RT, Bloom JD: Do-not-resuscitate orders for depressed psychiatric inpatients. <u>Hospital and Community Psychiatry</u> 43:915-919, 1992
6. Lee MA, **Ganzini L**: Depression in the elderly: Effect on patient attitudes toward life-sustaining therapy. <u>Journal of the American Geriatrics Society</u> 40:983-988, 1992
7. **Ganzini L**, Casey DE, Hoffman WF, Heintz RT: Tardive dyskinesia and diabetes mellitus. <u>Psychopharmacology Bulletin</u> 28:281-286, 1992
8. **Ganzini L**, Walsh JR, Millar SB: Drug-induced depression in the aged: What can be done? <u>Drugs and Aging</u> 3:147-158, 1993
9. **Ganzini L**, Lee MA, Heintz RT, Bloom JD: Is the Patient Self-Determination Act appropriate for elderly persons hospitalized for depression? <u>Journal of Clinical Ethics</u> 4:46-50, 1993
10. **Ganzini L**, Casey DE, Hoffman WF, McCall AL: The prevalence of metoclopramide-induced tardive dyskinesia and acute extrapyramidal movement disorders. <u>Archives of Internal Medicine</u> 153:1469-1475, 1993
11. **Ganzini L**, Millar S, Walsh J: Drug-induced mania in the elderly. <u>Drugs and Aging</u> 3:428-435, 1993
12. Lee MA, **Ganzini L**: The effect of recovery from depression on preferences for life-sustaining therapy in older patients. <u>Journal of Gerontology: Medical Sciences</u> 49:15-21, 1994
13. **Ganzini L**, Lee MA, Heintz RT, Bloom JD, Fenn DS: The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy. <u>American Journal of Psychiatry</u> 151:1631-1636, 1994
14. Joseph CL, Atkinson RM, **Ganzini L**: Problem drinking among residents of a VA nursing home. <u>International Journal of Geriatric Psychiatry</u> 10:243-248, 1995
15. Joseph CL, **Ganzini L**, Atkinson RM: Screening for alcohol use disorders in the nursing home. <u>Journal of the American Geriatrics Society</u> 43:368-373, 1995
16. Joseph CL, Goldsmith S, Rooney A, McWhorter K, **Ganzini L**: An interdisciplinary mental health consultation team in a nursing home. <u>Gerontologist</u> 35:836-839, 1995
17. **Ganzini L**, Edwards P, Surkan PJ, Drummond DJ: Characteristics of violent elderly in the emergency department. <u>International Journal of Geriatric Psychiatry</u> 10:945-950, 1995
18. Farrell K, **Ganzini L**: Misdiagnosing delirium as depression in medically-ill elderly patients. <u>Archives of Internal Medicine</u> 155:2459-2464, 1995

19. Lee MA, Nelson HD, Tilden VP, **Ganzini L**, Schmidt TA, Tolle SW: Legalizing assisted suicide—Views of physicians in Oregon. New England Journal of Medicine 334:310-315, 1996
20. **Ganzini L**, Fenn DS, Lee MA, Heintz RT, Bloom JD: Attitudes of Oregon psychiatrists toward physician-assisted suicide. American Journal of Psychiatry 153:1469-1475, 1996
21. Schmidt TA, Zechnich AD, Tilden VP, Lee MA, **Ganzini L**, Nelson HD, Tolle SW: Oregon emergency physicians' experiences with, attitudes toward, and concerns about physician-assisted suicide. Academic Emergency Medicine 3:938-945, 1996
22. Lee MA, **Ganzini L**, Brummel-Smith K: When patients ask about assisted suicide: A viewpoint from Oregon. Western Journal of Medicine 165:205-208, 1996
23. Levitte SS, **Ganzini L**, Keepers GA: Geriatric training in adult psychiatry residency training programs. Academic Psychiatry 20:226-231, 1996
24. Drickamer MA, Lee MA, **Ganzini L**: Practical issues in physician-assisted suicide. Annals of Internal Medicine 126:146-151, 1997
25. **Ganzini L**, Smith DM, Fenn DS, Lee MA: Depression and mortality in medically-ill elderly. Journal of the American Geriatrics Society 45:307-312, 1997
26. Young BK, Camicioli R, **Ganzini L**: Neuropsychiatric adverse effects of antiparkinsonian drugs: Characteristics, evaluation and treatment. Drugs and Aging 10:367-383, 1997
27. Joseph CL, Rasmussen J, **Ganzini L**, Atkinson RM: Outcomes of nursing home care for residents with alcohol use disorders. International Journal of Geriatric Psychiatry 12:767-772, 1997
28. Lewin L, Cowan M, **Ganzini L**, Gonzales L, Rasmussen J: Behavioral problem solving, contracting, and feedback with nursing home residents. Journal of Clinical Geropsychology 3:245-255, 1997
29. Sullivan M, **Ganzini L**, Youngner SJ: Should psychiatrists serve as gatekeepers for physician assisted suicide? Hastings Center Report 28:14-22, 1998
30. **Ganzini L**: An independent scientist (A Piece of My Mind). JAMA 280:950, 1998
31. **Ganzini L**, Johnston WS, McFarland BH, Tolle SW, Lee MA: Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. New England Journal of Medicine 339:967-973, 1998
32. Lee MA, Smith DM, Fenn DS, **Ganzini L**: Do patients' treatment decisions match advance statements of their preferences? Journal of Clinical Ethics 9:258-262, 1999
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BOOK CHAPTERS, INVITED ARTICLES, EDITORIALS, COMMENTARIES

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LETTERS

1. Lee MA, **Ganzini L**: Depression and decision-making. Journal of the American Geriatric Society 41:345, 1993
2. **Ganzini L**, Lee MA, Heintz RT, Bloom JD, Fenn DS: Life-sustaining treatment preferences of the elderly depressed: Dr. Ganzini and colleagues reply. American Journal of Psychiatry 152:1836-1837, 1995
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BOOK / VIDEO REVIEWS

1. Busse EW, Blazer PG (eds.): Geriatric psychiatry, in Community Mental Health Journal 26:375-376, 1990
2. Hendin H: Assisted suicide. Seduced by death: Doctors, patients and the Dutch cure, in JAMA 278:340-341, 1997
3. Filene PG: In the arms of others: A cultural history of the right-to-die in America. JAMA 281:289-290, 1999
4. Lutsky M: Self-Deliverance: A Film About Assisted Suicide. Journal of Palliative Medicine 5:763, 2002

GRANTS

Medical Research Foundation of Oregon "Depression following financial disaster in older adults."
Principal Investigator: **Ganzini L**
Co-Investigators: McFarland B, Cutler D
Dates of Project: 09/86-08/87
Total Cost: $4,655

VA-RAGS "Acute extrapyramidal syndromes in neuroleptic-treated elders."
Principal Investigator: **Ganzini L**
Co-Investigator: Casey DE
Dates of Project: 10/90-09/92
Total Cost: $35,800

Medical Research Foundation of Oregon "The effect of depression on elderly patients' decisions regarding life-saving interventions."
Principal Investigator: **Ganzini L**
Co-Investigators: Lee ML, Bloom JD
Dates of Project: 09/91-08/92
Total Cost: $14,850

VA Merit Review "Tardive dyskinesia following metoclopramide discontinuation."
Principal Investigator: **Ganzini L**
Co-Investigator: Casey DE
Dates of Project: 10/92-09/96
Total Cost: $340,900

VA Western Region Demonstration Project "Enhancing the management and continuity of mental health care of older veterans in the acute psychiatry and nursing home care unit settings."
Principal Investigator: Atkinson RM
Co-Investigators: **Ganzini L**, Hoffman WF
Dates of Project: 1993-1996
Total Cost: $286,000

Society for Academic Emergency Medicine "Identification of factors which predict adverse outcomes in elderly patients: A prevalence study of functional and cognitive impairment."
Principal Investigator: Kalbfleisch N
Co-Investigators: Brummel-Smith K, **Ganzini L**, Butcher J
Dates of Project: 1993-1994
Total Cost: $10,000

Janssen Research Foundation “An open, multicenter study to evaluate the tolerability and safety of Risperdal® tablets in elderly subjects with psychotic disorders (RIS-USA-64A).”
Principal Investigator: **Ganzini L**
Dates of Project: 1995-1996
Total Cost: $9,000

Medical Research Foundation of Oregon “Attitudes toward physician-assisted suicide among patients with amyotrophic lateral sclerosis.”
Principal Investigator: Johnston WS
Co-Principal Investigator: **Ganzini L**
Co-Investigators: Lee MA, Tolle SW, McFarland BH
Dates of Project: 09/95-08/96
Total Cost: $23,700

VA Merit Review “Desire for assisted suicide in terminally-ill patients.”
Principal Investigator: **Ganzini L**
Co-Investigators: Bagby Jr GC, Brouns MC
Dates of Project: 10/97-09/00
Total Cost: $220,000
VA Headquarters “Psychiatry Primary Care Initiative”
Principal Investigator: **Ganzini L**
Dates of Project: recurring from 1997
Total Cost: $80,000 per year

Project on Death in America Faculty Scholars Award “Legalization of physician assisted suicide in Oregon.”
Principal Investigator: **Ganzini L**
Dates of Project: July 1, 1998-June 30, 2000
Total Cost: $152,000

Greenwall Foundation “Oregon primary care physicians’ experiences with legalized assisted suicide.”
Principal Investigator: **Ganzini L**
Co-Investigators: Lee MA, Nelson H
Dates of Project: July 1, 1998-February 29, 2000
Total Cost: $94,000

Gerbode Foundation “Oregon primary care physicians’ experiences with legalized assisted suicide.”
Principal Investigator: **Ganzini L**
Co-Investigators: Lee MA, Nelson H
Dates of Project: May 10, 1999-October 30, 1999
Total Cost: $13,100

American Lung Association “Quality of dying in the intensive care unit.”
Principal Investigator: Mularski R
Co-Investigators: **Ganzini L,** Osborne M
Dates of Project: Summer 2000-Summer 2001
Total Cost: $15,000

NW Health Foundation “Quality of dying in the intensive care unit.”
Principal Investigator: Mularski R
Co-Investigators: **Ganzini L,** Osborne M
Dates of Project: Summer 2000-Summer 2001
Total Cost: $5,000

VA MIRECC “Integrated treatment of chronic mental illness in the primary care setting.”
Principal Investigator: Dobscha S
Co-Investigators: **Ganzini L**, Hoffman WF
Dates of Project: July 1, 2000-June 30, 2001
Total Cost: $13,000

Greenwall Foundation "Oregon hospice care providers' views and experiences with assisted suicide and voluntary refusal of food and fluids."
Principal Investigator: **Ganzini, L**
Co-Investigators: Harvath TA, Miller LL, Jackson A, Goy E
Dates of Project: July 1, 2001-June 30, 2002
Total Cost: $74,080
Medical Research Foundation of Oregon "Influence of mood state on capacity to consent to research in bipolar patients."
Principal Investigator: Misra S
Co-Investigator: **Ganzini L**
Dates of Project: December 1, 2002-November 30, 2003
Total Cost: $30,000

School of Nursing: Symptom Management Center Award "Pain as the 5th vital sign: impact on pain management at the VAPORHCS."
Principal Investigator: Mularski R
Co-Investigator: **Ganzini L,** Miller LL
Dates of Project: December 1, 2002-November 30, 2003
Total Cost: $15,000

Medical Research Foundation of Oregon "The end of life in patients with Parkinson's disease: caregiver perspectives."
Principal Investigator: Goy ER
Co-Investigator: **Ganzini L**
Dates of Project: September 1, 2003-August 31, 2004
Total Cost: $29,570

VA Merit Review "Prevalence of mental disorders in hospice patients."
Principal Investigator: **Ganzini L**
Co-Investigator: Bascom PB
Dates of Project: October 1, 2000-September 30, 2004
Total Cost: $495,600

Northwest Health Foundation "The roles of attachment, control, meaning and hopelessness in decisions for physician-assisted suicide."
Principal Investigator: **Ganzini L**
Co-Investigators: Goy ER, Dobscha SK
Dates of Project: January 1, 2004-December 31, 2005
Total Cost: $79,556

Greenwall Foundation "Family members' views on and experiences with loved ones who choose physician-assisted suicide."
Principal Investigator: **Ganzini L**
Co-Investigators: Goy ER, Prigerson HG, Dobscha SK
Dates of Project: January 1, 2004-December 31, 2006
Total Cost: $87,992

VA HSR&D "Methylphenidate for depressed cancer patients in hospice."
Principal Investigator: **Ganzini L**
Co-Investigators: Goy ER, Nail L, Bascom PB, Mori M
Dates of Project: October 1, 2004-September 30, 2008
Total Cost: $806,700

Medical Research Foundation of Oregon "Morbidity and mortality among dialysis patients after treatment for depression."
Principal Investigator: Watnick S
Co-Investigator: **Ganzini L**
Dates of Project: April 1, 2005-March 31, 2007
Total Cost: $30,000

Greenwall Foundation "End-of-Life Care: Health Professionals and Patient Deaths"
Principal Investigator: Cohen, LM
Principal Site Investigator: Goy, ER
Co-Investigator: **Ganzini,** L
Dates of Project: January 1, 2006-December 31, 2007
Total Cost: $27,000
HSR&D Research Enhancement Award Program "Portland Center for the Study of Chronic, Comorbid Mental and Physical Disorders"
Principal Investigator: **Ganzini L**
Co-Principal Investigator: Hickam, D
Dates of Project: October 1, 2006-September 30, 2013
Total Cost: $1,731,000

HSR&D "Outcomes and Correlates of Suicidal Ideation in OEF/OIF Veterans"
Principal Investigator: Dobscha SK
Co-Investigator: **Ganzini L**
Dates of Project: October 1, 2008-April 30, 2012
Total Cost: $783,000

OCTRI "Research Consent Capacity in Individuals with and without Traumatic Brain Injury"
Principal Investigator: Misra S
Co-Principal Investigator: Goy ER
Co-Investigator: **Ganzini L**
Dates of Project: August 1, 2010-July 31, 2011
Total Cost: $10,000

Methamphetamine Abuse Research Center (MARC) Pilot Project "Health Service Use and Outcomes in Veteran Methamphetamine Abusers"
Principal Investigator: **Ganzini** L
Co-Principal Investigator: Morasco BJ
Dates of Project: July 1, 2010-June 30, 2011
Total Cost: $25,000

American Lung Association Social Behavioral Research Award "Depression and Lung Cancer: Association with Mortality and Processes of Care"
Principal Investigator: Slatore C
Co-Investigator: **Ganzini L**
Dates of Project: July 1, 2010-June 30, 2012
Total Cost: $80,000

NIH "Oregon Alzheimer's Disease Center"
Principal Investigator: Kaye J
Consultant: **Ganzini L**
Dates of Project: April 1, 2010-March 31, 2015
Total Cost: $347,336

HSR&D "Veterans, Researchers and IRB Members Experiences with Recruitment Restrictions"
Principal Investigator: **Ganzini L**
Co-Investigators: Hickam DH, Misra S, Arar NH, Knight SJ, Penrod JD
Dates of Project: September 1, 2012-January 31, 2015
Total Cost: $391,806

U.S. Food & Drug Administration "Reducing Prescription Opioid Misuse and Abuse with Urine Drug Testing"
Principal Investigator: Morasco B
Co-Investigators: **Ganzini L**, Dobscha S, Peters D, Krebs E
Dates of Project: September 5, 2012-August 31, 2015
Total Cost: $177,651

HSR&D "HSRD Center to Improve Veteran Involvement in Care (CIVIC)"
Principal Investigator: Dobscha S
Co-Principal Investigator: **Ganzini L**
Dates of Project: October 1, 2013-September 30, 2018
Total Cost: $2,902,288

MSRC-FY13-22 "Home-Based Mental Health Evaluation (HOME) to Assist Suicidal Veterans with the Transition from Inpatient to Outpatient Settings: A Multi-Site Interventional Trial"
United States Army Medical Research
Principal Investigator: Matarazzo
Co-Investigator: **Ganzini L**
Dates of Project: September 2013-September 2015
Total Cost: $105,228

NIH/NCATS 5KL2TR000152-08 "The Impact of Specialist Palliative Care Utilization on Mortality and Other Outcomes Among Lung Cancer Patients within the Veterans Affairs Health Network"
Principal Investigator: Sullivan D
Co-Investigator (Primary Mentor): **Ganzini L**
Dates of Project: July 2014-June 2017
Total Cost: $300,000

LAW, ETHICS AND MEDICINE

Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups

Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D Onwuteaka-Philipsen

J Med Ethics 2007;**33**:591–597. doi: 10.1136/jme.2007.022335

Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a "slippery slope", predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period.

Methods: The data from Oregon (where PAS, now called death under the Oregon Death with Dignity Act, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought.

Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

See end of article for authors' affiliations

Correspondence to:
Margaret P Battin,
Department of Philosophy,
260 South Central Campus Drive, Rm 341, University of Utah, Salt Lake City, UT 84112, USA; battin@utah.edu

Received 10 July 2007
Accepted 10 July 2007

If physician-assisted suicide (PAS) and/or voluntary active euthanasia were legalised, would this disproportionately affect people in "vulnerable" groups? Although principles of patient autonomy and the right to avoid suffering and pain may offer support for these practices, concerns about their impact on vulnerable populations speak against them. Warnings about potential abuse have been voiced by many task forces, courts and medical organisations in several countries where the issue is under debate. Box 1 presents some of these concerns.

We must take these concerns seriously, not only because they are repeated so often but because they are of such gravity. Would accepting or legalising physician-assisted dying at a patient's explicit request weigh more heavily on patients in vulnerable groups—the elderly, women, the uninsured, the poor, racial or ethnic minorities, people with disabilities, people with sometimes stigmatised illnesses like AIDS, and others? Would vulnerable patients be especially heavily targeted? Would these patients be pressured, manipulated, or forced to request or accept physician-assisted dying by overburdened family members, callous physicians, or institutions or insurers concerned about their own profits? This slippery-slope argument assumes that abusive pressures would operate on all seriously or terminally ill patients but would selectively disfavour patients whose capacities for decision making are impaired, who are subject to social prejudice or who may have been socially conditioned to think of themselves as less deserving of care. These pressures would result, it is assumed, in heightened risk for physician-assisted dying among vulnerable persons compared with background populations.

These are concerns both for those who oppose physician-assisted dying on moral grounds and for those who support it but are uneasy about the possible social consequences of legalisation. They are also concerns for proponents of legalisation who assume that the risks for vulnerable patients are heightened if these practices remain underground, as well as for those who favour legalisation but fear that vulnerable patients will be denied a privilege reserved for better-situated patients and that healthcare inequities already affecting vulnerable persons will be exacerbated. In short, slippery-slope concerns about vulnerable patients confront both those who do and those who do not find physician-assisted dying objectionable on moral grounds.

Of course, to observe that patients are members of potentially vulnerable groups is to assert neither that each such person or the group as a whole is actually vulnerable nor that people who are seriously or terminally ill but not considering physician-assisted dying are not vulnerable. But it is to recognize a special and appropriate concern about persons and groups seen as vulnerable because of impairment, disadvantage or stigmatisation.

Warnings of potential abuse rest on predictive claims, claims typically assuming that higher rates of death in this way suggest abuse. We do not attempt to evaluate putative criteria

Abbreviations: ALS, amyotrophic lateral sclerosis; ODDA, Oregon Death with Dignity Act; PAS, physician-assisted suicide

Box 1 "Slippery-slope" concerns about vulnerable patients in health policy statements on physician-assisted dying

"… no matter how carefully any guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias that characterizes the delivery of services in all segments of our society, including health care. The practices will pose the greatest risks to those who are poor, elderly, members of a minority group, or without access to good medical care."
New York State Task Force on Life and the Law, 1994[1]

"… the State has an interest in protecting vulnerable groups—including the poor, the elderly, and disabled persons—from abuse, neglect, and mistakes. The Court of Appeals [Ninth Circuit] dismissed the State's concern that disadvantaged persons might be pressured into physician assisted suicide as ludicrous on its face….We have recognized, however, the real risk of subtle coercion and undue influence in end of life situations …"
US Supreme Court, joint opinion in *Washington v Glucksberg* (1997) and *Vacco v Quill* (1997)[2]

"Euthanasia and assisted suicide are opposed by almost every national medical association and prohibited by the law codes of almost all countries. … If euthanasia or assisted suicide or both are permitted for competent, suffering, terminally ill patients, there may be legal challenges … to extend these practices to others who are not competent, suffering or terminally ill. Such extension is the "slippery slope" that many fear."
Canadian Medical Association, 1998[3]

"Both society in general and the medical profession in particular have important duties to safeguard the value of human life. This duty applies especially to the most vulnerable members of society—the sick, the elderly, the poor, ethnic minorities, and other vulnerable persons. In the long run, such persons might come to be further discounted by society, or even to view themselves as unproductive and burdensome, and on that basis, "appropriate" candidates for assistance with suicide."
"… the ramifications [of legalization] are too disturbing for the … value our society places on life, especially on the lives of disabled, incompetent, and vulnerable persons."
American College of Physicians–American Society of Internal Medicine (ACP–ASIM), 2001[4]

"… the College concluded that making physician-assisted suicide legal raised serious ethical, clinical, and social concerns and that the practice might undermine patient trust and distract from reform in end of life care. The College was also concerned with the risks that legalization posed to vulnerable populations, including poor persons, patients with dementia, disabled persons, those from minority groups that have experienced discrimination, those confronting costly chronic illnesses, or very young children."
American College of Physicians, 2005[5]

"… allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks …"
"Euthanasia could also readily be extended to incompetent patients and other vulnerable populations …"
American Medical Association, 1996, 2005[6 7]

"In the BMA's view, legalizing euthanasia or physician-assisted suicide would have a profound and detrimental effect on the doctor–patient relationship. It would be unacceptable to put vulnerable people in the position of feeling they had to consider precipitating the end of their lives…The BMA acknowledges that there are some patients for whom palliative care will not meet their needs and wishes, but considers that the risks of significant harm to a large number of people are too great to accommodate the needs of very few."
British Medical Association, 2003[8]

for whether assisted dying might seem "appropriate" for some vulnerable groups. Rather, we ask the prior question of whether there is evidence that where assisted dying is already legal, the lives of people in groups identified as vulnerable are more frequently ended with assistance from a physician than those of the background population. We can now begin to evaluate this factual issue by examining directly what is happening in the two principal jurisdictions—Oregon and the Netherlands—where physician-assisted dying is legal and data have been collected over a substantial period.

DATA AVAILABLE IN OREGON AND THE NETHERLANDS

In Oregon, nine annual reports issued by the Department of Human Services cover the period since the Oregon Death with Dignity Act (ODDA) took effect in 1997.[9] Three surveys of Oregon physicians and hospice professionals add information beyond that drawn from official reports.[10–12] In the Netherlands, four nationwide studies (the first of which is known as the Remmelink report) commissioned by the Dutch government used cross-sectional analyses of data from interviews, death certificates and questionnaires to cover all end-of-life decision making in the years 1990,[13 14] 1995,[15] 2001[16] and 2005.[17] Several smaller, focused Dutch studies provide additional data, as noted below. The Oregon data are from the 2006 report and cumulative study[9] and the Dutch data are from the 2005 nationwide study[17] unless otherwise mentioned. The Oregon Department of Human Services data include all legal cases reported under the ODDA; additional surveys have not uncovered extralegal or unreported cases.[10 12] The nationwide Dutch data cover cases reported to the authorities as required under Dutch guidelines as well as extralegal, unreported cases.

Box 2 provides the legal background, incidence and regulation of assisted dying in the two jurisdictions. The term "physician-assisted suicide" was used by Oregon in reporting its data for the first several years of legalisation, but it does not appear in the statute; Oregon now refers to "death under the Oregon Death with Dignity Act". The term "physician-assisted suicide" is used here to distinguish the form of physician-assisted

Box 2 Legal background, incidence and regulation of assisted dying in Oregon and the Netherlands

Oregon

- The Oregon Death with Dignity Act was passed as a ballot initiative in 1994; implementation was delayed by a legal injunction and the measure was returned to the ballot by the legislature and passed again in 1997; the Act became law on October 27 of that year. A federal challenge to the ODDA was rejected by the US Supreme Court in 2006. Oregon is the only US state to legalize PAS (now referred to as utilisation of the ODDA). Euthanasia remains illegal.
- A total of 292 people have died under the ODDA in the 9 years since its enactment; this is approximately 0.15% of people who have died during this period.
- The Act allows terminally ill Oregon residents to obtain from their physicians a prescription for lethal medication for the purpose of ending their lives if the following conditions are met:
  - The patient must be adult (18 years of age or older) and a resident of Oregon.
  - The patient must be capable (defined as able to make and communicate healthcare decisions).
  - The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
  - The patient must be diagnosed by two physicians as having a terminal illness (defined as 6 months or less to live).
  - The patient must make two oral requests to his or her physician, separated by at least 15 days, and one witnessed written request.
  - If either physician believes the patient's decision may be influenced by a mental disorder, the patient must be referred for a mental health evaluation.
  - The patient must be informed by the prescribing physician of feasible alternatives, 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 request.
  - The physician must report the prescription for lethal medication to the Oregon Department of Human Services (formerly the Oregon Health Division); and the Department must make available an annual statistical report of information collected under the Act.[18]
  - Pharmacies are required to report filling such prescriptions.
- Oregon's statute requires terminal illness but makes no reference to the patient's pain, symptoms or suffering. It does not indicate whether the prescribing physician must, may or may not be present at the patient's death. It stipulates that ending one's life under the Death with Dignity Act does not constitute suicide.

The Netherlands

- Voluntary active euthanasia and PAS have been openly practised and, in effect, legal since the 1980s under guidelines developed in the courts and by the Royal Dutch Medical Association. According to an exception in the criminal code enacted in 2002, physicians who perform euthanasia or provide assistance in suicide commit no offense if they follow the guidelines for "due care".
- Of the total annual mortality of 136 000 (2005), approximately 1.7% of deaths are by voluntary active euthanasia and 0.1% by physician-assisted suicide; another 0.4% involve life-ending acts without explicit current request (known as LAWER).
- The guidelines require that:
  - The patient must make a voluntary, informed and well-considered request.
  - The patient must be facing unbearable and hopeless suffering, either currently or in the immediate future and with no outlook for improvement.
  - The physician must agree with the patient that no reasonable alternative treatment that might reduce the suffering is available.
  - The physician must consult with another, independent physician.
  - The action must be performed with due care.
  - The action must be reported to the appropriate authorities.
- Since 1998, five regional committees appointed by the Ministry of Justice review all reported cases. If they decide that the physician's behavior met the requirements of due care, their decision is final.
- Dutch law does not require that the patient be terminally ill but does require that the patient be facing "unbearable and hopeless suffering". Advance directives requesting euthanasia in the event that the patient becomes comatose or demented are also legal. Both before and after statutory legalization in the 2002 law, a physician has been protected from prosecution if the guidelines are met.

dying legally permitted in Oregon from the wider range of physician-assisted dying in the Netherlands, namely, both physician-assisted suicide and voluntary active euthanasia.

This paper examines available data concerning the use of physician-assisted dying (PAS in Oregon; PAS or voluntary active euthanasia in the Netherlands) to determine whether there is evidence of disproportionate impact on vulnerable populations. Are the lives of people in vulnerable groups more frequently ended with a physician's assistance than those of other, less vulnerable people? The results presented (table 1) move from the most robust data to that which is partial, inferential or in other ways less secure. Detailed accounts of the statistical and other methods used in each source study are available in those studies, variously including information on response rates, survey questions asked, sample sizes, actual numbers, statistical power and confidence intervals, methods of calculation of rate ratios, detectable differences, changes over time, and methodology, design and analysis techniques. We recognize that substantial differences in the methodologies of the source studies make it impossible to determine with certainty the actual incidence of assisted dying in several of the vulnerable groups studied. Our question is whether the available data show evidence of heightened risk to persons in vulnerable groups.

IS THERE EVIDENCE OF HEIGHTENED RISK TO PEOPLE IN VULNERABLE GROUPS?

Findings based on robust data

The elderly: *no evidence of heightened risk*

In Oregon, 10% of patients who died by PAS were 85 or older, whereas 21% of all Oregon deaths were among persons in this age category. Persons aged 18–64 years were over three times more likely than those over age 85 years to receive assisted dying. In the Netherlands, rates of assisted dying were lowest in the people over 80 (0.8% in 2005), next lowest in the age range 65–74 years (2.1%) and higher below age 65 (3.5%). People over 80 formed 30% of the group of patients whose requests were refused and 13% of those whose requests were granted and carried out.[19]

Women: *no evidence of heightened risk*

In Oregon, 46% of individuals receiving assisted dying were women and women were not more likely than men to use assisted suicide. In the Netherlands, despite some fluctuation in different years of the nationwide studies, the rates tend to be slightly higher in men.

Uninsured people: *no evidence of heightened risk*

Three Oregon patients (1%) did not have documented health insurance, and in four cases, insurance status was unknown. In contrast, 16.9% of non-elderly adults in Oregon were uninsured[20] (persons 65 and older are insured by Medicare). In the Netherlands, virtually all patients are covered by mandated nationwide health insurance.

People with AIDS: *heightened risk found*

In 9 years in Oregon, a total of six persons with AIDS died under the ODDA; although the numbers are small (2% of the total of 292 ODDA deaths), persons with AIDS were 30 times more likely to use assisted dying than those who died of chronic respiratory disorders in the interview portions of the nationwide studies in the Netherlands, very few patients with AIDS had received a physician's assistance in dying. However, in an Amsterdam cohort of 131 homosexual men with AIDS diagnosed between 1985 and 1992 who had died before 1 January 1995, 22% died by euthanasia or PAS.[21]

Findings based on partly direct, partly inferential data

People with low educational status: *no evidence of heightened risk*

In Oregon, the likelihood of dying by PAS was correlated with higher educational attainment. Terminally ill college graduates in Oregon were 7.6 times more likely to die with physician assistance than those without a high school diploma. While no direct quantified data are available in the Netherlands about the educational status of patients receiving assisted dying, information in the 1990 study about professional status, associated with educational status, showed no special relationships to patterns of euthanasia or PAS.

The poor: *no evidence of heightened risk*

The Oregon data do not include direct measures of income, employment or assets, but death under the ODDA was associated with having health insurance and with high educational status, both indirect indicators of affluence. In the Netherlands, data inferred from the postal codes of the location in which the person was living before death showed that the overall rates of assisted dying were somewhat higher for people of higher socioeconomic status.[22]

Racial and ethnic minorities: *no evidence of heightened risk*

In Oregon, 97% of the 292 patients who had a physician's assistance in suicide were white; six of the non-white patients were persons of Asian descent, one was Hispanic and one was Native American. Although 2.6% of Oregonians are African-American, no African-American has received physician-assisted dying under the Act. Dutch mortality statistics do not include information about race or ethnicity; however, even the most vocal opponents of assisted dying in the Netherlands do not claim that it is imposed more frequently on stigmatised racial or ethnic minorities.

People with non-terminal physical disabilities or chronic non-terminal illnesses: *no evidence of heightened risk*

In one sense, virtually all patients who are seriously or terminally ill are to some extent physically disabled and chronically ill. Patients who are dying lose functional capacities and may be bedridden toward the end; in this sense, most patients who received assistance in dying in either Oregon or the Netherlands were chronically ill and (recently) disabled. Cancer, the diagnosis in about 80% of all cases of assisted dying in both Oregon and the Netherlands, is often identified as a chronic illness; so is amyotrophic lateral sclerosis (ALS), also a frequent diagnosis. Concerns about persons in vulnerable categories have focused, however, on pre-existing physical disabilities and chronic non-terminal illnesses.

Although the data from Oregon do not indicate whether a person had a disability before becoming terminally ill (defined as having 6 months or less to live), no one received physician-assistance in dying who was not determined by two physicians to be terminally ill—that is, no one received such assistance for disability alone. That some patients received lethal prescriptions that they did not ingest and lived longer than 6 months may represent limitations in prognostication, although clinicians caring for terminally ill cancer patients are likely to overestimate rather than underestimate survival.[23 24] In the Netherlands, assisted dying for disability alone would not be illegal in principle; a terminal diagnosis is not required by the Dutch guidelines, and a person who faces unbearable suffering, in his or her own view, and who has been offered all forms of treatment but has no hope of improvement may request assistance in dying. Estimates made by physicians of the amount of life forgone can be used to make an approximation of disability or chronic illness status: about 0.2% of patients receiving euthanasia or assistance in suicide were estimated to have forgone more than 6 months of life, or less than 10 of the approximately 2400 cases in 2005. Dutch general practitioners infrequently grant and frequently refuse assistance in dying to patients whose diagnosis is "old age/general deterioration" or "other" (this includes the category of patients with no terminal illness and no ALS or multiple sclerosis).[19] There is thus no evidence that physician-assisted dying poses heightened risk to people with disabilities who are not also seriously ill.

Minors and mature minors: *no evidence of heightened risk*

The Oregon ODDA requires that a patient be an adult (18 years of age or older) before assisted dying is granted; no cases of physician-assisted death were reported among minors. In the Netherlands, mature and relatively mature minors are understood to have some decision-making capacity and are not excluded under the Dutch guidelines, but because they are below the age of majority must be regarded as "vulnerable". Since death rates among minors in the Netherlands (0.4% of all deaths) were the lowest in any age group, it is difficult to reach statistically firm conclusions. In 2001, less than 1% of all deaths of persons aged 1–17 years were the result of euthanasia: no cases of PAS were found in this age group.

The Netherlands has recently developed a protocol for euthanasia in newborns with very serious deficits who have a hopeless prognosis and experience what parents and medical experts deem to be unbearable suffering; the decision is to be made in collaboration with the parents and requires their full approval. This is known as the Groningen protocol.[25] Such cases are infrequent—22 cases have been reported to district attorneys in the Netherlands during the past 7 years, and there are an estimated 10 to 20 cases annually among the somewhat

Table 1 Physician-assisted dying in potentially vulnerable groups in Oregon and the Netherlands: overview of data from Oregon reports and studies, and Dutch nationwide and focused studies

	Oregon—PAS patients 1998–2006			**Netherlands*— PAS/euthanasia patients 2005 (n = 2400)**		
Potentially vulnerable group	**Characteristic**	**No. (%)**	**Rate ratio**	**Characteristic**	**No. (%)**	**Rate ratio**
Findings based on direct data						
The elderly (age in years)	18–44	11 (4)	3.4	0–64	900 (38)	1.7
	45–64	83 (28)	3.2	65–79	950 (39)	1.7
	65–84	170 (58)	2.3	80+	550 (23)	1.0
	85 +	28 (10)	1.0			
	Median 70 (range 25–96)					
Women	Male	157 (54)	1.1	Male	1350 (56)	1.3
	Female	135 (46)	1.0	Female	1050 (44)	1.0
Uninsured people	Private insurance	180 (62)		Not applicable (all are insured)		
	Medicare or Medicaid	105 (36)				
	No insurance	3 (1)				
	Status unknown	4 (1)				
People with AIDS	HIV/AIDS†	6 (2)	30.3	HIV/AIDS‡	29 (22)	7.9
Findings based on partly direct and partly inferential data						
People with low educational status	<High school	25 (9)	1.0	Indirect data (via SES); no direct relationship		
	HS graduate	82 (28)	1.8			
	Some college	64 (22)	3.2			
	Baccalaureate or higher	121 (41)	7.6			
The poor (people with low SES)	Rate low¶			Low SES§	1400 (38)	1.0
				Moderate SES	1200 (33)	1.0
				High SES	800 (22)	1.2
				Institutions§	300 (8)	0.3
Racial and ethnic minorities	White	284 (97)	1.0	No data (Dutch mortality statistics are not kept by race)		
	African-American	0 (0%)				
	Hispanic	1 (<1%)	0.4			
	Native American	1 (<1%)	0.5			
	Asian	6 (2)	1.8			
	Other	0	0			
People with chronic physical or mental disabilities or chronic non-terminal illnesses	Not legal; no cases reported or identified			No data to calculate denominator; probably 10 cases or fewer per year		
Minors	Not legal; no cases reported or identified			1.6% of all deaths of minors aged 1–16 years		
Findings based on inferential or partly contested data						
People with psychiatric illness, including depression and Alzheimer disease	Not legal; no clear cases; three disputed cases among those given prescription (n = 456)			No data to calculate denominator; increased requests among cancer patients with depression; probably rare for psychiatric illness as main diagnosis; legal in Alzheimer disease with advance euthanasia directive but compliance rare		

*All estimates are based upon data about a sample of 9000 deaths from August to November 2005, unless indicated otherwise; 2005 data are used for simplicity. Data are roughly comparable for entire period studied. Also see van der Heide *et al*, 2007.[17]
†Referent is chronic lower respiratory disorder.
‡Estimate based upon prevalence study from early 1990s.
¶Indirect data (via educational level and insuredness).
§Estimates based upon 2001 nationwide study; also see Onwuteaka-Philipsen *et al*, 2003.[16]
LAWER, life-ending acts without explicit current request; PAS, physician-assisted suicide; SES, socioeconomic status.

over 1000 children born in the Netherlands who die during the first year of life, about 1% of newborn deaths.

Findings based on inferential or partly contested data

Patients with psychiatric illness, including depression and Alzheimer disease: *no evidence of heightened risk*

Approximately 20% of requests for physician assistance in dying came from depressed patients, but none progressed to PAS.[10] None of the 292 patients who died under the ODDA were determined to have a mental illness influencing their decision, though there have been three disputed cases among the 9-year total of 456 who received prescriptions.[26] [27] Because not all patients who requested assistance were specifically evaluated by mental health professionals and because many cases of depression are missed in primary care, it is possible that some depressed patients received lethal prescriptions; it is also possible that a patient without a mental disorder at the time of receiving the prescription became depressed by the time they ingested it. There is, however, no direct evidence that depressed patients are at higher risk for receiving assistance in dying under the ODDA.

In the Netherlands, about two-thirds of explicit requests for assistance in dying are not granted. In 31% of all requests not granted in the 1995 study, the physician gave the presence of psychiatric illness as at least one reason for not complying. Physicians in the interview portion of the 1995 Dutch nationwide study mentioned depression as the predominant symptom in patients who died by PAS or euthanasia in 3% of all cases, compared with "loss of dignity" in 60%, pain as an associated complaint in 45% and debility in 43%. In one study, cancer patients with depressed mood were four times more likely to request euthanasia, but how often the request was granted is unknown.[28]

In 1994, the Dutch supreme court ruled in the *Chabot* case, in which a psychiatrist assisted with suicide for a woman with intractable depression but without concomitant physical illness, that "intolerable suffering" might consist in mental suffering alone without somatic origins and not involving the terminal phase of a disease, though the court commented that such cases would be rare and that they require heightened scrutiny.[29] The 2001 Dutch interview study estimated that about 3% of all requests for euthanasia or PAS that physicians had received the previous year were from patients with predominantly psychiatric or psychological illnesses, but none were granted. In the Dutch 1995 nationwide substudy on end-of-life decision making in psychiatric practice, there appeared to be about two to five physician-assisted deaths on request per year, mostly but not always in patients with a concurrent serious physical illness, often in the terminal phase. Explicit requests for a physician's assistance in dying are not uncommon in psychiatric practice in the Netherlands, and a majority of Dutch psychiatrists consider assisted suicide for psychiatric patients acceptable in certain circumstances. However, this rather liberal attitude appears to be associated with quite reluctant practice: despite the fact that Dutch law would permit it, it occurs only very rarely.

Since 2002, the Netherlands has also recognised as legal advance euthanasia directives of patients with dementia, including Alzheimer disease. Although approximately 2200 demented patients with advance directives requesting euthanasia after the onset of dementia die annually having been treated by a physician who knows about this directive—indeed, in 76% of such cases, compliance with the directive was discussed—euthanasia is seldom performed.[30]

Table 2 summarises the comprehensive data provided in table 1.

THE COMPREHENSIVE PICTURE IN OREGON AND THE NETHERLANDS

The data from Oregon and the Netherlands are the most informative sources concerning legal physician-assisted dying, though they are not comparable in a number of respects: they cover different time periods, were obtained by different methods, and are of different strengths. Neither the Oregon nor the Dutch studies were corrected throughout for considerations of whether diagnoses that may make physician-assisted dying attractive are equally distributed in vulnerable and non-vulnerable groups. Clearly, more work needs to be done.

Where they do overlap, however, the studies are largely consistent. Where the data are robust, the picture in Oregon and the Netherlands is similar: in both jurisdictions, a smaller percentage of older people received assistance in dying than of younger patients; gender ratios were slightly higher for males over time; and assistance was not more common among the uninsured. Socioeconomic data of intermediate strength, usually inferred from other, more robust data, also suggest similar pictures in the two jurisdictions: recipients of assistance in dying were likely to be of equal or higher educational status and were less likely than the background population to be poor. Data that are robust in one jurisdiction but partly inferential and hence less secure in the other did not reveal cases in either

Table 2 Summary of evidence of heightened risk in physician-assisted dying in Oregon and the Netherlands

Potentially vulnerable group	Evidence of heightened risk	No evidence of heightened risk
Direct data		
The elderly		×
Women		×
Uninsured people		×
People with AIDS	×	
Partly direct, partly inferential data		
People with low educational status		×
The poor: people with low socioeconomic status		×
Racial and ethnic minorities		×
People with chronic physical or mental disabilities or chronic non-terminal illnesses		×
Minors		×
Inferential or partly contested data		
People with psychiatric illness, including depression and Alzheimer disease		×

data set of assisted dying associated with physical disability alone without concomitant serious or terminal illness. The rates of physician-assisted dying among mature minors, which is legal in the Netherlands, were too low to be statistically valid. Although the rates of request for physician-assisted dying may have been higher among patients with depression, it appears that most such requests did not culminate in euthanasia, even though such cases may be legal in the Netherlands if given heightened scrutiny; studies of patients in the process of making requests are needed to clarify the risk conferred by depression. Even where the data involve very few cases or are absent in one or the other jurisdiction, the picture appears to match: neither in Oregon nor in the Netherlands was there any report of assisted dying disproportionately practised among racial minorities. Thus, there is no evidence of heightened risk of physician-assisted dying to vulnerable patients in either legal or extralegal practice groups, with the sole exception of people with AIDS.

Thus, we found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups. The evidence available cannot provide conclusive proof about the impact on vulnerable patients, and full examination of practice in Oregon would require studies of the complexity, duration and comprehensiveness of the four Dutch nationwide studies. Nevertheless, the joint picture yielded by the available data in the two jurisdictions shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges. This conclusion does not directly speak to the moral issues in physician-assisted dying; it does not argue whether physician-assisted dying would be more or less appropriate for people in some groups; and it does not show that people in vulnerable groups could not be disproportionately affected in the future or in other jurisdictions. It also does not show whether low rates of physician-assisted dying among vulnerable persons reflect a protective effect of safeguards or, rather, are evidence of unequal access to assistance. But it does show that there is no current factual support for so-called slippery-slope concerns about the risks of legalisation of assisted dying—concerns that death in this way would be practised more frequently on persons in vulnerable groups.

ACKNOWLEDGEMENTS

We are grateful to Katrina Hedberg, Mette Rurup, Hermann van der Kloot Meijberg and John Griffiths.

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Authors' affiliations

Margaret P Battin, Department of Philosophy and Division of Medical Ethics and Humanities, University of Utah, Salt Lake City, UT, USA
Agnes van der Heide, Department of Public Health, Erasmus Medical Center, Rotterdam, The Netherlands
Linda Ganzini, Oregon Health & Science University, Portland, OR, USA
Gerrit van der Wal, Bregje Onwuteaka-Philipsen, Department of Social Medicine, EMGO Institute, VU University Medical Centre, Amsterdam, The Netherlands

Competing interests: None declared.

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Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups

Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal and Bregje D Onwuteaka-Philipsen

J Med Ethics 2007 33: 591-597
doi: 10.1136/jme.2007.022335

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Notes

Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups—another perspective on Oregon's data

I G Finlay,[1] R George[2]

[1]Cardiff University, Velindre Hospital, Cardiff, UK
[2]Guy's and St Thomas' NHS Foundation Trust, St. Thomas' Hospital, London, UK

Correspondence to
Professor I G Finlay, Cardiff University, Velindre Hospital, Cardiff CF14 2TL, UK; finlayi@parliament.uk

Received 3 April 2010
Revised 14 September 2010
Accepted 25 September 2010

ABSTRACT

Battin *et al* examined data on deaths from physician-assisted suicide (PAS) in Oregon and on PAS and voluntary euthanasia (VE) in The Netherlands. This paper reviews the methodology used in their examination and questions the conclusions drawn from it—namely, that there is for the most part 'no evidence of heightened risk' to vulnerable people from the legalisation of PAS or VE. This critique focuses on the evidence about PAS in Oregon. It suggests that vulnerability to PAS cannot be categorised simply by reference to race, gender or other socioeconomic status and that the impetus to seek PAS derives from factors, including emotional state, reactions to loss, personality type and situation and possibly to PAS contagion, all factors that apply across the social spectrum. It also argues, on the basis of official reports from the Oregon Health Department on the working of the Oregon Death with Dignity Act since 2008, that, contrary to the conclusions drawn by Battin *et al*, the highest resort to PAS in Oregon is among the elderly and, on the basis of research published since Battin *et al* reported, that there is reason to believe that some terminally ill patients in Oregon are taking their own lives with lethal drugs supplied by doctors despite having had depression at the time when they were assessed and cleared for PAS.

The paper by Battin *et al*[1] titled above purports to examine 'whether there is evidence that, when assisted dying is legal, the lives of people in groups identified as vulnerable are more frequently ended with assistance from a physician than those of the background population'. However, their paper categorises vulnerability by reference to certain socioeconomic groups, relating to age, race, sex and economic and educational status, rather than by reference to emotional vulnerability and personality type, or other recognised markers of vulnerability among people seeking to end their lives, which exist across the spectrum of society.[2] They conclude that there is no evidence that legalised PAS in Oregon poses a risk to people who are, according to their definitions, vulnerable. We question the validity of this conclusion, as these factors are likely to be invisible to their traditional socioeconomic analysis.

BACKGROUND

A key concern over the legalisation of PAS is that a law enacted to provide PAS for self-reliant and strong-willed individuals with capacity might migrate into the population of terminally ill people as a whole, encouraging less resolute individuals to opt for PAS either as the result of real or perceived pressures from others or from within themselves, or under the influence of treatable and transient depression. Whether this is happening in practice in the US state of Oregon is the question that the study of Battin *et al*[1] sought to answer.

They examined Oregon's data on PAS since its legalisation under the Oregon Death with Dignity Act (ODDA) in an attempt to assess whether persons in certain socioeconomic groups are dying by PAS more often than others in the population at large. The categories selected by Battin *et al*[1] were as follows:

1. The elderly
2. Women
3. Uninsured people
4. People with AIDS
5. People with low educational status
6. The poor
7. Racial and ethnic minorities
8. People with non-terminal physical disabilities or chronic non-terminal illnesses
9. Minors and mature minors
10. Patients with psychiatric illness, including depression and Alzheimer's disease

They concluded that all these categories show 'no evidence of heightened risk' in Oregon.[1]

THE CATEGORIES

We call into question the methodology used and the conclusions derived from it on four distinct grounds. First, Battin *et al*'s conclusions of vulnerability to PAS among elderly people in Oregon seem at variance with official Oregon Health Department (OHD) data.[3] Second, some of the other socioeconomic categories used (in particular, women, racial minorities and people of low educational or economic status) seem to be of questionable relevance in the context of vulnerability to PAS, whereas other vulnerabilities have not been discussed. Third, the distinctions and legal implications are not discussed between terminal illness, which the ODDA covers, and chronic illness or disability for which the ODDA does not license PAS. Finally, we cite more recently published Oregon-based research suggesting that, contrary to the conclusion reached by Battin *et al*,[1] persons with depression are indeed vulnerable to PAS; we also discuss how vulnerability may be categorised. We deal with these four concerns in turn.

PAS and the elderly

Battin *et al*[1] have compared the proportion of deaths from PAS and deaths from other causes for two groups of people in Oregon—those aged 85 years or over, who they define as elderly, and those aged 18–64 years. They report that 'in Oregon 10% of patients who died by PAS were 85 or older, whereas 21% of all Oregon deaths were among persons in this age category'. They state that 'persons aged 18–64 years were over three times more likely than those over age 85 years to receive assisted dying'. From this they draw the conclusion that there is 'no evidence of heightened risk' to the elderly from the legalisation of PAS.

There are a number of problems with this approach. Traditionally, the threshold of the beginning of old age is 65 years, subcategorised by subsequent decades.[4] Eighty-five years is far too high to indicate the beginning of old age. Second, Battin *et al*'s calculations and comments omit deaths among Oregonians aged between 65 and 84 years, despite the OHD annual reports on the operation of the ODDA since 1998, showing that the majority (60%) of all PAS deaths occur in these demographically recognised decades, 65–84 years, which are usually called elderly. A third problem lies in the method of calculation itself that is vulnerable to a systematic error. Since death rates from non-PAS causes among persons aged 85 years or over are naturally very high, it follows that almost any rate of PAS in this age bracket is likely to show up as proportionately less than the rate of deaths from other causes. Conversely, as deaths from non-PAS causes are relatively less frequent among the young and middle-aged (18–64 years), even a relatively small rate of PAS will loom large in this age group as against other deaths.

The 12 OHD annual reports issued between 1998 and 2009 show that, of the 460 persons who have died in Oregon by PAS over this 12-year period, 314 (68.3%) were aged 65 years or over, whereas 146 (31.7%) were aged between 18 and 64 years. Moreover, the median age for PAS recorded in the reports over the 12-year period is 71 years. Battin *et al*'s conclusion that the elderly are not at higher risk of PAS would appear to be at variance with these official data.

Irrelevant groups

The socioeconomic groups selected by Battin *et al*[1] as measures of vulnerability are commonly used in sociological research to address questions in fields such as employment, education, housing, health (eg, malnutrition) and life expectancy. It is questionable, however, whether many of them can be regarded as indicators of vulnerability in the context of PAS. Conversely, in qualitative research, vulnerability in end-of-life decision-making has been shown to be more related to communicative difficulties, situation, having unrelieved symptoms or a distressing medical condition, or being socially undervalued. These factors transcend socioeconomic groupings.[2] While some of the groupings selected by Battin *et al*[1] (eg, the elderly, those with illnesses or disabilities and persons with psychiatric illness) are clearly relevant, there is no explanation offered as to why others such as women, racial minorities, the less well educated or less wealthy should be regarded as vulnerable to taking their own lives through PAS.

Battin *et al*[1] state that 'in Oregon 46% of individuals receiving assisted dying were women and women were not more likely than men to use assisted suicide'. Battin *et al*[1] do not say whether women were being compared with men as the PAS data on gender was available or because the hypothesis was that they might have been considered potentially more vulnerable to PAS than men. It is worth noting that studies have suggested that suicide risk and suicide rates overall are higher among men than women in both the USA and Europe.[5] [6]

Similarly, we are told that 'in Oregon 97% of the 292 patients who had a physician's assistance in suicide were white'. Given that white individuals comprise some 90% of Oregon's population, this is also unsurprising. Again, Battin *et al*[1] do not state why ethnicity was included in their analysis of the impact of legalised PAS on vulnerable groups. Although members of ethnic minorities tend to be socioeconomically disadvantaged, the linkage is far from being universal. Interestingly, one might expect trends in the other direction, for example, members of ethnic minorities often hold religious or moral beliefs that are unfavourable to the concept of PAS. Their lower access to health care and palliative care in the USA, and mistrust of authority in general, may in fact make these groups less vulnerable to PAS.[7] [8]

Battin *et al*[1] state that 'in Oregon the likelihood of dying by PAS was correlated with higher educational attainment'. They continue: 'Terminally ill college graduates in Oregon were 7.6 times more likely to die with physician assistance than those without a high school diploma'.[1] Two questions arise from this finding. First, are people who are better educated more vulnerable, in the context of PAS, because illness and potential dependence are more frightening to them or because they have fewer psychosocial supports? Second, perhaps more interestingly, why did the finding that college graduates were 7.6 times more likely resort to PAS than others not lead Battin and her associates to question whether, if the less well educated are not especially vulnerable to PAS, perhaps the better educated are? There is a need to dig somewhat deeper in order to try and establish whether, for example, educated patients may resort more frequently to PAS because they are people who are familiar with the intricacies of the law and can argue more persuasively with their physicians (J Griffiths, personal communication, 2010). Alternatively, they may be vulnerable to factors invisible to rigid demographic analysis.

We are told that 'death under the ODDA was associated with having health insurance and with high educational status, both indirect indicators of affluence'.[1] The OHD reports that 2.6% of those dying by PAS cited financial implications of treatment as an end-of-life concern, but only 1.3% had no health insurance of any type, suggesting that perceptions of cost rather than absolute economic disadvantage might influence vulnerability to PAS in a healthcare system that does not provide equitable universal coverage. Yet Battin *et al*[1] do not reflect on the vulnerabilities that wealth may bring, for example, perceptions of suffering, dignity, control, or the stigmatisation of illness and disability. These merit discussion, if only to establish that they are not clear forces towards the desire to die or that the data simply do not exist to confirm or refute hypotheses. There are, however, within the existing more detailed data, pointers that seem to have been overlooked.

The Oregon data on factors such as loss of control, indignity and being a burden suggest that such vulnerabilities cannot be ignored when set alongside the relative prosperity of those resorting to PAS as a solution to their suffering. The authors appear to have seen the concept of vulnerability from one perspective only—as something to which only less educated or less wealthy persons might succumb. In any research analysis or critique, it is necessary to recognise what anthropologists call the 'insider–outsider' polemic in which those who see a problem from within a set of values have difficulty imagining a view from elsewhere.[9]

Battin *et al*[1] do not discuss the ongoing—currently fourfold—rise in PAS in Oregon, but media coverage and possible contagion need consideration.[10] Also, there may be a subliminal unintended coercive influence from proponents of PAS, Compassion in Dying of Oregon, who often broker contact between the patient and prescriber of PAS and who 'guided most of those availing themselves of an assisted death'.[11] Coercion is notoriously slippery to unmask, especially in consumerist societies in which citizens may be more sensitive to fashion and the new and when it is all too easy to project one's own view of best interest upon another, or to feel oneself that not to conform to the new way is in some manner politically incorrect.

The sick and disabled

It is important to establish whether persons who are chronically rather than terminallyill—that is who do not meet the ODDA's criterion of a 6-month prognosis of death—are receiving PAS in Oregon. Battin *et al*[1] state that in Oregon 'no one received physician assistance in dying who was not determined by two physicians to be terminally ill'. They concede that 'some patients received lethal prescriptions that they did not ingest and lived longer than 6 months' and observe that this 'may represent limitations in prognostication'.

Indeed, prognostication is notoriously difficult,[12] but other factors need consideration. The statement that no one received lethal drugs who was not terminally ill is based on voluntary declarations by prescribing doctors, who are hardly likely to make such declarations if this key criterion in the assessment process for PAS has not been met. Indeed, the OHD annual reports on PAS repeatedly observe that 'our numbers are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the provisions of the Death with Dignity Act'.[13]

As Battin *et al*[1] state, prognosticating is not an exact science. The OHD data from 1998 to 2009 reveal the median length of time between first request for PAS and death was 43 days (range 15—1009 days).[14] Therefore, in at least one instance a patient was issued with lethal drugs by a physician on the understanding that he or she had 6 months or less to live but lived for some 3 years thereafter. This is not to suggest that Oregon physicians are incompetent or breaking the law but rather that the difficulties of prognostication are such that persons who are chronically rather than terminally ill can find themselves inadvertently accessing PAS within the terms of the ODDA.

Some of Battin *et al*'s observations appear to blur the distinction between terminal and chronic illness. They state that 'virtually all patients who are seriously or terminally ill are to some extent physically disabled and chronically ill'; that 'patients who are dying lose functional capacities and may be bedridden towards the end'; that 'in this sense, most patients who received assistance in dying in either Oregon or The Netherlands (which we do not deal with specifically here, but nevertheless informs the Oregon debate) were chronically ill and (recently) disabled'; and that 'cancer, the diagnosis in about 80% of all cases of assisted dying in both Oregon and The Netherlands, is often identified as a chronic illness'. This begs the question: what definition of chronic illness is being used? The term is normally employed to designate an illness that persists for some considerable time and that may—but will not necessarily—be the eventual cause of death. Therefore, illnesses such as multiple sclerosis, Parkinson's disease and cardiopulmonary disease pretty well universally have a chronic and disabling prelude before they become predictably terminal as defined by less than 6 months to live. Unlike some advanced malignancies, they are not terminal in the sense that they have set the patient on a trajectory to death within a relatively short space of time. While some cancers may go into remission and persist in the background of a patient's life for a number of years, many others come unforeseen and bring about the patient's death within a matter of months or even weeks.

Depression

In referring to psychiatric illness, the authors state that 'approximately 20% of requests for physician assistance in dying [in Oregon] came from depressed patients but none progressed to PAS', that is one in five applicants for PAS in Oregon was diagnosed as having depression and was not allowed to proceed. It does not account for those with undiagnosed depression who proceeded to PAS.

On this crucial, latter question, since Battin *et al*'s paper, a co-author, Ganzini, has published a case-based study of 58 patients who requested PAS, 18 of whom were given clearance for PAS by the assessing physicians. Of these 18, three (ie, one in six) had treatable but undiagnosed depression at the time of their assessment.[15] She concluded that Oregon's Death with Dignity Act 'may not adequately protect all mentally ill patients'. While Battin *et al*[1] acknowledge that 'not all patients who requested assistance were specifically evaluated by mental health professionals', there may be a proper and more urgent cause for concern as this understates the OHD's data on the operation of Oregon's PAS law with respect to psychiatric and psychological assessment. By 2009, only 38 (8.4%) of the 460 people who had ended their lives under the terms of the Act had been referred for psychiatric evaluation, with a drop in referrals in recent years to zero or near zero.[14] Ganzini's empirical data appear to cast doubt on Battin *et al*'s statement that 'there is no direct evidence that depressed patients are at higher risk for receiving assistance in dying under the ODDA'.

CONCLUSION

We challenge the underlying assumptions and the methodology chosen by Battin *et al*[1] in their 2007 examination of PAS risks among vulnerable groups. Many of the socioeconomic categories against which the operation of Oregon's PAS law has been tested have little or no relevance to concepts of vulnerability to 'assisted dying'.

Socioeconomic categories are not necessarily a proxy for vulnerability to accessing PAS. The Oregon data demonstrate a greater resort to PAS among better educated and financially affluent persons, particularly those over 65 years of age. This warrants further enquiry to ascertain whether they have vulnerabilities to influence to accessing PAS, which are not adequately addresses in their healthcare system.

More recent research calls into question the conclusion that persons with depression are not being put at risk of PAS. In short, we believe Battin *et al*'s analysis of the data as regards the PAS scene in Oregon is incomplete.

Competing interests IGF and RG have both spoken against changing the law on physician-assisted suicide/euthanasia in the UK. IGF is a Director of Living and Dying Well (not remunerated).

Provenance and peer review Not commissioned; externally peer reviewed.

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Journal of
Medical Ethics

Law, ethics and medicine:
Paper: Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups—another perspective on Oregon's data
I G Finlay, R George
J Med Ethics 2011;**37**:3 171-174 Published Online First: 11 November 2010 doi:10.1136/jme.2010.037044
[Abstract] [Full text] [PDF]

Legal physician-assisted dying in Oregon and the Netherlands: The question of "vulnerable" groups. A reply to I.G. Finlay and R. George

Margaret P. Battin, Professor, University of Utah Margaret P. Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D. Onwuteaka

In their critique of our paper "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups," I.G. Finlay and R. George claim to challenge our underlying assumptions and methodology with "another perspective on Oregon's data." In our view, however, they miss the point of our paper and address a quite different issue. While we welcome their attempt to further explore issues about assisted dying, we do not believe they have in any way undercut our argument that where assisted dying is already legal (at the time of our study, Oregon and the Netherlands), there is no current evidence for the claim that legalized physician-assisted suicide or euthanasia will have disproportionate impact on patients in vulnerable groups.

Our paper was developed in response to the "slippery slope" concern widely prevalent in statements and position papers from variety of groups, including many professional medical groups. We cited among others this sample:

"Both society in general and the medical profession in particular have important duties to safeguard the value of human life. This duty applies especially to the most vulnerable members of society--the sick, the elderly, the poor, ethnic minorities, and other vulnerable persons. In the long run, such persons might come to be further discounted by society, or even to view themselves as unproductive and burdensome, and on that basis, "appropriate" candidates for assistance with suicide." "...the ramifications [of legalization] are too disturbing for the...value our society places on life, especially on the lives of disabled, incompetent, and vulnerable persons." American College of Physicians--American Society of Internal Medicine (ACP -ASIM), 2001

Drawing on this and many similar statements in the medical. policy, and bioethics literatures, we examined 10 groups variously identified here and in inequality studies generally as "vulnerable." We explicitly refrained from assuming that people in these groups are actually vulnerable and that people not in these groups are not, and we did not assert that issues about vulnerability could not be examined in other ways --as Finlay and George have undertaken to do. We did seek, however, to examine objectively this particularly widespread form of slippery-slope argument because it has played such a major role in the public, political, and professional debates over physician assistance in dying. We insisted that the careful examination of objective evidence should be of concern to those who oppose physician-assisted dying on moral grounds, to those who support aid-in-dying but are uneasy about the possible social consequences of legalization, to proponents of legalization who assume that the risks for vulnerable patients are heightened if these practices remain underground, and to those who favor legalization but fear that vulnerable patients will be denied a privilege reserved for better situated patients and that health care inequities already affecting vulnerable persons will be exacerbated--that is, to both those who do and those who do not find physician-assisted dying objectionable on moral grounds.

We certainly do not claim that people not in the 10 groups identified as vulnerable might not seek physician assistance in dying for the "wrong" reasons--disturbed emotional states, reactions to loss, personality types, and other factors Finlay and

George mention. That is not the focus of our paper. Finlay and George provide as it were a supplemental look at the same issue, but with an entirely different focus. However, our paper does indirectly address some of their concerns. Not only do we examine rates of assisted dying in depression (rates of depression are elevated in people seeking assistance in dying, but may not be elevated in people receiving it), but in conditions like physical disability, stigmatized illnesses such as AIDS, chronic nonterminal illness, and psychiatric illness (all conditions in which physician-assisted suicide and euthanasia may be legal in the Netherlands). All may all be associated with distressed emotional states and loss, but, with the exception of AIDS (largely prior, it can be noted, to the development of highly active antiretroviral therapy), in none of these conditions are rates of assisted dying elevated. We did not assume that the categories we examined identified were the only respects in which individuals could be "vulnerable" and we did not attempt to distinguish between relevant and, as Finlay and George charge, "irrelevant" vulnerable groups; rather, we examined the categories we did because they had played such a prominent role in public and professional argumentation over the risks of legalization.

Although our paper examined data from both Oregon and the Netherlands, Finlay and George address only that of Oregon. Thus they do not recognize the relevance of data about chronic (nonterminal) illness or disability, conditions in which a patient may legally seek the assistance of a physician in dying in the Netherlands but not in Oregon. They misread our analysis of data about old age, claiming that we omit deaths among Oregonians aged between 65 and 84 years; this data does indeed not appear in the discursive text but is clearly displayed in Table 1, and supports our claim that there is no evidence of heightened risk of assistance in dying among the elderly (construed as age 65 and over). We do not see a "systematic error" here, though the fact that very elderly people die less frequently of cancer (the most frequent condition associated with assisted dying in both Oregon and the Netherlands, approximately 80%) may explain the some of the finding.

Finlay and George also refer to a "four-fold rise" in physician assistance in dying in Oregon between the initial years of the Death With Dignity Act and the present. Patients ingesting lethal medications represented 6/10,000 deaths in Oregon in 1998, the first full year of legalization, 9/10,000 deaths in Oregon in both 1999 and 2000, and 21/10,000 deaths in Oregon in 2010. Some increase subsequent to the first year of legalization represents persons who received prescriptions from the previous year dying in the subsequent year. It is a misleading representation of the trend to call this a four-fold increase.

Most of Finlay and George's comments are not really about our data and analyses; rather, they mainly concern the limitations of our study. A careful reading of our study will show that most of these concerns have already been addressed, and that we have been particularly careful to refrain from conjectural claims about the motivations of people who died with physician assistance, claims that are, in contrast, central to the concerns of Finlay and George. We welcome further attempts to examine what really happens where physician assistance in dying is legal, both concerning individuals who are members of groups identified in the literature as vulnerable and those who are not, including people with high SES and other indicators of comparative privilege. However, we do not welcome the seemingly ideologically biased assumption evident in the Finlay and George critique that requesting or receiving such assistance is itself a symptom of vulnerability; such an assumption would make it impossible to examine the facts of the matter in either Oregon or the Netherlands in any objective way.

Conflict of Interest:

None declared

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RESEARCH

Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey

Linda Ganzini, professor,[1,2] Elizabeth R Goy, assistant professor ,[1,2] Steven K Dobscha, associate professor[1,2]

[1]Columbia Center for the Study of Chronic, Comorbid Mental and Physical Disorders, Health Services Research and Development, Portland Veterans Affairs Medical Center, PO Box 1034, Portland, OR 97239, USA

[2]Department of Psychiatry, Oregon Health and Science University

Correspondence to: Linda Ganzini Linda.Ganzini@va.gov

Cite this as: *BMJ* 2008;337:a1682
doi:10.1136/bmj.a1682

ABSTRACT

Objective To determine the prevalence of depression and anxiety in terminally ill patients pursuing aid in dying from physicians.

Design Cross sectional survey.

Setting State of Oregon, USA.

Participants 58 Oregonians, most terminally ill with cancer or amyotrophic lateral sclerosis, who had either requested aid in dying from a physician or contacted an aid in dying advocacy organisation.

Main outcome measures Diagnosis of depression or anxiety according to the hospital anxiety and depression scale and the structured clinical interview for the Diagnostic and Statistical Manual of Mental Disorders.

Results 15 study participants met "caseness" criteria for depression, and 13 met criteria for anxiety. 42 patients died by the end of the study; 18 received a prescription for a lethal drug under the Death with Dignity Act, and nine died by lethal ingestion. 15 participants who received a prescription for a lethal drug did not meet criteria for depression; three did. All three depressed participants died by legal ingestion within two months of the research interview.

Conclusion Although most terminally ill Oregonians who receive aid in dying do not have depressive disorders, the current practice of the Death with Dignity Act may fail to protect some patients whose choices are influenced by depression from receiving a prescription for a lethal drug.

INTRODUCTION

In 1994 the voters of Oregon passed the Death with Dignity Act, which legalised the practice of physicians' aid in dying for terminally ill patients. This law authorises a physician to prescribe a lethal dosage of drug, usually a short acting barbiturate, to a competent, requesting patient for the purposes of self administration.[1] Several safeguards in the law ensure that patients are adult, competent, terminally ill, and choosing to end life voluntarily but not impulsively (box). Since enactment of the law in 1997, between one and two out of every thousand deaths in Oregon has been by lethal ingestion.[1]

The extent to which potentially treatable psychiatric disorders may influence patients' decisions for aid in dying has been debated. For people at the end of life, depression, hopelessness, and psychosocial distress are among the strongest correlates of desire for hastened death.[2-9] Eighty per cent of patients with cancer who complete suicide have a mood disorder, and, in primary care populations, treatment of depression reduces suicidal ideation.[10-14] The Death with Dignity Act requires that if the prescribing or consulting physician is concerned that the patient's judgment is impaired by a mental disorder (such as depression) the patient must be referred to a psychiatrist or a psychologist. No drug can be prescribed until the mental health professional determines that the patient does not have a mental disorder causing impaired judgment.[1] Physicians, hospice professionals, and family members of patients in Oregon who pursue aid in dying generally do not believe that depression influences choices for hastened death.[15-17] In 2007 none of the people who died by lethal ingestion in Oregon had been evaluated by a psychiatrist or a psychologist.[1] Healthcare professionals, however, often fail to recognise depression, particularly among medically ill patients.[18-20] The goal of this study was to determine the prevalence and severity of psychological distress, including major depressive disorder, in Oregonians who request aid in dying.

METHODS

We used several sources to notify patients of the opportunity to participate in our study. Some potential participants had contacted Compassion and Choices of Oregon for information about accessing aid in dying. Compassion and Choices is an organisation that offers information and assistance to people who choose aid in dying in Oregon. In 2006 Compassion and Choices gave information to or attended the deaths of three quarters of patients who chose aid in dying.[21] Other potential participants made an explicit request for aid in dying to a physician as outlined in the Death with Dignity Act. Ethics consultants and palliative medicine and oncology specialists in northwest Oregon invited these patients to participate. Patients referred from all sources contacted study personnel directly for more information about enrolling. All patients gave written informed consent to participate.

The study psychologist (ERG) administered all measures in the participant's home. We used the

Legal requirements of the Oregon Death with Dignity Act[1]

The attending physician who is responsible for care of the patient's terminal illness must ensure that:

- The patient is aged 18 years or above
- The patient is a resident of the state of Oregon
- The patient has made one written and two oral requests separated by 15 days
- The patient understands the risks of aid in dying and the alternatives, including hospice and comfort care
- The patient is assessed by a consulting physician
- Information about the patient is reported to the Oregon Department of Human Services

The attending and consulting physicians must ensure that:

- The patient is capable of making and communicating healthcare decisions
- The decision is voluntary
- The patient has a terminal illness that would, within reasonable medical judgment, cause death within six months
- The patient is referred to a psychologist or psychiatrist if concern exists that the patient has a psychiatric disorder including depression that may impair judgment

Information from statistical reports are compiled by the Oregon Department of Human Services and published yearly[1]

MacArthur competence assessment tool to determine participants' capacity to consent to research.[22] Once enrolled, participants confirmed that they had expressed interest in obtaining aid in dying through Compassion and Choices or explicitly requested aid in dying from a physician. The protocol required exclusion of participants with cognitive impairment (23 or less on the Folstein McHugh mini-mental state examination or 7 or less on the short portable mental status questionnaire[23-25]). The psychologist administered the hospital anxiety and depression scale,[26] which includes seven depression items and seven anxiety items, each rated on a 0-3 scale. For the purposes of identifying cases and consistent with expert recommendations, we identified participants with hospital anxiety and depression scale depression scores of 11 or greater as "depressed" and those with anxiety scores of 10 or greater as "anxious."[27] The psychologist administered the 20 item Beck hopelessness scale,[28] a well validated measure of hopelessness, which is a predictor of suicidal ideation and suicide attempts.[29 30] We designated those with scores of 10 or greater as "hopeless."

The psychologist completed the current mood disorder section of the structured clinical interview for American Psychiatric Association Diagnostic and Statistical Manual-IV axis I disorders (SCID-I), a standard research instrument for diagnosing mental disorders.[31] Because knowing that the patient has requested aid in dying may influence diagnostic thresholds for depression, the SCID interview was audiotaped and the tapes were reviewed by a research psychiatrist (SKD) who did not know if the patient had requested aid in dying (19 audiotapes from terminally ill patients who had not requested aid in dying were randomly interspersed). Based on studies by Chochinov and colleagues,[32] the severity of depressed mood or anhedonia needed to be at least moderate for the two weeks before the interview in order to reach the threshold for diagnosis. Chochinov et al also reported that when moderate thresholds were used for mood criteria, presence or absence of physical symptoms (such as weight loss or fatigue) no longer influenced categorisation of depression. Using an inclusive approach, we attributed all physical symptoms of depression to the diagnosis of depression, even if they might be a result of terminal disease. Thoughts of death or suicide and suicidal plans or attempts are criteria for major depressive disorder in the American Psychiatric Association Diagnostic and Statistical Manual.[31] We attributed suicidal ideation to a diagnosis of depression only if the patient endorsed suicidal thoughts or plans aside from aid in dying. The final SCID diagnosis of major depressive disorder was reached by consensus if ERG and SKD disagreed. For the purposes of identifying cases of depression, we considered participants to be depressed if their SCID was positive or their hospital anxiety and depression scale depression score was 11 or greater.[27]

Participants rated their overall suffering in the two weeks before the interview on an 11 point scale with end points labelled 0="I have not suffered" and 10="I have suffered severely."[33] They rated their quality of life in the previous two weeks on an 11 point scale with 0="Quality of life as good as it can be" and 10="Terrible, very bad quality of life." Participants rated their desire for death in the two weeks preceding the interview on an 11 point scale with end points labelled 0="I desire to live as long as possible" and 10="I have a strong desire to die soon." Participants rated the influence of depression as a reason for requesting aid in dying on a scale on which 1="depression not at all important in the decision to request a lethal prescription" and 5="depression very important in the decision to request a lethal prescription."

All participants diagnosed with major depressive disorder were notified of this result at the time of the study visit, and the study psychologist recommended treatment and offered to facilitate counselling. As is standard at our institution, a safety plan was developed so that all patients who seemed upset by participation in the study or were found to be imminently suicidal by means other than legalised assisted dying would be referred for an evaluation of mental health. Otherwise, participants were assured confidentiality in order to facilitate honest disclosure. We obtained information on outcomes—whether the study participant received a prescription of a lethal drug or died by lethal ingestion—six months or more after all other data collection was complete.

Data analysis

We present data as frequencies and proportions for categorical items and as means and standard deviations for normally distributed continuous items. We used Student's t test to compare means. All tests were two tailed and α was set at 0.05.

RESULTS

Of 178 Compassion and Choices clients notified of the opportunity to participate in the study, 12 were ineligible or deceased and 47 (28%) enrolled. The other 11 participants were referred from clinicians at other medical centres. No patients were excluded because of cognitive impairment or lack of capacity to consent to research. The mean age of the 58 patients requesting aid in dying was 66 (SD 12) years. Thirty one participants were women, 22 were married, and 21 were enrolled in a hospice at the time of the interview. The most common terminal diseases were cancer (n=44) and amyotrophic lateral sclerosis (n=7). At the time of the study interview 46 patients had explicitly requested aid in dying from a physician and 47 had contacted Compassion and Choices to obtain aid in dying.

Eight participants scored 11 or higher on the hospital anxiety and depression scale for depression, 13 scored 10 or greater on the anxiety subscale, and 11 scored 10 or higher on the Beck hopelessness scale. Twelve participants were diagnosed with depression by the SCID. Fifteen participants met our criteria for depression by being depressed on the SCID or having a hospital anxiety and depression scale depression score of 11 or higher. The mean desire to die among depressed participants was 5.7 (SD 3.0) on our 11 point scale. Seven of the depressed group did not attribute their pursuit of aid in dying to depression at all (score=1), but six felt that depression somewhat or strongly influenced their preference for hastened death (scores=3, 4, or 5). An offer to facilitate counselling was made to all depressed patients, but only one participant (patient C below) agreed.

Among the 42 participants who died by the end of the study, 18 received a prescription for a lethal drug and nine died by lethal ingestion. Among decedents, no significant differences existed between those who received a prescription for a lethal drug and those who did not on measures of psychosocial distress, except that those who received a prescription had (surprisingly) a lower desire to die and a trend toward lower hopelessness scores (table 1).

Table 1 | Comparison of deceased participants who received and did not receive prescription for lethal drug. Values are mean (SD) unless stated otherwise

Measure	Received prescription (n=18)	Did not receive prescription (n=22)	P value (*t* test
Hospital anxiety and depression scale—anxiety*	4.8 (3.2)	7.0 (5.1)	0.12
Hospital anxiety and depression scale—depression†	5.7 (3.4)	7.3 (4.4)	0.19
Hospital anxiety and depression scale—total‡	10.5 (5.4)	14.3 (8.6)	0.10
Beck hopelessness scale§	5.0 (3.0)	7.5 (5.4)	0.08
Desire to die¶	1.5 (2.6)	4.7 (3.7)	0.004
Suffering**	3.7 (2.7)	4.5 (2.9)	0.36
Quality of life††	4.0 (1.8)	5.1 (2.9)	0.13

*Scores range from 0 (no anxiety) to 21 (severe anxiety).[26]

†Scores range from 0 (no depression) to 21 (severe depression).[26]

‡Sum of anxiety and depression scales.[26]

§Scores range from 0 (not hopeless) to 20 (very hopeless).[28]

¶11 point scale: 0=I desire to live as long as possible; 10=I have a strong desire to die soon.

**11 point scale: 0=I have not suffered in the past two weeks; 10=I have suffered severely in the past two weeks.[33]

††11 point scale: 0=quality of life in past two weeks is as good as it can be; 10=quality of life in past two weeks is terrible, very bad.

Three of the 18 participants who received a prescription for a lethal drug met our criteria for depression on either the SCID or hospital anxiety and depression scale (table 2), and 15 did not. All three died by lethal ingestion in their home within two months of the interview. None had been evaluated by a mental health professional before participation in the research. Patient A, an elderly man with cancer who was receiving home hospice services, met "caseness" criteria on the hospital anxiety and depression scale with a depression score of 12, although his SCID result was negative. Patient B, a middle aged woman with cancer who was receiving home hospice services, was depressed by SCID criteria. She declined to complete the hopelessness scale because she had "trouble with the entire concept of hope." She rated her desire to die and her suffering as quite high. Whether patients A and B received mental health evaluation or treatment after participation in the study is unknown. Patient C, an elderly woman with cancer, was depressed by SCID criteria. She received treatment for depression with a psychostimulant after completion of the survey, was subsequently enrolled in a hospice, and was documented by a psychiatrist to have a remission in her depression before her death. She received the prescription when she was depressed, and she reported that depression somewhat influenced her decision to pursue aid in dying.

DISCUSSION

Among patients who requested a physician's aid in dying, one in four had clinical depression. However, more than three quarters of people who actually received prescriptions for lethal drugs did not have a depressive disorder. Our findings also indicate that the current practice of legalised aid in dying may allow some potentially ineligible patients to receive a prescription for a lethal drug; two of those who ultimately died by lethal ingestion had depression at the time they received a prescription for a lethal drug and died by ingesting the drug. A third patient was depressed at the time that she requested a physician's aid in dying and probably received her prescription; she was successfully treated for her depression before she died by lethal ingestion.

Strengths and limitations

Although many investigators have examined the degree to which depression is associated with a desire to die among terminally ill patients,[2-9] we believe that our study is the first to use standardised measures to examine the prevalence and severity of depression and anxiety in a group of patients who have actually requested and are potentially eligible to receive aid in dying.

The strengths of our study include a standard measure of depression (SCID) and a blinding system that controlled for the effect on the ultimate psychiatric diagnosis of the psychiatrist knowing that the patient had requested a physician's aid in dying. The other measures of depression and anxiety are commonly

Table 2 | Measures of psychological distress in depressed participants who received a physician's aid in dying

Measure	Case A	Case B	Case C
SCID depression*	–	+	+
Hospital anxiety and depression scale—anxiety†	7	4	8
Hospital anxiety and depression scale—depression‡	12	10	9
Hospital anxiety and depression scale—total§	19	14	17
Beck hopelessness scale¶	9	NA	9
Desire to die**	6	8	5
Suffering††	4	8	5
How much depressed mood influenced decision‡‡	1	1	3

NA=not available; SCID=structured clinical interview for American Psychiatric Association Diagnostic and Statistical Manual-IV

*+ indicates major depressive disorder present; – indicates major depressive disorder absent.[31]

†Scores range from 0 (no anxiety) to 21 (severe anxiety).[26]

‡Scores range from 0 (no depression) to 21 (severe depression).[26]

§Sum of anxiety and depression subscales.[26]

¶Scores range from 0 (not hopeless) to 20 (very hopeless).[28] Case B declined to complete this scale.

**11 point scale: 0=I desire to live as long as possible; 10=I have a strong desire to die soon.

††11 point scale: 0=I have not suffered in the past two weeks; 10=I have suffered severely in the past two weeks.[33]

‡‡1=depressed mood not at all important in decision to request prescription; 5=depressed mood very important in decision to request prescription.

used and well validated in terminally ill patients. Our study has several limitations. Use of an inclusive approach to categorise somatic symptoms, which, if present, were attributed to depression and not to terminal disease, carries the risk of inflating the prevalence of depressive disorder. In addition, only 28% of invited patients who requested aid in dying agreed to participate; uncertainty exists about the degree to which our data are generalisable to the entire population of patients who request physicians' aid in dying. In a study of Oregon physicians who reported on 141 requests for aid in dying, only 36% of patients were in a hospice at the time of the request—similarly, only a third of our participants were yet enrolled in a hospice.[34] In contrast, data collected by the Oregon Department of Human Services indicates that 86% of patients who die by prescription of a lethal drug are enrolled in a hospice before death.[1] This suggests that most patients begin inquiring about a physician's aid in dying before they enrol in a hospice. Our finding of a low proportion in hospice enrollees reflects this fact, rather than differences between our sample and all Oregonians who die by legal lethal ingestion.

The possibility remains that the three depressed patients who died by lethal ingestion satisfied the requirements of the Death with Dignity Act if the attending physician determined that depression was present but not influencing their judgment. The study participants themselves were divided in whether to attribute their interest in aid in dying to low mood. Although diagnosing depression can be relatively straightforward, determining its role in influencing decision making is more difficult, even by expert assessment. For example, in a study of 321 psychiatrists in Oregon only 6% were very confident that in a single evaluation they could adequately determine whether a psychiatric disorder was impairing the judgment of a patient requesting assisted suicide.[35] In a study of 290 US forensic psychiatrists, 58% indicated that the presence of major depressive disorder should result in an automatic finding of incompetence for the purposes of obtaining assisted suicide.[36] These data support that of the two components of the mental health assessment—presence of a disorder and determination of its influence—the greatest weight in determining eligibility for aid in dying should be on whether a relevant mental disorder such as depression can be diagnosed.

Depression and desire for death

Other studies and surveys from Oregon have indicated that aid in dying among depressed patients is very rare. Physicians in Oregon who received requests for aid in dying from 143 patients after enactment of the Death with Dignity Act reported that 20% were depressed—a proportion comparable to what we found in this study. None of the depressed patients on whom they submitted information received a prescription for a lethal drug.[34] Studies of healthcare providers, including hospice professionals, and family members in Oregon indicate that they believe that depression was rarely a factor influencing requests for a physician's aid in dying.[15-17] Our study suggests that in some cases depression is missed or overlooked.

In contrast, studies of interest in euthanasia from populations outside of Oregon suggest that depression and psychosocial distress are prominent among patients who endorse an interest in hastened death. For example, in a study of 200 terminally ill inpatients with cancer, the prevalence of depressive syndromes was 59% among patients with a serious and pervasive desire to die but only 8% among patients without such a desire.[6] In a study of 988 terminally ill patients living in areas where physicians' aid in dying was not legal, 10.6% reported seriously considering euthanasia or a physician's aid in dying for themselves, and those with depressive symptoms were 25% more likely to endorse this.[9] In a study of 98 patients admitted to a palliative care inpatient setting in the northeast United States, patients with major depression were four times more likely to have a high desire for hastened death.[8]

Whether findings from these patient groups can be extrapolated to patients who have actively requested legal physicians' aid in dying has remained uncertain—although 17% of Oregonians are potentially interested in aid in dying, only 1-2% actually request it.[34 37] For example, in a study of 161 patients with cancer in Oregon who were longitudinally examined for interest in a physician's aid in dying, 19 had a serious interest in aid in dying, fewer than half with a serious interest discussed aid in dying with their physician, two requested a prescription for a lethal drug, and none received one.[38] This suggests that most terminally ill patients who declare interest in aid in dying do not actively pursue aid in dying under legalised conditions. As such, studies of preferences for aid in dying in these groups may misrepresent actual requesters of aid in dying. In contrast, our surveyed participants had taken active steps to pursue a physician's aid in dying in one of the few jurisdictions where it is legal—all either

WHAT IS ALREADY KNOWN ON THIS TOPIC

The state of Oregon legalised physicians' aid in dying in 1997

Physicians, hospice professionals, and family members of patients who request a lethal drug do not believe that depression is an important reason why patients pursue aid in dying

WHAT THIS STUDY ADDS

Among terminally ill Oregonians who participated in our study and received a prescription for a lethal drug, one in six had clinical depression

explicitly requested aid in dying from a physician or contacted Compassion and Choices for information on the Oregon Death with Dignity Act. Before death, almost half had obtained a prescription for a lethal drug under the law.

Conclusions

Our study suggests that most patients who request aid in dying do not have a depressive disorder. However, the current practice of the Death with Dignity Act in Oregon may not adequately protect all mentally ill patients, and increased vigilance and systematic examination for depression among patients who may access legalised aid in dying are needed. Tools for screening for depression such as those used in our study are easy to administer and may help to determine which patients need further evaluation by a mental health professional. Further study is needed to determine the effect of treatment of depression on the choice to hasten death.

Contributors: LG participated in the design, receipt of funding, data analysis, and manuscript preparation. ERG participated in the design, data gathering, and manuscript preparation. SKD participated in the design, data analysis, and manuscript preparation. All authors saw and approved the final version. LG is the guarantor.
Funding: Northwest Health Foundation. The funding source had no role in any aspect of the study or this paper.
Competing interests: None declared.
Ethical approval: The study was approved by the institutional review board of the Portland Veterans Affairs Medical Center and the participating medical centres.
Provenance and peer review: Not commissioned; externally peer reviewed.
The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs.

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Accepted: 2 August 2008

The Oregon Death with Dignity Act:

A Guidebook for Health Care Professionals

Developed by
The Task Force to Improve the Care of Terminally-Ill Oregonians

Convened by
The Center for Ethics in Health Care, Oregon Health & Science University

Patrick Dunn, M.D., Task Force Chair and Co-Editor
Bonnie Reagan, M.D., R.N., Co-Editor
Susan W. Tolle, M.D., Reviewer and Major Contributor
Sarah Foreman, Manuscript Preparation

Initial writing of the Guidebook was supported in part by
The Greenwall Foundation

First Edition (print): March 1998

Current Edition (2008): Published on this website
Updated as information becomes available

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

1. Purpose of the Guidebook

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

About the Task Force

In November 1994, Oregon voters passed the Oregon Death with Dignity Act. This unprecedented passage of a measure to allow competent, terminally ill adult patients to obtain a physician's prescription for drugs to end life sparked intense public debate, opened discussions among health care professionals and institutions, and initiated a complex series of judicial challenges. After extensive judicial, legislative, and public review, the Oregon Death with Dignity Act has become law (see Appendix A, *The Oregon Death with Dignity Act*).

The initial passage of the Oregon Act catalyzed the Center for Ethics in Health Care, Oregon Health & Science University, to convene the Task Force to Improve the Care of Terminally-Ill Oregonians. The Task Force is a consortium of health professional organizations, agencies, and institutions which seek to promote excellent care of the dying and to address the ethical and clinical issues posed by enactment of the Oregon Death with Dignity Act. While individual Task Force members and the organizations they represent have differing viewpoints and values regarding the Oregon Act, the Task Force has endeavored to maintain a neutral position on this issue. We appreciate that Oregon is a geographically and culturally diverse state. The contents of this Guidebook are meant to honor this diversity and facilitate access to all aspects of the highest quality of care for Oregonians.

Patrick Dunn, M.D. chairs the Task Force. Susan Tolle, M.D. chairs the Subcommittee on Resources for Compassionate Care of the Dying. Bonnie Reagan, M.D., R.N. chairs the Subcommittee on Guidelines for the Oregon Death with Dignity Act. The overall goal of the Task Force has been to thoughtfully consider how to improve end-of-life care in our state. Our mission statement reflects this broad charge.

Mission of the Task Force

Share information, experience, and understanding of available resources for the care of terminally ill Oregonians and assist in the development and coordination of services where needed. Through open and respectful communication, we wish to facilitate understanding of diverse viewpoints and cooperate to improve the care of all terminally ill persons and their loved ones.

Facilitate the development of professional standards relating to the Oregon Death with Dignity Act that will protect vulnerable persons; set standards for quality care of the dying; and respect the values and privacy of persons in need of care, health care professionals, and health care systems.

Develop and coordinate educational resources on all aspects of the competent and compassionate care of terminally ill patients for the health care community and the general public.

Foster relationships and networking on issues related to compassionate care of the terminally ill.

Some aspects of improving the care of dying Oregonians are beyond the scope of this Task Force. For example, a terminally ill patient may not have access to adequate comfort care resources. To provide a means for obtaining a prescription under the Oregon Act without access to comfort care may place undue pressure on a patient and his/her family. The Task Force strongly endorses universal access to hospice care in Oregon. We encourage public policymakers to develop methods and funding to assure that all Oregonians have access to comfort care resources such as hospice in the final months of life.

About the Guidebook

Without endorsing or opposing the principles embodied in the Oregon Death with Dignity Act, the Task Force has developed this Guidebook for Health Care Professionals as a collective response to its enactment. We designed the Guidebook to be a useful resource for health care professionals and institutions as they contemplate the Oregon Act's implications for practice. Underlying this work is the assumption that regardless of the health care professional's personal view regarding the Oregon Act, open communication, consideration of comfort needs, and respect for divergent views are necessary components of care. We present ethical and practical guidelines to enhance compassionate care whether or not a physician or health care system is willing to participate in providing a prescription as set forth in the Oregon Act.

We developed the Guidebook originally through discussion and debate, followed by identification of issues and consensus development in Task Force meetings. Individual Task Force members researched and drafted chapters, which were then reviewed by the entire group and revised to reflect group consensus. Organizations represented on the Task Force and other interested parties were asked to review and comment on the final draft of the first edition of the Guidebook. The Guidebook is revised by Task Force consensus periodically to remain current with ethical standards, the law, and clinical practice. Participation by any professional organization, including the Center for Ethics, does not constitute an endorsement of this document, nor does it indicate a particular viewpoint about the Oregon Death with Dignity Act. Publication of this document is not our only responsibility.

We recognize the controversy regarding terms to describe the provisions under the Oregon Death with Dignity Act. "Physician-assisted suicide" or "physician-assisted death" are terms used in the medical and bioethics literature to refer to a physician providing information or the means for a patient to end his/her own life. The Oregon Act specifically states that the ingestion of a lethal dose of medication under the Oregon Act is not considered suicide. To comply with statutory definitions, the Oregon Department of Human Services no longer uses the term "physician-assisted suicide" to describe the practice. In this Guidebook, we use the terms "the Oregon Death with Dignity Act" or "ODDA" or "the Oregon Act" to refer to the provisions under Oregon law.

How to Use the Guidebook

In creating a new legal option for terminally ill patients, the Oregon Death with Dignity Act has added a new dimension to medical practice. This Guidebook was designed to be a comprehensive reference book on all aspects of putting the Oregon Act into practice. Some users may wish to read it from beginning to end, while others will prefer to skip to chapters that interest them. Because each chapter can stand alone, some ideas appear in more than one chapter. Wherever possible, we have used cross-referencing to direct the reader to more in-depth discussions of ideas in other chapters.

Each chapter begins with a philosophy section, followed by guidelines and references. Longer chapters have headings to direct the reader. The references are of two types: some are footnotes found in the text of the chapter; others are resources suggested for follow-up or additional reading. The guidelines are recommendations for practice based on Task Force consensus. We recognize that many patients who request a prescription as set forth in the Oregon Act will never receive a prescription.[1,2,3] Of those who do receive a prescription, a significant number never take it and die of their underlying condition. We also acknowledge that health systems and physicians will have differing views about the acceptability of providing such a prescription and about the appropriate degree of involvement. Our intent in developing the Guidebook has been to carefully think through scenarios in detail and to recommend actions that will optimize care and minimize harm, no matter where the health care professional sets the limit of involvement along the spectrum of possible scenarios. In our discussions we go beyond the letter of the law because the attending physician is the health care professional who is most intimately involved with the patient at this time and who has the greatest responsibility under the Oregon Act. This is an attempt to envision how the Oregon Act should be implemented in practice.

The Oregon Revised Statute citation of the Oregon Death with Dignity Act, hereafter referred to as the Oregon Act or ODDA, is not given each time it is mentioned in the text. The full text of the Oregon Act can be found in Appendix A, *The Oregon Death with Dignity Act*. Throughout the guidebook, we refer to Oregon Revised Statute as ORS and Oregon Administrative Rules as OAR.

Another Task Force project, *The Final Months of Life: A Guide to Oregon Resources*, is available on the Center for Ethics web site.

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Acknowledgments

The Greenwall Foundation, a New York-based foundation, provided financial support for initial publication of the Guidebook. The Greenwall Foundation has a long-standing interest in end-of-life care and did not take a position on the Oregon Death with Dignity Act. The views expressed in this document are those of the Task Force and do not necessarily represent the views of The Greenwall Foundation.

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2. The Meaning Behind the Patient's Request

Written February 1998; Revised: October 2004, March 2005, September 2007, December 2008

This chapter has been written primarily for the attending physician who has the initial discussion with a patient who requests a lethal dose of medication. However, it is applicable to others who may be involved in the care of a terminally ill person who requests a prescription under the Oregon Death with Dignity Act. For example, when surveyed almost two thirds of hospice nurses and social workers in Oregon reported having at least one patient ask them about the option during the previous year.[1]

Complex questions of motivation on the part of the patient and health care professionals arise when a patient begins this discussion. The patient's choices may involve an interactive set of factors that include the patient's religion, the doctor-patient relationship, perceptions of quality of life, and other psychosocial circumstances.[2] A health care professional may be motivated by compassion for the patient, feelings about participating in the Oregon Death with Dignity Act, or moral and religious beliefs, when considering how to respond. Whether or not a health care professional chooses to participate, he/she has an obligation to openly discuss the patient's concerns, unmet needs, feelings, and desires about the dying process. The physician and patient should explore each of these issues in depth. Open communication is a vital part of any end-of-life decision making.

Supportive communication will help patients with life-threatening illnesses make informed decisions about end-of-life care including advance directives, do-not-resuscitate orders, completion of a POLST form, hospice or palliative care, and other options. Only by appreciating the range of available options for end-of-life care can a patient make rational choices about the dying process. The patient may initiate a discussion in the context of these issues. If the patient asks about the Oregon Death with Dignity Act the attending physician should assess the patient's understanding of his/her illness, motivations, and desires.

The American Medical Association (AMA) has recommended that regardless of a physician's moral views on responding to a patient's request for a lethal dose of medication, the physician has an obligation to explore the meaning behind the question with the patient and provide reassurance that the patient will not be abandoned, nor symptoms left untreated, during the dying process.[3,4] Learning the meaning behind the patient's question and attempting to respond to the patient's concerns can be a potent therapeutic intervention.[5] Most patients who initially consider obtaining a lethal dose of medication do not persist with their requests when they feel their concerns are effectively addressed.[6] While approximately one out of 1,000 dying Oregonians obtain and use a lethal dose of medication, 17% personally considered it as an option.[7]

Although requests for a lethal dose of medication are often attributed to uncontrolled pain, research has shown that other physical symptoms, as well as psychological or existential distress, may be equally or more important (see *Mental Health Consultation*). For some patients, unresolved prior loss, feelings of frustration and hopelessness, or perceived lack of support from loved ones may produce anxiety or depression. It has been said that terminally ill patients who are used to being in control may be particularly prone to difficulties during this time. Existential issues like futility, meaninglessness, disappointment, remorse, death anxiety, or a disturbed sense of personal identity can contribute to a patient's suffering.[8] A study of patients in Oregon and Washington with ALS found that hopelessness was a factor in considering making a request under the Oregon Death with Dignity Act .[9] In 1999, physicians in Oregon reported that the most common reasons patients made requests for a lethal dose of medication were loss of independence, poor quality of life, and because they feel ready to die and have a desire to control the circumstances of death. Pain and other physical symptoms counted as less than half.[10] According to the second year report on the Oregon Death with Dignity Act from the Oregon Department of Human Services - Health Division, family members reported that a loved one requested a lethal dose of medication for several reasons, including loss of autonomy, loss of control of bodily functions, an inability to participate in activities that make life enjoyable, and a determination to control the manner of death.[11] These findings have remained consistent. According to the 2007 State Health Division report on Oregon's Death with Dignity Act, the most commonly reported concerns were decreasing ability to participate in activities that make life enjoyable (86%), losing autonomy (100%) and loss of dignity (86%).[12] All these studies suggest that the reasons for making a request are complex, not simply a matter of symptom control.

In addition to probing the patient's issues, the attending physician needs to contemplate his/her own motivations and beliefs. He/she will have emotional reactions and will need to consider the personal consequences of agreeing to provide a lethal dose of medication. The attending physician's beliefs about death and the meaning of pain and suffering are likely to impact how he/she interacts with patients and presents care options (see *Attending Physician and Consulting Physician*). Health care professionals need to explore their own attitudes about suffering. From this introspection, they can develop their own perspectives on care of the dying. Their beliefs will be transferred to their care of patients.[13]

In deciding how to proceed, physicians must act in ways that are consistent with their personal beliefs and respectful of the health system in which they practice, while still respecting the beliefs of the patient (see *Conscientious Practice*). After exploring the issues and alternatives, some health care professionals will choose to honor the patient's request. Others will decide that participating in the Oregon Death with Dignity Act violates their moral or professional code or their institutional mission. Some physicians who may agree with the Oregon Act philosophically may decide against participating with a particular patient or a particular set of circumstances. Currently, Oregon physicians explore interventions to relieve suffering when patients request a lethal dose of medication, and in the many cases the patients do not continue to pursue the request.[6,7,9]

Guidelines

2.1 When a patient asks about the Oregon Death with Dignity Act, the health care professional's initial response should be to explore the meaning behind the question, regardless of his/her personal views or willingness to participate. Loss of control, abandonment, financial hardship, burden to others, and personal or moral beliefs may be areas of concern to many patients.

2.2 The attending physician should seek to understand what constitutes unacceptable suffering in the patient's view. Pain, other physical symptoms, psychological distress, and existential crisis are potential causes of suffering.

2.3 The attending physician has an obligation to explore treatment for symptoms for which there are treatment options available. This includes hospice, psychological support, and other palliative care.

2.4 The attending physician should reflect on his/her own beliefs and motivations and the policies of the health care system, and consider the impact of those motivations on decision-making with patients near the end of life.

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3. Conscientious Practice

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The issue of obtaining a prescription for the purpose of ending life raises many ethical considerations and generates great differences of opinion, touching on questions and values rooted in philosophy, religion, and morality. The rights of patients and their surrogates to participate in medical decision-making is a firm principle in American bioethics. Because patients may make choices that challenge or conflict with the ethical codes or moral values of health professionals who care for them, it becomes necessary to state the principles of conscientious practice and how they apply to the Oregon Death with Dignity Act.

Conscientious practice applies to both participants and non-participants in the Oregon Death with Dignity Act. Physicians, other health care professionals, and health care systems have deeply-held values regarding end-of-life issues. It is important to recognize the rights of persons with conflicting views. Conscientious practice is the action that comes of respecting one's own moral beliefs while at the same time respecting the moral beliefs of others.

Conscientious objection arises from the concept that people are not obligated to perform acts that violate their conscience, even if the acts are legally or professionally sanctioned. Conscientious objection by health care professionals is a principle that is upheld by professional codes of ethics, for example, the refusal of a nurse to participate in an abortion done in a hospital. The Oregon Death with Dignity Act endorses conscientious practice and respect by stating unequivocally "No health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the provision to a qualified patient of medication to end his/her life in a humane and dignified manner."[1]

Sometimes patients' and health care professionals' rights directly conflict with each other under the Oregon Act. The patient's right to privacy may conflict with the rights of health care professionals to make informed personal decisions. This applies particularly to emergency personnel who may not have access to information about a patient's wishes but who have to make resuscitation decisions quickly (see *Emergency Department and Emergency Medical Services*). In this chapter, we examine some of the potential conflicts and, where possible, offer suggestions for resolution.

Patients have the right to information regarding their conditions and treatment options. When a patient asks about obtaining a prescription as set forth in the Oregon Act, the attending physician may give information about this option. The attending physician has no responsibility under the Oregon Act to initiate a discussion about obtaining a prescription. Whether the attending physician should initiate this conversation when discussing options is not discussed in the Oregon Act, and is left up to the individual health care professional. We believe that the attending physician should not initiate the discussion, because if he/she does, the patient may feel pressured, even though obtaining a prescription under the Oregon Act is a legally available option.

An individual health care professional, such as a physician or a hospice nurse, who is opposed to the Oregon Death with Dignity Act, may want to refrain from discussing it with an inquiring patient. However, the desire to avoid discussion of what is morally reprehensible to the health care professional may prematurely stifle discussion of the patient's overall needs. The Council on Ethical and Judicial Affairs of the American Medical Association, in its 1992 report, "Decisions Near the End of Life," urges physicians to examine "the needs behind the demand" for an active end to life. "The existence of patients who find their situations so unbearable that they request help from their physicians to die must be acknowledged, and the concerns of these patients must be a primary focus of medicine."[2] An AMA report issued two years later states: "Requests for physician-assisted suicide should be a signal to the physician that the patient's needs are unmet and further evaluation to identify the elements contributing to the patient's suffering is necessary. Multidisciplinary intervention, including specialty consultation, pastoral care, family counseling and other modalities, should be sought as clinically indicated."[3]

Through open communication with the patient, the health care professional may discover a true difference in values regarding this aspect of end-of-life care. Exploring these differences at the time the patient initially requests a prescription under the Oregon Act may prevent difficult time-pressured decisions and actions later. The health care professional can work with the patient to find an agreeable course of action; sometimes this means the patient must find another provider. The health care professional may decline to help in finding a new professional as part of his/her conscientious practice; however, he/she may not obstruct the change (for physicians, see *Attending Physician and Consulting Physician*). It bears emphasizing that if the health care professional cannot accommodate the patient's desire for a prescription under the Oregon Act, he/she must try to meet the other needs of the patient while transfer of care is being arranged.

All health care professionals have a right to know whether their care of patients involves actions that would be morally objectionable for them. This applies to all health care professionals, including hospice nurses and pharmacists, who have rights to be knowing participants. Nevertheless, attending physicians must respect the confidentiality of the patient's request unless otherwise waived (see *Liability and Negligence*).

Like health care professionals, institutions and health care systems also have the right to refuse to participate in the Oregon Death with Dignity Act. This right was further defined in the 1999 legislative revision of the Oregon Act, permitting health care systems to impose certain restrictions and sanctions on health care professionals assuming that the professionals are notified first of that policy (see *The Oregon Death with Dignity Act*). Institutional refusal may create conflicts for both patients and health care professionals. An attending physician may wish to provide a prescription for an eligible patient under the Oregon Act but be prohibited from doing so by the institution or system. In such an instance, his/her responsibility to the system conflicts with responsibility to the patient. The physician may also be limited in his/her ability to refer the patient to another physician for continuity of care if the patient's health care system doesn't participate in the Oregon Death with Dignity Act or restricts referrals (see *Attending Physician and Consulting Physician*). Systems that choose not to participate in the Oregon Act should notify patients and health care professionals in advance. It may also be important for institutions to inform prospective employees about policies that might influence their desire for employment.

The health care institution has certain obligations to patients, such as ensuring continuity of care and fulfilling medical needs. For a patient who chooses to participate in the Oregon Death with Dignity Act, there are many possible interactions with the system: relationships with the attending physician, the consulting physician, the psychiatrist or psychologist, the pharmacist, and the hospice staff (see *The Role of Other Health Care Professionals*). Only rarely would someone be an inpatient at the time the prescription is self-administered, making interactions with hospital nursing staff and other support staff likely.

Systems and institutions need to communicate expectations to employees about the care of a patient who chooses to take a lethal dose of medication as set forth in the Oregon Act and develop plans to ensure continuity of care in the event of conscientious objection by a staff member. Although most patients will choose to take the medication in the privacy of a home, if a patient is in a hospice or other health care facility, employees should be expected to provide for the patient's other care needs or arrange transfer of care in an appropriate manner. Difficulty transferring from a health care professional unwilling to participate in the Oregon Act to another who is willing may be compounded when the system itself is opposed to participation in the Oregon Death with Dignity Act. Health care systems may need to consider transfers between systems to maintain conscientious practice.

To date, financial issues have not been identified as a primary factor in patients' requests for prescriptions pursuant to the Oregon Act.[4,5]

Health care systems may want to develop multidisciplinary forums that would allow staff members to voice concerns about controversial procedures and practices. Systems will also need to develop processes for resolution of conflicts. The hospital ethics committee or system ethics resource may be the most obvious forum for conflict resolution and discussion of the Oregon Act.

The Oregon Death with Dignity Act is controversial in our society; therefore concern for the privacy of the people in situations involving a terminally ill patient's request for a prescription under the Oregon Act is critical. Privacy of patients, families, and health care professionals must be respected so that decisions can be made without threat of harassment or intimidation.

Guidelines

3.1 Conscientious practice refers to taking professional actions that are consistent with one's moral and ethical beliefs and avoiding actions that are contrary to one's beliefs.

3.2 Health care workers, institutions, and systems have the right to refuse to participate in the Oregon Death with Dignity Act.

3.3 Systems that elect not to participate in the Oregon Death with Dignity Act should notify patients and health care professionals in advance.

3.4 Health care systems and health care professionals need to develop guidelines to ensure continuity of patient care should the system or health care professional be unwilling or unable to participate in the Oregon Act. Skilled and humane care should be provided until transfer of care is complete, so that abandonment does not occur.

3.5 Expectations about care of the patient who chooses to participate in the Oregon Act need to be communicated to employees so that continuity of care can be maintained. Although taking the lethal dose of medication would usually occur in the privacy of a home, if a patient is in a hospice or other health care facility, employees should be expected to provide for the patient's other care needs or arrange transfer of care in an appropriate manner.

3.6 Health care systems need to develop a process for the resolution of conflicts.

3.7 Patients and health professionals have the right to privacy and freedom from harassment or intimidation, whether they choose to participate in the Oregon Death with Dignity Act or not.

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4. Hospice, Palliative Care, and Comfort Care

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Hospice enrollment of persons who ingested lethal medication under the Oregon Act increased to 88% in 2007, from 76% in 2006, the lowest rate since 1998. . Pain or fear of pain decreased to 33%, from 48% in 2006, the highest rate. Between 1997 and 2005, 87% of those who used a lethal dose of medication were enrolled in hospice, and pain or fear of pain, at 22%, was not considered a major factor.[1] This observation leads the Task Force to reaffirm its recommendation of referrals to hospice for persons who are interested in a prescription under the Oregon Death with Dignity Act, or any other end-of-life option, if they are not already receiving hospice or palliative care services. Oregon hospices respect the right of dying Oregonians to choose legal end-of-life options. The high quality of hospice and palliative care in Oregon is offered as one explanation for the low number of deaths under the Oregon Act.[2]

Persons in their final months of life have a variety of needs, including comfort, family support and counseling. Most benefit from care or consultation with an interdisciplinary group such as hospice or palliative care teams. The physician has an ethical obligation to explore and offer such options, and a legal obligation to offer alternatives when a patient no longer responds to other treatment or requests a prescription for medication to end his/her life. Health care professionals should know about hospice and palliative care, as well as other end-of-life options. When concerns are identified and addressed, patients are less likely to ask for or use a prescription under the Oregon Act.[3]

Hospice, palliative care and comfort care are defined separately in state and federal laws governing health care benefits and reimbursement. This chapter provides a brief overview of these services and benefits and how to access them.

Palliative care and "comfort care", as defined under the Oregon Health Plan, are medical and related services designed to alleviate pain and other symptoms. Hospice is a coordinated group of services that focus on comfort measures and palliative care and is available to a patient/family/caregiver during the dying process and bereavement. Hospice, palliative care and comfort care for the terminally ill are available throughout Oregon.

Hospice

Hospice is a coordinated program of care across all settings that utilizes an interdisciplinary team to provide palliative care and other support to a patient and family.[4] Hospice establishes pain and symptom control as an appropriate clinical goal. The hospice plan of care is developed by a team comprised of the patient's attending physician/nurse practitioner/clinician, and the hospice medical director/physician, nurse practitioner, nurse, social worker and spiritual or other counselor. Other team members include home health aides, therapists, dietitians, bereavement counselors and respite volunteers. Patients, family members and caregivers participate in developing and implementing the plan of care, choosing those hospice services most appropriate or desirable. Providing support for the family is a key advantage of hospice. Patients enrolled in hospice have access to hospice personnel 24 hours a day, seven days a week, for telephone advice or home visits. All hospice patients receive a psychosocial evaluation from a social worker and psychosocial issues are monitored by the hospice team. A psychosocial evaluation will assess for mood disorders and allow screening for patients appropriate for further evaluation by a mental health professional, as required under the Oregon Act. A new study recommends more thorough examination for depression among those requesting a lethal dose of medication under the Oregon Act.[5]

Hospice offers support or respite for the primary caregiver on an intermittent basis, but it does not routinely provide substitute caregivers. Some patients are able to manage their care without a primary caregiver, especially during the earlier stages of their illness, and some patients are willing to risk safety for independence. Others will reconsider living arrangements as the disease progresses, accepting or hiring a caregiver or moving. Sometimes all that is needed is a neighbor or relative or hospice volunteer to look in on a patient on a regular basis. The costs of substitute caregivers may be covered by a long-term care or custodial care benefit or carved out of a hospital benefit.

The hospice team manages the patient's care across all settings, admitting patients to an inpatient facility when necessary for acute or respite care. More than 92% of hospice care is provided in the patient's home or place of residence. Hospice teams care for patients who live in nursing facilities, residential or assisted care facilities, foster homes, and residential and inpatient hospices. Approximately 2% of hospice patients in Oregon die in a hospital.[6]

Palliative Care

Palliative care, a newly recognized medical subspecialty, focuses on reducing or abating physical and other symptoms of an illness or condition. The goals of palliative therapy are to achieve comfort, to manage symptoms and to improve quality of life. Palliative care benefits may be covered by health plans, sometimes on a case-by-case basis.

Palliative care services, as separate from hospice services, are provided by inpatient palliative care teams palliative care specialists and hospices. Palliative care services may be provided by independently defined or incorporated "palliative care programs."

Comfort Care

Comfort care is a benefit of the Oregon Health Plan. Comfort care includes hospice, palliative care, and services under the Oregon Death with Dignity Act. It is not limited to care provided through a hospice program. Comfort care, in this context, does not include diagnosis or cure-oriented treatment or active treatment intended to prolong life.[7]

Hospice, Palliative Care, and Comfort Care Benefit Plans

Hospice is a covered benefit under the Medicare Hospice Benefit, the Oregon Health Plan, CHAMPUS (Civilian Health And Medical Program of the Uniformed Services), the Department of Veteran Affairs, and private and employee health insurance plans. Hospice is most often reimbursed on a per diem basis. Attending and consulting physicians are reimbursed for medical services and oversight. The hospice benefit usually covers the costs of all medical and other services related to the terminal illness, including drugs, biologicals and inpatient admissions, although the patient may be asked to make a small co-payment. The savings in out-of-pocket expenses to patients and their families can be considerable. Bereavement services following the death of the patient are also covered.

Hospices in Oregon may practice "open access", broadening admission criteria to include persons who are receiving or considering treatment or medication that may have the effect of prolonging life.[8]

The Task Force to Improve the Care of Terminally-Ill Oregonians supports universal access to hospice and comfort care. We support public policies that would 1) expand the Oregon Health Plan's Hospice Benefit to cover uninsured or underinsured Oregonians, usually the working poor, and 2) ensure that health plans offered in Oregon include a comprehensive hospice benefit for the last months of life.

Medicare Hospice Benefit The Medicare Hospice Benefit is available to qualified patients eligible for Medicare Part A. The patient may choose any Medicare-certified hospice. Patients who elect the Medicare Hospice Benefit have access to medical services not related to their terminal diagnosis through their regular Medicare Part A, B, and D coverage or MedAdvantage plan, as long as premiums are paid. The Medicare Hospice Benefit is independent of any MedAdvantage, health maintenance organization (HMO) or Medicare supplemental health plan.

Medicare does not offer a defined palliative care benefit. Medicare managed care plans may, however, cover palliative care services.

Oregon Health Plan The Oregon Health Plan's Hospice Benefit mirrors the Medicare Hospice Benefit and is available to OHP Standard and Plus clients who have a terminal illness or condition. Qualified clients also have access to a "comfort care benefit" or palliative care on a fee-for-service basis. Hospice services must be provided by a hospice listed on the State of Oregon's Hospice Registry. Comfort care services may be provided by a hospice or other qualified individuals or agencies.

Other Health Plans Most private and employee health plans offer a comprehensive hospice benefit of coordinated services and reimburse the hospice on a per diem basis. Under Oregon law, a hospice benefit may not exclude or limit core hospice services. Some health plans will create a hospice benefit for their terminally ill clients, if not otherwise covered, out of unused skilled nursing, hospitalization, or custodial care benefits. Most health plans offer or will consider comfort care or palliative care benefits for their clients who are undergoing life-prolonging treatment, whose estimated life expectancy is longer than six months, or whose prognosis is still unpredictable.

Private Pay or Uninsured Patients Hospices generally use a sliding fee scale to bill for services and provide services without regard to a patient's ability to pay.

Eligibility

Individuals are eligible for hospice and comfort care, under the Oregon Health Plan's Medicaid Demonstration Project, and for hospice, under the Medicare Hospice Benefit and most health plans, when estimated life expectancy, in the physician's judgment, is less than six months, if the disease follows its natural course.[9] Medicare services must be medically necessary. Local coverage determinations (LCDs) have been formally adopted by fiscal intermediaries under CMS (Centers for Medicare and Medicaid Services) to specify clinical criteria for establishing a patient's six-month prognosis. LCDs may be used as a guideline, but clinical judgment is a more important factor. Persons who elect comfort care or hospice under Medicaid, Medicare, and most health plans, will be required to waive coverage for other treatment related to the terminal diagnosis. Election statements include acknowledgment by the patient of the palliative nature of care.

Making Referrals to Hospice

Referrals to hospice should be timely. The attending physician, if a patient has one, and the hospice medical director or physician must certify that, in their judgment, the patient has a life expectancy of six months or less, if the disease follows its normal course. If prognosis is uncertain, hospices will make an assessment. Hospice physicians are also available to make visits to provide information about hospice. Recertification is required periodically throughout the illness. Patients whose condition stabilizes or improves may no longer meet eligibility requirements. Patients who are discharged or who revoke a hospice benefit during any certification period are immediately eligible for any remaining benefit periods. The hospice medical director or physician may act as a patient's attending physician. Under state and federal law, a hospice patient's "attending physician" includes nurse practitioners. However, nurse practitioners may not certify or recertify a terminal prognosis.

Preparing Patients for Hospice

An early and frank discussion between doctor and patient about the disease and its expected outcomes allows a patient to make informed end-of-life decisions when treatment for cure or remission is questionable. Informal surveys at support group meetings of people with life-threatening illnesses suggest that possible death is a common thought at the time of diagnosis and may be an opportune time to have a brief conversation about what a patient will want to know. When physicians dismiss comments about death, they may inadvertently create barriers to future discussions and timely referrals to hospice and palliative care.

Oregon Health and Science University's palliative care team is finding that open and honest discussions about end-of-life options are of great value in the decision-making process.[10] A one-time physician consultation about end-of-life options is available through hospices. Hospice teams may make assessments related to prognoses. CMS considers the prognosis an estimate, based on the clinical judgment of the attending physician and the hospice medical director. A referral to hospice is a "win-win" proposition: a patient can revoke a hospice benefit at any time, if he/she changes his/her mind; and a patient will be discharged, if he/she is no longer has a limited prognosis.

"Why didn't we have hospice sooner?" is the most common complaint of hospice patients and families. The median length of stay in an Oregon hospice program, the time between admission and death, was 18days in 2007. Most hospice benefits are unlimited; it is not true that patients are discharged because they live longer than six months. *Hospice Care: A Physician's Guide,* is available at the *Oregon Hospice Association* website.[11]

Hospice, DNR Orders, and POLST Orders

Do-not-resuscitate (DNR) orders are not required for hospice patients. All hospices in Oregon use Physician Orders for Life-Sustaining Treatment (*POLST*) forms, and options are not limited to comfort measures.[12] A hospice plan of care, however, is not likely to include emergency calls and intensive care unit (ICU) admissions. Unless an emergency is unrelated to the terminal illness and otherwise covered by insurance, patients and families may have to assume costs associated with a call to 9-1-1.

Hospice, the Oregon Death with Dignity Act, and Other End-of-Life Options

Options for terminally ill Oregonians include hospice, palliative care, comfort care, pain management, the right to refuse or withdraw treatment, and the right to request a prescription for medication to end life.

Hospice respects and supports a patient's right to choose any or all legal options. Oregon's hospices will not refuse to admit or care for a patient or deny support to a patient's family because the patient intends to end his/her life under the Oregon Death with Dignity Act. Hospice policies differ in the extent of involvement, and some hospices allow employees to be at the bedside of a patient when a lethal dose of medication is self-administered. Other programs provide all aspects of hospice care, but ask staff to leave the room when a lethal dose of medication is taken. The Oregon Hospice Association and Oregon's hospice professionals recommend and encourage referrals and admissions to hospice during the fifteen-day waiting period following a request for a prescription or at any time before the medication is self-administered, if the patient is not already enrolled in hospice.[13]

Hospice philosophy seeks to neither hasten death nor prolong life, but hospices support the aggressive treatment of symptoms even if medication or other treatment may inadvertently affect the course of the disease. Comfort measures, such as good pain control, blood transfusions, or short-course radiation, may have the effect of prolonging life. Others, such as sedation or general anesthesia for severe pain and symptoms, may hasten a patient's death. Patients who are especially concerned about distressing symptoms may be comforted to know that sedation to unconsciousness is a treatment option.[14]

The Task Force is concerned that federal attempts to prohibit the use of controlled substances under the Oregon Death with Dignity Act may have a negative impact on pain and symptom management at the end of life. Regulatory scrutiny is a factor in physician reluctance to prescribe pain medications, even if necessary to control symptoms.

Hospices have developed guidelines to support patients who choose to discontinue nutrition and hydration as a means of hastening death. Patients should be informed of their right to refuse nutrition and hydration when complying with the informed decision provision of the Oregon Death with Dignity Act. Stopping nutrition and hydration may be an option for patients who are unable to self-administer medication.[15]

The *Oregon Hospice Association* has chosen to serve as a resource for honest and open communication about all of Oregon's legal end-of-life options. Because the Oregon Death with Dignity Act is currently a legally available option in Oregon, the Oregon Hospice Association has developed a bulletin that introduces the Oregon Act in the context of other end-of-life options to help facilitate conversations.[16]

Guidelines

4.1 The Task Force encourages physicians to talk to patients about the medical outlook and the possibility of hospice and palliative care early in the course of a life-threatening illness. Physicians may assist patients and their families in meeting with a hospice or palliative care team as early as possible for information, if not for referral, should the disease progress. Most patients and families are comforted by knowing what support will be available if the disease cannot be controlled, but may need encouragement to take these steps.

4.2 Physicians should become familiar with hospice and palliative care resources in their communities. Physicians can contact the Oregon Hospice Association, (888) 229-2104 or at info@oregonhospice.org. Oregon's Hospice Registry is located at *Oregon Hospice Association*. The Oregon Hospice Association keeps the Registry on behalf of the State of Oregon. A comprehensive list of resources is available.

4.3 Physicians should complete the necessary documents of admission as soon as possible after a patient decides to enter a hospice program. Hospices can begin providing services on the day of referral and complete the admission process within 24 hours.

4.4 Hospices encourage attending physicians to manage their patient's care after admission to hospice. If a physician chooses not to do so, he/she may refer the patient to the hospice medical director or another palliative care or hospice physician or clinician. Medical directors of hospice programs are a resource available to attending physicians of hospice patients.

4.5 If a patient decides not to enroll in hospice or other palliative care program, we strongly recommend that the physician ensure that necessary care is provided from another source. As the patient's needs change, the physician is encouraged to explore again the prospect of hospice care.

4.6 When a patient requests a prescription to end his/her life, the Oregon Death with Dignity Act requires physicians to inform patients of feasible alternatives, such as hospice admission or comfort care consultation, if the patient is not already enrolled in a hospice program. Both patients and their families will benefit from hospice support during the required waiting period.

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Website Resources

Oregon Hospice Association

National Hospice and Palliative Care Organization

Hospice Foundation of America

Medicare

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5. Patient Rights and Responsibilities

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Health care systems, health plans, health care professionals, and institutions recognize the mutual responsibilities in the partnership as health care professionals and patients. Understanding these mutual commitments is essential for respecting the dignity of each patient, the integrity of each health care professional, and the core values of the institution. In this chapter we will review patients' rights and responsibilities under current standards of practice, then those specific to the Oregon Death with Dignity Act.

Health professionals have a duty to provide considerate and respectful care and to treat patients with dignity at all times. Patients have the right to receive information about their care and to have questions answered honestly. Patients, within the context of their primary relationships, are the principle decision-makers concerning their own health care. The process by which a competent patient agrees to or refuses medical intervention is called informed consent. Health care professionals must give a patient, in a manner the patient can readily understand, material information about his/her diagnosis, the course of a disease process, prognosis, treatment options, expected outcomes, possible complications, and the consequences of refusal in order for the patient to be able to give informed consent. In order to make truly informed decisions about care, patients also need the freedom to explore feelings and spiritual needs in an environment that shows respect for their ethnic, cultural, or religious values. Health care systems have a duty to promote that freedom by providing supportive social work services, counseling services, and spiritual/pastoral services that will enhance patients' decision-making.

Patients have a right to expect that the confidentiality of their health care history will be respected by their caregivers and health care institutions to the extent provided by law. Confidentiality applies to communications and medical records.

In those rare instances when a physician believes that a patient's refusal to divulge information to a third party puts that party at risk for serious harm, the physician should seek legal and ethical advice to determine if the sharing of information with that party, even without the consent of the patient, is legally or ethically permissible or required. If the physician feels that he/she has a personal duty to protect some third party that is not recognized by the law, it can in some instances be permissible for that physician to exercise a degree of influence to persuade the patient to divulge information or to give permission to the physician to divulge it. A physician should never coerce the patient to divulge such information, even if ultimately the physician feels ethically obligated to do so himself/herself.

Patients have the responsibility to communicate their medical history and treatment goals, stressors, fears, and needs as completely and accurately as possible. They are responsible for letting health care professionals know when they have unrelieved pain, distressing symptoms, and/or suffering so that the health care professionals can promptly evaluate and treat them.

Patients are responsible for voicing their concerns about treatment goals or procedures and informing their physicians if they cannot or will not follow a treatment plan. Although patients do not have to explain or justify themselves to their physician, doing so may be helpful to finding an alternative approach or promoting the quality of the physician/patient relationship. Patients and their health care professionals have a responsibility to engage in some form of advance care planning so that, in the event the patient should become unable to make decisions for him/herself, health care professionals will have guidance as to how to proceed. A patient may do this by executing an advance directive for health care and/or name a health care representative to make decisions as provided under Oregon law. Patients who choose not to execute such decisions should be aware of the surrogate law in Oregon so that they will know who, in the absence of an advance directive or health care representative, will be making their care decisions for them.

Patients facing the end of their life especially should have access to a compassionate, knowledgeable, interdisciplinary team that is committed to understanding their needs. In addition, consultation with hospice, supportive care, or palliative care teams may enhance the comfort of both the patient and loved ones (see *Hospice, Palliative Care, and Comfort Care*).

Patients often need help from and for their significant others in accepting death. They should be given the opportunity to die in peace and in a setting reflecting their dignity, and not with the sense that they are alone. Meaningful presence, generous hospitality, and faithful companionship are essential. Oregon law[1], as well as traditional principles in health care ethics, requires that patients from whom life-sustaining procedures or artificially administered nutrition and hydration are withheld or withdrawn shall be provided humane care to ensure comfort and cleanliness. "Medication, positioning, warmth, appropriate lighting and other measures to relieve pain and suffering" are listed as essential elements of compassionate and skilled care in Oregon's 1993 advance directive statute.[2]

The Oregon Death with Dignity Act makes specific reference to rights and responsibilities within the patient and health care professional partnership. Health care professionals have a duty to give patients honest and accurate prognostic information while respecting cultural values. Patients have a right to know if they have a life-threatening illness that will probably result in death within six months because they may wish to make personal plans, seek hospice benefits, or request a prescription for a lethal dose of medication as set forth in the Oregon Act. An eligible patient who desires a lethal dose of medication must make two oral requests and, after a 15-day waiting period, one written request for the medications (see Appendix A, *The Oregon Death with Dignity Act*).

Patients have a right to know whether their health care professionals are willing to participate in the Oregon Death with Dignity Act and provisions under the Oregon Act are allowed in their health care system (see *Conscientious Practice*). Patients have a right to know any limitations of their health insurance plan with regard to the Oregon Death with Dignity Act and any potential conflicts of interest that may impact decisions about care. Patients need also to respect the integrity of their health care professionals and the institutions where they access care. Oregon law allows individuals, insurance plans, and institutions or systems to exercise a right not to participate in the Oregon Act. Oregon law does not consider referral by one physician who chooses not to participate in the Oregon Death with Dignity Act to one who will to constitute participation in the Oregon Act, although it does not require a physician to do so. Similarly, the law does not require insurance companies to consider the Oregon Act as a covered benefit. Both physicians and patients have a responsibility to be aware and respectful of each other's personal convictions and the institutional policies that may apply to them.

Eligible patients who choose to request a prescription under the Oregon Act have a responsibility to consider the needs of health care professionals other than the attending physician involved in their care (see *The Role of Other Health Care Professionals* and *Emergency Department and Emergency Medical Services*). This is necessary to ensure conscientious practice and to prevent unexpected problems, such as an uninformed emergency medical technician (EMT) attempting resuscitation after finding the patient comatose following taking the lethal dose of medication. If the patient is unwilling to inform a health care professional, he/she should consider terminating the relationship.

When the Oregon Death with Dignity Act is the reason for a change of physician, the physician, health care system, or health plan may decline to help in finding a new physician as part of their conscientious practice. They may not, however, obstruct the change. The health care professional must continue to offer humane and skilled care until the transfer is complete (see *Conscientious Practice*).

Guidelines

5.1 Patients have the right to all material information about their medical condition and prognosis in order to be able to make informed decisions about treatment.

5.2 Patients have a right to be told if they have a life-threatening illness that will probably result in death within six months so that they can make personal plans, which may include seeking hospice care or requesting a prescription under the Oregon Act.*

5.3 Patients have a right to know whether or not their health care professional, insurance plan, or system will participate in or support the Oregon Death with Dignity Act, and a responsibility to be respectful of the convictions that underlie those policies.

5.4 Patients who plan to take a prescription obtained under the Oregon Act have a responsibility to consider the needs of family and health care professionals other than the attending physician to respect conscientious practice and to prevent unexpected problems.

5.5 If a patient seeks to change physicians in order to obtain a prescription under the Oregon Act, the transferring physician must continue to offer humane and skilled care until the transfer is complete.

** Not all cultures have the same appreciation for direct information regarding diagnosis and prognosis, so this "right to be told" will often need to be nuanced with cultural sensitivity.*

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6. Family Needs and Concerns

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Patients exist in a complex social network that includes family, friends, and other intimate relationships. These relationships provide the support and foundation for the patient's values, beliefs, and priorities, and often empower the patient to exercise autonomy. Because some patients' closest relationships are with friends, not members of their biological family, we use the term "family" broadly to include spouse, significant other, children, close friends, and other intimate relations.

The number of patients who personally consider the option of the Oregon Death with Dignity Act and talk with family about the option is far greater than the number of those who ultimately take a lethal dose of medication under the Oregon Act.[1] Seventeen percent of terminally ill persons at some point consider taking a lethal dose of medication, while one person in a thousand ultimately takes the medication as prescribed under the Oregon Death with Dignity Act.[2]

Family members and friends can provide knowledge of a patient's values over time and insights into personality and character which may aid a physician caring for that patient. Any decision that affects a patient affects the family; decision-making at the end of life can profoundly affect the lives and memories of the patient's family and friends. In this chapter, we explore the role of the family when a terminally ill patient requests a lethal dose of medication.

The process for requesting a lethal dose of medication starts with the patient. Most patients have discussed their wishes and values regarding the dying process with their family members long before this specific request occurs. Others may approach the subject with family when they are close to wanting the prescription. Still others may choose not to disclose their wishes to family for a variety of reasons, including protection of those persons, fear of being hurt or rejected, a lack of closeness with family, or a difference in religious or moral views. In a survey of physicians' experiences with the Oregon Death with Dignity Act, for 80% of the patients requesting a prescription under the Oregon Act, family members knew of the request.[3] Physicians spoke with family members about the request in 73% of patients. Nine percent of patients kept their intentions from their families and five percent had no family to inform.

If a patient announces a wish to use a prescription under the Oregon Act, there are several responses that may occur. Searching the meaning behind the patient's request is important not only for the physician and other health care workers but also for family and friends (see *The Meaning Behind the Patient's Request*). Issues and concerns may be alleviated by a frank discussion with family members. Supportive interventions such as referral to hospice, referral to a mental health professional, or an improvement in pain management may not only improve the dying process for the patient but may impact the patient's desire for a prescription under the

Oregon Act. In the Ganzini study, 46% of patients for whom major interventions were made changed their minds about participation in the Oregon Death with Dignity Act.[3]

Good communication is critical at such an intense time, as values and attitudes need to be discussed and decisions made. These issues can be difficult to discuss even in families with a history of open communication and supportive relationships. The conversations may increase or alleviate stress. The dying process does not automatically ensure that communication will come easily and effectively for families. Families have styles of communication that they bring to the dying process. In addition, the patient's moods and symptoms, created by the disease and by its treatments, can affect communication.

Communication becomes particularly important when the dying person is considering participating in the Oregon Death with Dignity Act, especially to clarify the issues that motivate the person to do so. Open communication, perhaps with the help of a health care professional or counselor, can help to clarify and correct assumptions and may even change the patient's wishes for a lethal dose of medication. At the least, good communication may help to generate solutions to problems and ease the dying process for all concerned. Discussion regarding the dying process can bring relief to patients and families, or it may increase tension due to the difficult nature of the subject.

There is no question that supportive intervention benefits dying patients and their loved ones.[4] Assistance with practical matters (e.g., bathing, food preparation, errands) can be invaluable and can relieve stress for both patients and caregivers. The need for psychosocial and, as appropriate, spiritual support for patients and families is of great importance. Evaluation and treatment of distress, anxiety, and depression is helpful in maintaining quality of life throughout the dying process. Such support is available through home health services or hospice. Different hospices have different policies with regards to the practice of the Oregon Death with Dignity Act. Patients and families are urged to clarify the policy of their specific hospice program when considering participation in the Oregon Act. Other *community resources* may be available.

Some patients, despite substantive interventions, are determined to obtain prescriptions under the Oregon Act. Some may have families who are willing to support them or who are opposed to this option. Of those who are opposed, some family members may eventually be swayed by the patient's arguments or circumstances and others will remain opposed. This may affect the patient's final decision, as in the case of a patient with amyotrophic lateral sclerosis (ALS), featured in the series "*On Our Own Terms*", by Bill Moyers, who did not pursue obtaining a prescription for a lethal dose of medication largely out of respect for his wife's religious beliefs.[5] For those patients who do obtain prescriptions under the Oregon Act, and who choose not to inform some or all of their family members, their wishes not to disclose should generally be respected by health care professionals on the basis of confidentiality. However, there may be circumstances that create concerns regarding an adverse impact on family members, and would indicate the need for further dialogue.

The patient who desires a lethal dose of medication needs to explore this option with his/her physician and clarify the physician's willingness to participate in the Oregon Act (see *Attending Physician and Consulting Physician*). If the physician is unwilling, the persistent patient will need to find a physician who is willing to participate; sometimes the family helps with this search. If a willing physician is found, there still may be other health care professionals and institutions involved whose moral values don't allow participation in the Oregon Act. Patients and their families are urged to respect these values (see *The Role of Other Health Care Professionals*). The non-participating physician who has a significant relationship with the patient may still participate in some aspect of the patient's care, as agreed to by the patient and participating physician (see *Attending Physician and Consulting Physician*).

The Oregon Death with Dignity Act focuses almost exclusively on the patient and physician. However, the statute references the family in several instances. The physician is required to recommend that the patient notify the next of kin of his or her request for medication under the Oregon Act (although the law states that a patient who declines or is unable to tell next of kin shall not have his or her request denied for that reason). One of the two witnesses to the patient's written request can be a relative. In the 1999 amendment to the Oregon Act, the physician is required to counsel the patient about the importance of having another person present when the medication is taken. This may be family, although there is no published data. Finally, like health care professionals, family members and others have legal immunity from prosecution for being present at the time of the patient's ingestion of the lethal dose of medication, if the requirements of the Oregon Act have been met.

Most of the literature on the subject of the Oregon Death with Dignity Act specifically, and ingesting a lethal dose of medication generally, acknowledges the primary role of the patient in decision-making. Many patients request assistance under the Oregon Act because of loss of autonomy and a determination to control the manner of their death.[6] Some families have discussed this issue for years and are familiar and comfortable with their loved one's attitudes.[7] Some family members start out being opposed to their loved one's decision, for various reasons, including religious and moral beliefs, denial of the seriousness of the disease, or a desire to rescue the patient. A prominent reason is the sadness that family members feel at the impending loss of their loved one. In some cases of completed death by a lethal dose of medication, the family eventually comes to terms with the patient's decision, feeling that it was right for that patient. Barry Siegel summarizes this process: "It was hard to imagine that someone wanted to go, someone you didn't want to let go. ... And yet, Joan now realized, it wasn't so much that Mark wanted to go. He needed to go. It was right for him, she decided, so that meant it was right for her."[8] Other family members remain opposed to the request, sometimes altering the patient's decision.[5]

In the published reports on the Oregon Death with Dignity Act, as well as in cases from the Netherlands, commonly a great deal of interaction exists between the family and the health care team. Often the contact is only with physicians, but it may involve nurses, pharmacists, social workers, other members of the hospice team or health care system, and volunteers. In Oregon, a number of family members expressed frustration at not being able to find health care professionals to help them, but once they had an attending physician, that person coordinated care.[6] Because this law is relatively new, it is unfamiliar ground for many health care professionals as well as families.

Patients and families have expressed the need for information about the process of participation in the Oregon Act. This information and planning should include:

a. The specific requirements and process of the Oregon Act, including a timeline.

b. Alternatives to the Oregon Death with Dignity Act, including comfort care, hospice care, and pain control.

c. Discussion of disclosure to family members; discussion of who will be present at the time the patient takes the lethal dose of medication, including health care professionals or volunteers.

d. Suggesting that *Advance Directives* and *Physician Orders for Life-Sustaining Treatment* (*POLST*) are appropriately completed and available where the patient is receiving care.

e. An idea of what to expect during the ingestion itself, and contingency plans if things do not proceed as expected, especially if the death takes longer than expected. Death may not be immediate and may take hours.

f. Discussion of the availability of the attending physician, either in person or by phone, to deal with questions and complications, or for support.

g. Information on funeral arrangements, including a plan to have the attending physician notify the hospice and funeral home that the death was expected and that he/she will sign the death certificate.

It is natural for a person who is terminally ill to withdraw from worldly attachments – things, places, people. Written discussion about any rituals associated with taking a lethal dose of medication are lacking, aside from the practical details of the preparation of the medication and its ingestion. There may be more of a need for a family or caregiver to have a ritual than for the dying person.

Bereavement is the experience of and adjustment to the loss of a loved one after death.[9] It may begin before death as anticipatory grief, a phenomenon that has been described as rehearsal for loss. Numerous variables affect the grieving process, including the circumstances of the death itself.[10] Traditionally, bereavement following suicide has been described as complex and more difficult to resolve due to the nature of the cause of death.[11] There is no written information on how legally permitted death by a lethal dose of medication affects bereavement, and the traditional literature on bereavement following suicide cannot be easily generalized to the bereavement experience following participation in the Oregon Death with Dignity Act.

Theoretically, with participation in the Oregon Act, there may be some opportunity for discussion and closure, and available data suggests that some family members seem to develop respect for the loved one's choice, even if different from their own.[6,7] Some families indicated that supporting their loved one's wishes in these matters has been comforting, as the perceived suffering has been relieved. These aspects may make bereavement easier. However, any complications that occur, or the perception or fact of disapproval by family members or others in the community, could make bereavement more difficult.

One frequent theme in the published literature is the concern about secrecy during the process leading up to, during, and after the death by a lethal dose of medication, which can make the grieving process last longer and be more difficult.[7] This is especially true when such a death is done illegally:

> "One of the ways that people normally deal with their grief is by talking about the death. This option is closed to them in an assisted death, unless one has participated with other family members or close friends. Those who assist may come to feel that they have no one they can talk to, no one with whom they can share what may well be one of the most powerful experiences of their lives. They may be too frightened or ashamed to tell others in their own family or their closest friends, who might not be supportive of such an act."[12]

In Oregon, it remains difficult for some to be open about the manner of death under the Oregon Act:

> "For Beth, the hardest part has been continued public opposition to assisted suicide. She has felt stung by opponents' remarks to the media about assisted suicide. She has worked to reconcile her mom's death with her own faith, ultimately believing in a merciful and forgiving God. But Beth has not told many people how her mother died. She still goes back and forth in her mind about it."[13]

Families who are involved with the Oregon Death with Dignity Act have strong and sometimes conflicting needs and emotions about this intense experience: "Family members expressed profound grief over their loss. However, mixed with this grief was often great respect for the patient's choice. One man said about his wife of almost 50 years, 'She was my only girl: I didn't want to lose her...but she wanted to do this."[6] And, after the death of a young person, her mother thanked the physician and said: "In preparing her ingestion, I gave my daughter the most important gift I could give, and the most difficult one I could give."[14] It should be noted that this is an emerging field of study, and more data is needed to understand the full impact of the Oregon Death with Dignity Act on bereavement, family, and community relationships.

The following are suggested as guidelines for participating physicians and other health care professionals in working with families:

Guidelines:

6.1 It is important for health care professionals to recognize the critical role that family and friends play in the life and care of a patient. Families can provide knowledge of a patient's values and personality. Families are profoundly affected by the care of the patient at the end of life.

6.2 It is also important to recognize the different responses family members may have to a patient's request for a prescription under the Oregon Act. Some may be supportive, others may become supportive, and still others may be consistently opposed.

6.3 Physicians who agree to participate in the Oregon Death with Dignity Act are required to recommend to the patient that the next of kin be notified of the request for a lethal dose of medication. However, a refusal to do so does not in itself make a patient ineligible for the Oregon Act. Some patients have difficult relationships or religious or moral differences with family members; their decisions regarding disclosure generally should be respected on the basis of confidentiality. However, there may be circumstances which create concerns regarding an adverse impact on family, and that would indicate the need for further dialogue.

6.4 Physicians are required to counsel patients about the importance of having another person present when the medication is taken. The Oregon Act does not require another person to be present.

6.5 Patients and family members have a great need for information about the Oregon Act and its requirements, what to expect during the ingestion of a lethal dose of medication itself, and what to expect afterwards. Also, the attending physician should confirm that the members of the health care team are willing to participate. It behooves the attending physician and other appropriate health care professionals or volunteers to supply the needed information in as much detail as possible, and to plan strategies for care. This planning should include:

a. The specific requirements and process of the Oregon Act, including a timeline.

b. Alternatives to the Oregon Death with Dignity Act, including comfort care, hospice care, and pain control.

c. Discussion of disclosure to family members; discussion of who will be present at the time the patient takes the lethal dose of medication.

d. Suggesting that *Advance Directives* and *Physician Orders for Life-Sustaining Treatment* (*POLST*) are appropriately completed and available where the patient is receiving care.

e. An idea of what to expect during the ingestion itself, and contingency plans if things do not proceed as expected, especially if the death takes longer than expected. Death may not be immediate and may take hours.

f. Discussion of the availability of the attending physician, either in person or by phone, to deal with questions and complications, or for support.

g. Information on funeral arrangements, including a plan to have the attending physician notify the hospice and funeral home that the death was expected and that he/she will sign the death certificate.

6.6. Health care professionals should understand the special needs of families involved with the Oregon Death with Dignity Act for discussion of their experiences and the concern about secrecy. The secrecy may prolong the grieving process.

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

7. Attending Physician and Consulting Physician

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

In this chapter, we use the following terms as defined by the Oregon Death with Dignity Act in order to describe the physician's roles and responsibilities. "Physician" means a doctor of medicine or osteopathy licensed to practice medicine by the Oregon Medical Board. "Attending physician" refers to the physician who has primary responsibility for the care of the patient and treatment of the patient's terminal disease. A "consulting physician" is a physician who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's disease.

The physician's unique professional responsibility to his/her patients is particularly evident in a patient's last months of life. The physician offers the patient relief from suffering through compassion and palliative care. When asked about the Oregon Act, some physicians may have examined their personal and professional values and determined the degree to which they could be involved. Other physicians may still be struggling with the issue and feel uncertain about their own values and how to respond to a patient's request. Physicians will be more effective in their care of terminally ill patients if they have examined their values regarding end-of-life care and the Oregon Death with Dignity Act.

Traditionally, physicians have had difficulty talking about death with their patients. They have been taught to cure; therefore, not to do so could signify failure. Instead of wanting a prolonged life at all costs, many patients are now asking physicians to provide high quality treatment and excellent palliative care, and some are asking assistance in ending life.

Advance planning about one's own dying, as challenging a consideration as it is for patients, can be a powerful process for physicians. This personal exploration can deepen understanding about the nature of suffering and the goals of medicine.[1] We encourage all physicians to discuss their values with loved ones and to make their end-of-life care preferences known, and consider completing an advance directive. This personal exploration may help the physician to clarify his/her feelings about other aspects of end-of-life care, such as those provided under the Oregon Act.

In probing a deeper understanding of personal values regarding the Oregon Death with Dignity Act, the physician does not function alone. He/she must consider these values in the context of relationships with colleagues, institutions, and organizations. Discussing provisions of the Oregon Act with colleagues in advance can promote respect for differing values and prevent unwanted conflicts. Some physicians may prefer greater privacy and choose not to discuss such a sensitive issue with colleagues.

The physician also must be aware of the policies of his/her professional group, care setting, health system, malpractice carrier, health plans, and professional organizations. These policies may conflict with the physician’s values (see *Conscientious Practice*). Provisions clarified the relationship of health care professionals and institutions under the Oregon Act in the amended law (see *Section 9, ORS 127.865*; *Liability and Negligence*; and Appendix A, *The Oregon Death with Dignity Act*). The goal of these provisions is to respect the values of health care institutions and their health care professionals. Institutions (such as a hospital system) may prohibit a physician from participating under the provisions of the Oregon Act on its premises if the institution has previously notified the physician in writing of the non-participation policy. A physician who violates institutional policy may be subject to loss of privileges, loss of membership or other sanctions provided in medical staff bylaws, termination of lease or other property contract, and termination of contract. These sanctions are not reportable to the Oregon Medical Board. The physician may still participate if he/she acts outside the course and scope of his/her role in the institution. The scope and circumstances for sanctions are complex and are covered in more detail in chapter 15 of this Guidebook, *Liability and Negligence*.

Physicians’ professional organizations have taken different positions on the provisions of the Oregon Act. The American Medical Association (AMA), among others, is opposed as described in its Code of Medical Ethics:

> “It is understandable, though tragic, that some patients in extreme duress such as those suffering from a terminal, painful, debilitating illness may come to decide that death is preferable to life. However, allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.
>
> Instead of participating in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Multidisciplinary interventions should be sought including specialty consultation, hospice care, pastoral support, family counseling, and other modalities. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication.”[2]

During the 1994 referendum campaign, the Oregon Medical Association (OMA) chose to neither support nor oppose the Oregon Death with Dignity Act, consistent with the nearly evenly divided views of its membership. In July 1997, the Executive Committee of OMA’s Board of Trustees agreed to an operational policy for the association to support repeal of Oregon’s Death with Dignity Act, as mandated by the action of the House of Delegates in April 1997. The organization did not join or endorse coalitions to campaign in support of or in opposition to repeal of the Oregon Act.

The position of the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) is as follows:

> “[It] does not support the legalization of physician-assisted suicide. The routine practice of physician-assisted suicide raises serious ethical and other concerns.

> Legalization would undermine the patient-physician relationship and the trust necessary to sustain it; alter the medical profession's role in society; and endanger the value our society places on life, especially on the lives of disabled, incompetent, and vulnerable individuals. The ACP-ASIM remains thoroughly committed to improving care for patients at the end of life."[3]

The position of the American Academy of Hospice and Palliative Medicine (AAHPM) is described here:

> Despite all potential alternatives, some patients may persist in their request specifically for physician-assisted death (PAD). The AAHPM recognizes that deep disagreement persists regarding the morality of PAD. Sincere, compassionate, morally conscientious individuals stand on either side of this debate. AAHPM takes a position of "studied neutrality" on the subject of whether PAD should be legally regulated or prohibited, believing its members should instead continue to strive to find the proper response to those patients whose suffering becomes intolerable despite the best possible palliative care. Whether or not legalization occurs, AAHPM supports intense efforts to alleviate suffering and to reduce any perceived need for PAD.[4]

While the Oregon Medical Board has taken no position, in 1993 it adopted a statement of philosophy on pain management in acute conditions and in terminal illness (see Appendix E, *Oregon Medical Board Statement of Philosophy*). It has also amended its rules to clarify that good faith compliance with the Oregon Act will not subject licensees to discipline for unprofessional conduct. In 1999, the Board took the unprecedented step of disciplining a physician for egregious under-prescribing of medication needed for the comfort of seriously ill and dying patients.

One of fifty patients with a terminal condition asks his/her physician about the provisions of the Oregon Act.[5,6] When a patient requests a prescription under the Oregon Act, the physician must explore the meaning behind the question (see *The Meaning Behind the Patient's Request*). Patients may communicate one thing, yet mean quite another. Patients frequently visit physicians with a particular symptom yet have deeper worries that remain hidden. Eliciting hidden factors may promote healing and reduce suffering. [7]

According to the Oregon Department of Human Services, Health Services surveys, physicians report that patients request a prescription under the Oregon Act for several reasons, including loss of autonomy (100%), a decreasing ability to participate in activities that make life enjoyable (86%), and loss of dignity (86%).[8]

Interviews with patients' families also indicated that these patients were often determined to control the timing and manner of their death.[9] A statewide survey of Oregon physicians found that important considerations in patients' decisions to request a prescription for a lethal dose of medication included unrelieved or anticipated symptoms (pain - 43%, fatigue - 31%, and dyspnea - 27%). Financial burden to others (11%) and lack of social support (6%) were found to be uncommon reasons for requests for a prescription under the Oregon Act.[10]

Examining the meaning behind the request for a prescription under the Oregon Act may lead to new physical or psychosocial interventions that might obviate the patient's desire for a prescription under the Oregon Act.[11,12] (see *The Meaning Behind the Patient's Request*). Control of pain or other symptoms, referral to a hospice program, or a trial of antidepressant medication has been found to alter the requests of 46% of patients who had sought a prescription under the Oregon Act.[10] Research indicates that most patients request the medication to remain in control, avoid a period of dependence on others before death, and because of existential reasons, such as not seeing any point in continuing to live. These patients wish to avoid being a burden on others, even when family members find caring to be meaningful.[10]

The health care team should attempt to help the patient find meaning, and maximize the sense of control in all aspects of their lives. Since the Oregon Act was enacted improvements in end-of-life care has been a focus of education of health care professionals. In a survey of Oregon physicians experienced in caring for patients with terminal illness, 76% indicated that they had made efforts to improve their knowledge of the use of pain medications in end-of-life care.[11] In the Netherlands such improvements in care may have resulted in a "modest decrease in the rates of euthanasia and physician-assisted suicide".[13] (see *Hospice, Palliative Care, and Comfort Care* and *Mental Health Consultation*).

Also, sensitive discussions about end-of-life issues give terminally ill patients the opportunity to express their life values orally and in writing by completing an advance directive. These values can best be respected by the physician completing a Physician Orders for Life-Sustaining Treatment (*POLST*) form (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*).

For some patients, clarifying preferences for life-sustaining treatment, discovering underlying reasons for the request, and addressing unmet needs may not relieve the desire for a prescription for medication to end life. After thoughtfully considering his/her own values, the attending physician has the right not to participate in the provision of a prescription under the Oregon Act. Through open communication with the patient, the physician may discover a true difference in values regarding this aspect of end-of-life care. Exploring these differences at the time the patient initially requests a prescription under the Oregon Act may prevent difficult time-pressured decisions and actions later. The physician can work with the patient to find an agreeable course of action; sometimes this means the patient must find another physician. The physician may decline to help in finding a new physician as part of his/her conscientious practice; however, he/she may not obstruct the change.[14] In fact, a significant percentage (59%) of patients, ultimately receive their prescription under the Oregon Act from a physician other than their original attending physician.[8] In this situation, the goals are to honor the integrity of both patient and physician, to preserve the continuity of the relationship if possible, and to prevent abandonment of the patient.

The attending physician may feel more comfortable collaborating in the overall care of a patient with a colleague who is willing to provide the prescription under the Oregon Act. Alternatively, the attending physician may prefer to transfer care of the patient to a colleague who agrees to assume all aspects of care, including participation under the Oregon Act. Some attending physicians may feel that providing such a referral is participating in the Oregon Act and may not be willing to assist in any way. These physicians should consider referring the patient to their office administrator, the hospital medical staff office, the local medical society, the patient's health plan, or another resource. As with any other transfer of care the attending physician has a duty to provide the patient's records in a timely manner and to offer care, including comfort measures, until the patient has had a reasonable time to find alternative care.

For the attending physician who is willing to provide the prescription the patient requests, there are specific responsibilities defined in the Oregon Act (see *Oregon Department of Human Services Reporting* and Appendix B, *Oregon Department of Human Services Reporting Documents*).[14] Prior to writing a prescription, the attending physician must be personally confident that each safeguard has been met and documented. The remainder of this chapter will focus on the participating attending and consulting physicians' roles and responsibilities as set forth in the Oregon Act.

Qualifications of the Patient Under the Oregon Act

The attending physician must determine if the patient is eligible for a prescription for medication for the purpose of ending his/her life as outlined in the requirements of the Oregon Act (see Appendix A, *The Oregon Death with Dignity Act* and *Liability and Negligence*). First, the attending physician must determine that the patient is an Oregon resident over 18 years of age. The 1999 Oregon legislature clarified the Oregon Act's definition of residency. Factors demonstrating Oregon residency include but are not limited to: possession of an Oregon driver's license, registration to vote in Oregon, evidence of property lease or ownership in the state, or most recent filing of an Oregon tax return. Second, the physician must determine that the patient has a terminal disease, defined by the Oregon Act as having a condition with less than six months to live. Several studies indicate there is inherent inaccuracy in predicting the course of a patient's illness and exact timing of expected death.[15,16,17,18] Despite this challenge, attending physicians are called upon to use their best judgment in making such predictions. The difficulties of making these predictions are practical barriers to some terminal patients who need earlier referral for high quality end-of-life care, such as hospice.[19] Third, the attending physician must determine that the patient is capable of making his/her own health care decisions and has made the request voluntarily. In determining the decision-making capacity of a patient, the patient must be able to understand the information provided (medical diagnosis, prognosis, potential risks associated with taking the medicine), weigh this information and communicate a choice. The physician is required to determine that the patient does not have a mental health condition that impairs judgment. Oregon primary care physicians have appropriately expressed doubt about their ability to diagnose depression in patients who qualify under the Oregon Act.[20] Mental health professionals have similar difficulty in distinguishing a major depressive disorder from the effects from the underlying terminal illness. Despite this challenge, of the 49 people who died by lethal medication under the Oregon Act in 2007, none were referred for mental health evaluation.[8] Further in a study of 58 individuals seeking a prescription under the Oregon Act, one in four were assessed to have major depressive disorder.[21] Of the 18 who received a lethal prescription three were diagnosed with major depression. All three died by lethal ingestion within two months of the research interview. This suggests that the practice of the Oregon Death with Dignity Act through 2006 did not adequately protect all mentally ill patients from receiving prescriptions for lethal medications and there is need for more vigilance and systematic examination for depression. If the physician is concerned that such a condition exists, the physician is required to refer the patient for counseling (see *Mental Health Consultation*). Given data indicating the lack of adequate mental health assessment and the gravity of the decision to prescribe under the Oregon Act, it is strongly recommended that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the Patient Health Questionnaire (*PHQ-9*). If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist (see *Mental Health Consultation*).

Requirements of the Oregon Act for Consultation

The Oregon Act requires the attending physician to consult with a second physician to confirm the diagnosis and to determine that the patient is capable and acting voluntarily. In selecting a consulting physician, the attending physician should consider three issues. First, the consultant should have expertise in managing the patient's terminal disease, including palliative therapies. Second, the consulting physician must be willing to serve as a consultant for a patient who is seeking a prescription under the Oregon Act. Finally, the consulting physician should not have a financial or other relationship that has the potential to constitute a conflict of interest.

The consulting physician is responsible for providing a thoughtful second opinion about the patient's diagnosis, prognosis, and capacity for health care decision-making, and the voluntary nature of the request. This consulting opinion is distilled from careful review of medical records, patient interview and examination, and other means to clarify the patient's condition, mental state, and prognosis. Like the attending physician, the consulting physician needs to sensitively explore the meaning underlying the patient's request for a prescription under the Oregon Act (see *The Meaning Behind the Patient's Request*). The consultant's involvement is a process that includes patient, family (as allowed by the patient), and other health care professionals and may require more than a single patient encounter.

As with the attending physician, the Oregon Act requires that the consulting physician determine that the patient does not have a mental health condition that impairs judgment. Again, given data indicating the lack of adequate mental health assessment and the gravity of the decision to prescribe under the Oregon Act, it is strongly recommended that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the *PHQ-9*. If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist (see *Mental Health Consultation*).

The consulting physician is required to complete the documentation under the Oregon Act as described by the *Oregon Department of Human Services*.

Physician Responsibilities for Informed Decision

The attending physician should continue to explore and offer alternatives, assure comfort, and remind the patient that he/she can change his/her mind about the plan of treatment at any time, including the request for a prescription for medication to end life. The Oregon Act specifically requires that the patient be informed of his/her diagnosis, prognosis, potential risks, feasible alternatives, (including, but not limited to, comfort care, hospice care and pain control) and probable results of taking the prescribed medication. The statute also requires that the patient be given an opportunity to rescind the request for a prescription under the Oregon Act at the end of a fifteen-day waiting period and make an informed decision immediately before the attending physician writes the prescription for medication. Of note, studies show that a majority of patients seeking a prescription under the Oregon Act were enrolled in hospice during this waiting period.[8,9] At this time the physician should inform the patient that the Oregon Department of Human Services has a role in collecting information relevant to the Oregon Act. Each step of this process should be documented in the patient's medical record. It can be done most easily using the Oregon Department of Human Services forms (see Appendix B, *Oregon Department of Human Services Reporting Documents*).

Planning for the Patient's Death

Once a qualified patient has carefully considered his/her options and has requested a prescription under the Oregon Act, the attending physician should address a number of planning issues. These include exploring relationships with family and other health care professionals; completing an advance directive and POLST document; obtaining the medication; planning the self-administration of the lethal dose of medication; and making funeral arrangements.

Relationship with Family

Most people do not want to die alone. The attending physician is required by law to recommend to the patient that he/she inform the next of kin about the request for a prescription for medication to end life. If the patient intends to take the medication, the attending physician should clarify whom the patient wants to inform about the decision. Some patients may choose family members and significant others to be aware or present. If a patient declines any family involvement, the attending physician should explore the meaning behind this decision (see *Family Needs and Concerns* and *Emergency Department and Emergency Medical Services*). Although most patients prefer dying in a private setting, the attending physician is required by the Oregon Act to counsel the patient about the importance of not taking the medication in a public place.

Once family members or close friends are aware of the request for a prescription under the Oregon Act, the physician should be available to explore their feelings and beliefs about the patient's desire. This can be a time of family closeness and sharing. Family conflict is a reason for the physician to look more deeply, just as it is when considering the withdrawal of life-sustaining treatments. Sometimes these conflicts can be addressed best by referral to or consultation with other resources, such as family or community support services, pastoral or spiritual care, hospice team members (if applicable), or ethics committee consultation. For hospice patients, the team routinely assesses psychosocial and spiritual aspects of care.

The attending physician also may establish with the patient whom he/she would like present at the time of self-administration. The physician may inform family or friends of potential complications as desired by the patient. In working closely with the patient, the attending physician can help support family members, lessening their suffering and easing grief.

Relationship to Other Health Care Professionals

The attending physician has responsibility not only to the patient and family (as the patient allows) but also to other involved health care professionals (see *The Role of Other Health Care Professionals* and *Pharmacists and Pharmacy-Related Issues*). Each health care professional has the right to choose whether or not to participate in the provisions under the Oregon Act (see *Conscientious Practice*). The attending physician has the responsibility to explain to the patient the importance of notifying these other health care professionals if he/she plans to take the medication to end life as set forth in the Oregon Act. The decision to disclose must be based on the need for the other health care professional to know about the planned self-administration of the lethal dose of medication in order to give him/her an opportunity to decide whether or not to participate. Some health care institutions have developed a confidential central resource to provide referrals thereby maintaining privacy for each patient and all health care professionals. The attending physician should discuss with the patient whether the physician or other health care professional(s) will be present for the patient's self-administration of the lethal dose of medication. The attending physician or other health care professional(s), especially hospice, may be able to provide comfort care to the patient and family, avoid notification of emergency medical services, and notify the funeral home and/or other proper authorities.

Importance of an Advance Directive and POLST

If not already available, advance directive and Physician Orders for Life-Sustaining Treatment (POLST) documents should be completed to ensure that patient preferences are honored (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*). Without an advance directive or POLST containing a do-not-resuscitate (DNR) order, the patient has a greater risk of receiving unwanted interventions.

The attending physician should inform the patient (and family, as allowed by the patient) that involvement of emergency medical services may result in a resuscitation attempt and/or notification of the Medical Examiner or local law enforcement officials (see *Oregon Department of Human Services Reporting*). The authority may investigate, allowing for limited public disclosure about the patient, questioning of the family or retention of the body for investigative purposes. If hospice is not involved, family should be told that instead of calling 9-1-1 when the patient dies, the funeral home should be contacted.

Obtaining the Medication

If the attending physician is registered as a dispensing physician with the Oregon Medical Board, he/she may dispense medication directly, including ancillary medications to minimize the patient's discomfort. If the attending physician is not a dispensing physician, then with the patient's written consent, the attending physician must deliver the written prescription either personally or by mail to the pharmacist, who will then dispense the medication to either the patient, the attending physician, or an expressly identified agent of the patient (see *Pharmacists and Pharmacy-Related Issues*). The prescribing physician should contact the pharmacist and inform the pharmacist of the prescription. The pharmacist has the opportunity to decide whether or not to participate. Should he/she choose not to participate, the refusing pharmacist may, but is not obligated to, suggest a pharmacist who is willing to fill the prescription under the Oregon Act (see *Conscientious Practice*). Compassion & Choices (*www.compassionoforegon.org*, phone: 503-525-1956, email: *or@compassionandchoices*) advocates for the Oregon Act and is the only resource known to the Task Force to maintain a list of pharmacists willing to participate.

There are substantial challenges for patients, attending physicians, and pharmacists concerning the dispensing of medication under the Oregon Act. These challenges include the need to protect patient privacy, to ensure a thoughtful, informed decision process, to prevent diversion of a lethal dose of medication to others, to protect the right of conscientious practice of the dispensing pharmacist, and to encourage accurate reporting to the Oregon Department of Human Services.

The attending physician and patient together can carefully consider how to obtain the medication. The physician can present two options to the patient: 1) the attending physician can obtain the medication; or 2) the patient or family can obtain the medication from a pharmacy. Although the first option may have some benefits, the Oregon Board of Pharmacy is not aware of any cases in which the medication has been delivered to the physician to hold until the intended time. The experience reported to the Board is that family members are usually the ones obtaining the medication and usually near the time of ingestion. Regarding the second option, the attending physician is required to give or mail the written prescription to the pharmacist and must inform the pharmacist of the intent. The pharmacist who is willing to fill the prescription is required to offer counseling regarding its use and complications. The pharmacist is also responsible for notifying the attending physician of the date the prescription was filled. The Oregon Department of Human Services requires the attending physician, pharmacist, or health system to file a copy of the dispensing record with the department (see *Oregon Department of Human Services Reporting*; Appendix B, *Oregon Department of Human Services Reporting Documents*; and *Pharmacists and Pharmacy-Related Issues*).

Planning the Self-Administration of the Lethal Dose of Medication

The attending physician should discuss with the patient the details of taking the medication. The attending physician can inquire about the time and place with the patient, family, and other involved health care professionals with whom the patient has consented to share the information. The timing of the patient's self-administration is best planned in advance to allow the attending physician and/or other support persons to be present. The physician's presence assures continuity of care with other members of the health care team, and avoids involving covering colleagues who conscientiously are opposed to the Oregon Act or are less informed about the patient's plan for taking the medication to end life in accordance with the Oregon Act. If present, the attending physician can offer counsel and support to the patient and family during and after the patient's self-administration of the medication. If not present, being available by phone at the pre-arranged time will provide some support to patient, family, and other health care professionals. If the attending physician cannot be continuously available from the patient's self-administration until death, he/she should inform covering colleagues of the patient's plan.

Complications may occur in some cases of self-administration of the lethal dose of medication under the Oregon Act (see *Pharmacists and Pharmacy-Related Issues*).[8,9,22,23] Complications include side effects such as nausea, vomiting, seizures and prolonged time (greater than four hours) from ingestion of the medication until death.

By the end of 2007, 341 patients died after ingesting a lethal dose of medication.[8] Complications were reported for 20 patients. Of these, 19 involved regurgitation and none involved seizures. The median time between ingestion and unconsciousness was 5 minutes with a range of 1 to 38 minutes. The median time between ingestion and death was 25 minutes with a range of 1 minute to 48 hours. One patient (2007) lived 3 ½ days and one (2005) regained consciousness after ingesting the lethal dose of medication and then died 14 days later from his illness rather than from the medication. Emergency medical services were called for 4 patients, 3 to pronounce death and one to help a patient who had fallen.

Comfort measures consistent with patient preferences as documented in advance directive and POLST documents remain appropriate. Under the Oregon Act, physicians are *not* legally permitted to provide a lethal injection if the patient's self-administered medication does not result in death. Such an act could leave the physician open to homicide charges and disciplinary action.

Funeral Arrangements

Most patients have wishes regarding how his/her body will be cared for after death and how he/she would like family and friends to reflect on his/her life. However, it is often challenging for patients to talk about death and funeral arrangements. The attending physician or other health care professionals, especially hospice, can help facilitate this aspect of end-of-life care. Once determined, the patient's wishes can be communicated to loved ones and made available once death has occurred. Making the arrangements with the funeral home in advance has major advantages. Not just talking, but signing the contract, makes the move to the funeral home smoother and without involvement of emergency medical services.

After Death Occurs

If the patient dies as a result of self-administering the lethal dose of medication, the physician continues to have responsibility, as with other patient deaths, for supporting loved ones in their bereavement. A note or card sent by mail can help the bereavement of those who cared for the patient. It is helpful to notify office staff that the patient has died so that subsequent contacts by the office with family members can be handled with sensitivity. The manner of death should not be disclosed to persons not previously involved. Family members are encouraged to dispose of any unused medication after the patient's death to avoid accidental or purposeful ingestion by others. Usually the physician does not have to notify the medical examiner. Hospice deaths occurring more than 24 hours after hospice enrollment do not need to be reported to the medical examiner or investigated. [24]

The attending physician is responsible for completing the death certificate as provided by the funeral home. The death certificate has been designed to ensure confidentiality of the patient's medical condition(s) and the cause of death (see *Oregon Department of Human Services Reporting*). The Oregon Department of Human Services recommends that the attending physician complete the death certificate with the underlying terminal condition(s) as the cause of death, and the manner of death as "natural". The required "Reporting Physician Interview Form" completed by the physician after the patient's death will alert the Oregon Department of Human Services whether the death was from ingesting the lethal dose of medication or from the underlying disease.

Physician Experience with the Oregon Act

There is little written on the effect that the Oregon Death with Dignity Act has on physicians and other health care professionals. There is even less written on how refusing to participate impacts the physician. To our knowledge, this topic has not been formally studied. There are a number of first hand accounts that describes the physician experience. These are available through first person reports or newspaper articles and may not be statistically representative.[25]

From these stories, there are several repeating themes. One theme is the difficulty of deciding whether or not to prescribe under the Oregon Act. One Oregon physician is quoted in The Oregonian about his feelings after he was asked by a colleague to consider being involved in a case: "I was frightened. I was honored. Worried in the sense of whether I was up to the details and the emotional impact and all that. I was trembling."[22] Another Oregon physician, who voted against the Oregon Death with Dignity Act, published the story of his struggle, writing that his intellect and his soul "engaged in unresolvable debate."[23] A Dutch physician, writing in a book about euthanasia, described the decision in this way: "[I]t is the most difficult decision a physician can make in his or her professional life,"[26] and another Dutch physician, in the same book: "I spend months pondering the details of the situation before I ever come to a decision. My patient's plight invades every aspect of my thinking... I can say that each time a patient asks me for help in dying, it is like starting a Herculean task all over again."[27] In a statewide survey of Oregon physicians, one third indicated that they would never provide a patient with a prescription under the Oregon Act for religious or moral reasons.[10,20] Little is written about the feelings these physicians may have if a long-standing patient transfers care to obtain a prescription under the Oregon Act. According to the Oregon Department of Human Service data, 59% of patients who took a prescription were reported to have made a request of more than one physician before finding a doctor who was willing to prescribe.[6]

Refusing to participate has taken its toll on some physicians. One Dutch physician, quoted above, wrote of a patient for whom he refused to participate in prescribing a lethal dose of medication: "This is the only case I have regretted – because she really meant it when she asked me to help her die... I worry she felt abandoned... was this patient harmed more by my refusal to comply with her wishes for euthanasia than she would have been if I had agreed?"[28] An Oregon physician, quoted in The Oregonian, spoke of his patient's anger when he refused: "Before the law went into effect, I had one specific request in my life from a person who would have qualified, and he died absolutely white-hot furious because I refused. He died in a fury over a period of weeks. And when he was admitted to a nursing home and I went to see him frequently, because I felt I owed it to him, there was nothing but fury that he had for me."[29]

These individual stories give us only a partial picture of how physicians feel and respond to patient requests. Those physicians who believe providing a prescription under the Oregon Act is wrong and therefore may feel less conflicted declining a patient's request may be underrepresented in media reports. In addition, those physicians who wish to maintain their privacy about this sensitive issue may have points of view or concerns and their views are also likely to be underrepresented in media reports.

After the Oregon Death with Dignity Act was implemented, Oregon physicians often recommended interventions to patients for relief of their suffering. In 46% of cases where interventions were accomplished, the patients' desire for a prescription under the Oregon Act was altered.[10] One of the consequences of the Oregon Death with Dignity Act is that many physicians in Oregon have been educated in end-of-life care and have more alternatives to offer patients, ones which are universally endorsed by medical ethics groups. However, some patients who persist in their request for a prescription under the Oregon Act may continue to seek physicians who are willing to participate. In some circumstances, patients may be unable to find a willing physician.[6]

Working through the process as defined in the Oregon Act is burdensome in the amount of work and time spent, as well as emotional expenditure. Both in the Netherlands and in Oregon careful documentation is required. One Oregon physician is described as saying of the process: "I remember feeling trembly. Every time I checked things off, I felt it was really happening."[30]

After the experience of participating, according to anecdotes from Oregon physicians, and writings from Dutch physicians, there is often a huge emotional impact. Dr. Gerritt Kimsma of Amsterdam says: "Euthanasia and assisted suicide bring out intense grief, as you have developed a deep relationship with the patient who will die. You have a very personal relationship with the dying patient, more so than with other patients. You, the doctor, become more vulnerable. You have to let go of the patient. You will have feelings of guilt, and you should have feelings of guilt... It is highly emotional for the doctor; it can throw you off your feet. It can cause you to become dysfunctional. It is hard to cope with; it is a huge and impressive action. You need to brace yourself for it."[31] Dr. Kimsma also speaks of secrecy surrounding the assisted death as making the grieving process more difficult.

Physicians who have written or publicly spoken about participating under the Oregon Act also speak of new appreciation for what their patients experience: "I have also redefined intolerable suffering. I now believe that it may occur in ways quite different from those that we as physicians normally consider and that intolerable suffering is best defined by the patient. My patient was suffering at the core of her being without agonizing pain, anorexia, or night sweats. She had become increasingly dependent on others for virtually all activities. Her dignity, her self-esteem had been stripped away. The vitality of her being had passed. Yes, her life, as she defined it, had become futile."[32] The physician quoted in The Oregonian said: "As Helen's doctor during her last days, I developed an emotional bond with her and her family in the many hours of forthright conversation I had with them. This depth of relationship allowed me to see for myself how intensely she wanted to die. I remain profoundly transformed by her reality."[33]

Physicians who have described their experiences in Oregon, though few in number, have agreed that the act of participation should be difficult: "I have a feeling of responsibility that I can't say I'm entirely proud of. I did what I thought was right, given bad choices... it's better to not feel good about this."[33] And, "My emotional turmoil in greater part reflected my entrance into uncharted territory for physicians. Although we have accepted our roles as comforters in end-of-life care, we have not struggled with or found solutions to active roles in aiding patients in accomplishing their deaths. I am grateful for the great disruption in my emotional stability that this experience precipitated. This act should never be easy, never routine. It should be among the most difficult and disquieting acts we embark upon."[23]

Guidelines

7.1 Physicians should explore their own values regarding end-of-life care and determine in advance whether they would assist, refer, or transfer the care of a patient who requests a prescription for the purpose of ending life.

7.2 Physicians may wish to discuss their values regarding ODDA with colleagues in advance of any patient request.

7.3 Physicians should be aware of and respect the policies of the institutions in which they practice and not participate in the Oregon Act on the premises of a non-participating institution.

7.4 Physicians should consider the consequences of participating or not participating under the Oregon Act within the context of the community in which they practice.

7.5 It is always appropriate for the attending physician to explore the meaning underlying a patient's request for a prescription under the Oregon Act.

7.6 The attending physician is obligated to identify and where possible treat physical, emotional, and spiritual pain and suffering experienced by the patient, understanding that such interventions may avert a patient's desire for a prescription under the Oregon Act.

7.7 The attending physician and/or consulting physician may choose to participate under the Oregon Act or not based on his/her personal or professional values.

7.8 Physicians who choose not to participate in provisions under the Oregon Act should strive to treat the patient with respect, preserve the continuity of the relationship, and ensure that the patient is not abandoned if it is not possible to preserve the patient-physician relationship. The physician must not hinder the transfer of care and must provide care until transfer of care is complete.

7.9 For the attending physician who is willing to provide a prescription for a lethal dose of medication, there are specific responsibilities defined in the Oregon Act.

> a. The attending physician must verify that the patient qualifies under the Oregon Act, including a confirmation of residency.
>
> b. The attending physician must arrange for a second physician to confirm the patient's diagnosis, prognosis, potential risks, feasible alternatives, (including, but

not limited to, comfort care, hospice care and pain control), probable results of taking the prescribed medication and capacity in making the decision. When the consulting physician practices outside the attending physician's professional group, it reduces the appearance of a financial or other conflict of interest.

c. We strongly recommend that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the Patient Health Questionnaire (*PHQ-9*). *Other possible instruments could be used*. If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist. **d.** The attending physician must ensure an informed decision as defined in the Oregon Act.

e. The Oregon Act requires the attending physician to counsel the patient as to the importance of notifying family members if the patient has decided to take the medication for the purpose of ending life. The attending physician also is required to counsel the patient to avoid taking the lethal dose of medication in a public place.

f. If the patient plans to take the medication, the attending physician should prepare the patient and family (if the patient agrees) for potential complications. Physicians should encourage patients to complete an advance directive and Physician Orders for Life-Sustaining Treatment (POLST) form, which includes a do-not-attempt-resuscitation (DNR) order.

g. The attending physician should work with the patient to identify any members of the health care team that might be involved if the patient decides to take the lethal dose of medication. The physician, with the patient's consent, should disclose the patient's plan to other health care professionals so they can decide whether or not to participate.

h. The attending physician may dispense medication, if registered, or with written patient consent is required to inform and deliver or mail the prescription to the participating pharmacist. The physician should inform the pharmacist in advance about the prescription.

i. The attending physician and/or other support persons are encouraged to be present at the time the patient takes the lethal dose of medication to help provide comfort to the patient and family.

j. The attending physician is responsible for providing care to the patient, arranging comfort care including pain medication and limiting life-sustaining treatment as directed by the patient's wishes. It is illegal for the physician to administer a lethal injection or otherwise intentionally cause the patient's death.

k. After a patient dies from taking medication prescribed under the Oregon Act, the attending physician should notify and comfort family members. Physicians are encouraged to develop bereavement procedures to help grieving family members.

l. The attending physician is responsible for completing the death certificate, accurate and complete notes in the medical record, and providing appropriate documentation to the Oregon Department of Human Services as outlined in Appendix B, *Oregon Department of Human Services Reporting Documents*.

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

8. The Role of Other Health Care Professionals

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Oregon's Death with Dignity Act (ODDA) implies a relationship between a terminally ill person and his/her physician. However, a terminally ill patient is likely to have established ongoing relationships with other members of the health care team, both professional and volunteer, in addition to the physician.

The team approach is essential in supporting the terminally ill patient and family. The entire health care team, including physicians, pharmacists, nurses, nurses aides, social workers, spiritual care providers, and other health care professionals, as well as volunteers, must recognize that in providing care to a patient who requests a prescription for medication to end life, roles frequently overlap, especially in the provision of support and psychosocial care. A collaborative approach, open communication, and respect for the patient are essential.

The impact of place of death on health care professionals is different depending on the setting. The place of death for those who utilized the Oregon Death with Dignity Act from 1998-2006 is overwhelmingly at home. "Home" is defined by the Oregon Department of Human Services (ODHS) as the place of residence excluding a long-term care facility or hospital. Hospice is provided wherever the patient lives, crossing all settings; 291 out of 341 (86%) of those Oregonians who utilized the Oregon Act were enrolled in hospice.[1] The option of ODDA has prompted the need for health care professionals, such as long-term care facilities, hospices, assisted living, and other community based settings, to maintain policies and procedures that acknowledge the Oregon Act and that tailor their practices to meet their mission of caring for dying patients.

Nurses and social workers are often the professionals with whom patients choose to talk regarding end-of-life decisions. They are trained to evaluate patents' and families' medical and psychosocial needs. They are in a pivotal position to evaluate requests for exploration of the Oregon Act in the context of the patient's experience. They explore the meaning of the request, alleviate symptoms that may be contributing to the patient's distress, and facilitate communication between the patient, family, and health care team (see *The Meaning Behind the Patient's Request* and *Hospice, Palliative Care, and Comfort Care*).[2-8] Studies suggest that nurses and social workers employed in hospice, despite their personal opinions about the Oregon Act, respect patients' autonomy and self-determination in end-of-life decisions.[9] Nurses and social workers struggle with the complexities of this option, yet their professional values and ethics guide exploration and assessment of the request within the philosophy of hospice care.[10,11] In addition, individuals in pastoral care and clergy may have an ongoing relationship with the patient for spiritual support. Ultimately, the patient will decide with whom, among members of the health care team or his/her support system, he/she will choose to discuss this important decision.

A nurse practitioner or physician assistant may be involved with a patient who desires medication to end life in accordance with the Oregon Death with Dignity Act, but the Oregon Act allows only for the attending physician (as defined in the Oregon Act) to write a prescription for a patient to self-administer for the purpose of ending life. Nurse practitioners and physician assistants, who may have prescriptive authority in Oregon, are not authorized by the Oregon Act to serve as the attending or consulting physician and so cannot prescribe under the Oregon Act. Nurse practitioners and physician assistants may respond to patient inquiries for information about end-of-life options. Referral to an attending physician will be necessary for continued assessment and decision-making within the provisions of the Oregon Act.

Volunteers play an important role in many end-of-life care settings and their involvement on the hospice team is mandated by law. Volunteers perform a wide range of support and assistance to health care institutions, the terminally ill person, and his or her family. Because volunteers provide so many different services at end of life, it is possible that a volunteer may know about or be involved in the decision-making process regarding use of the Oregon Death with Dignity Act. Health professionals who care for the terminally ill and utilize volunteers should develop policies and standards of practice for the role and responsibilities of the volunteer in relation to the Oregon Act, including language about conscientious objection by unpaid or non-professional staff. This information should be included in orientation activities.

Personal care professionals and aides give personal care to patients who are dying and sometimes see patients more frequently and for longer periods than other health professionals. Because of this, the personal care professionals or aides may develop relationships with patients that could make them aware of patients' thoughts regarding the use of the Oregon Death with Dignity Act. Health care professionals who care for the terminally ill and utilize personal care professionals or aides should develop policies and standards of practice for the role and responsibilities of the health care workers in relation to the Oregon Act, and include this information in orientation activities.

Balancing the right of the patient to confidentiality with the "need to know" of health care professionals is a significant issue. The Oregon Act specifies that all health care professionals shall have the right to choose whether to participate, but does not ensure them the right to know about the patient's request for a life-ending medication.[12] If informed, a health care professional could choose to continue to give appropriate care or exercise the right for conscientious practice under the law. If not informed, health care professionals could become unknowing participants in the process of a patient utilizing the Oregon Act regardless of their personal views (see *Conscientious Practice*). As is the case with other legally authorized medical interventions, health care professionals may be caught in the middle of conflicting personal and professional values and loyalties. The health care professional may personally disagree with a patient's decision to end life as set forth in the Oregon Act, but feel an ethical and professional responsibility to provide all legal options to all patients, including those who request medications as provided under the Oregon Act. The resulting internal conflict may make it difficult for the health care professional to decide whether or how to participate in ongoing care for the patient.[13,14]

Each health care professional should consider personal and professional values and ethics, and determine whether he/she might be willing to be involved when a patient decides to request a prescription under the Oregon Act, or maybe the professional will always decline to be involved for reasons of conscience. If a health care professional has responsibility to care for a patient who requests a prescription for medication to end life, but declines to participate, the professional should inform the employer as soon as possible and ask for assistance in transfer of responsibility. When the health care professional has contracted directly with an individual patient who is considering utilizing the Oregon Act, the professional who objects to involvement should work with the patient to transfer responsibility to another qualified health care professional.

Health care professionals, especially those who care for patients with terminal illness, should be familiar with the Oregon Death with Dignity Act and related administrative rules and evolving case law. They should also be familiar with their agency's policies and procedures within the Oregon Act, and the ethical and moral issues associated with end-of-life decisions, personal choice, advance directives, and POLST (Physician's Orders for Life Sustaining Treatment). Some health care institutions, considered health care professionals under the Oregon Act, will choose not to participate in the Oregon Act and individual health care professionals must respect the mission, values, and policies of these institutions. Discussions between the patient and the health care professional regarding end-of-life options, including Oregon's Death with Dignity Act, should not, however, be prohibited by institutional policy (see *The Meaning Behind the Patient's Request*).

Health care professionals may need to review cases, both formally and informally, where ODDA was chosen by a patient. This review allows staff to discuss their concerns, review cases after the death, and/or to debrief situations that may warrant further discussion or intervention. Health professionals may already have mechanisms in place that deal with staff or employee concerns that arise from the request for exploration and/or use of ODDA, the implementation of the Oregon Act, and/or a review of the case after the death. These could include team meetings, ethics committees, staff support, or bereavement follow-up.

The Oregon Act requires the physician to counsel the patient to have another person present when the patient takes the medication. A health care professional may be the person present when the patient takes the medication to end life, but the level of assistance he or she may give to the patient is not clear. Lack of clarity in the Oregon Act leaves it to licensed health care agencies and professional organizations to establish policies and standards regarding assisting patients in self-administering medication as set forth in the Oregon Act. A qualified patient who is capable of requesting the prescription under the Oregon Act may not be able to self-administer the medication without assistance. The Oregon Act is clear that no individual is authorized to end a patient's life by lethal injection, mercy killing, or active euthanasia.[15] In making a decision to assist a patient with self-administering the medication, the health care professional should be certain that the patient remains in control of the decision, timing, and every aspect of the action.

A health care professional may not know all of the details regarding the patient's decisions about ODDA, advance directives or POLST. However, the professional is responsible within his or her scope of practice and with the available information to assess the patient's condition and to provide appropriate intervention. A decision to initiate life-saving interventions should be based on the information available about the patient's decisions regarding ODDA, advance directives, POLST and on professional judgment.

Under the Oregon Act the patient may rescind his or her request at any time and for any reason without regard to his or her mental state.[16] If, after taking the prescribed medication, the patient indicates a change of mind, any health care professional who is present or called should take steps to initiate life-saving measures. An added complexity occurs when a family member, rather than the patient, communicates the patient's decision to rescind. The potential for conflict between the patient and family on this matter puts the health care professional in a difficult position with regard to appropriate action. The Oregon Act clearly provides that only the patient may rescind the decision.

Guidelines

8.1 Health care professionals who care for patients with terminal illness should consider their personal values and ethics relative to participation under the Oregon Act.

8.2 Within his or her competence and scope of practice, the health care professional should explore the meaning behind a patient's request for a lethal dose of medication, determine what information or other care options the patient may need, and refer the patient to his or her attending physician.

8.3 The health care professional who declines to care for a patient who plans to take medication to end life under the Oregon Act should arrange a transfer or request assistance from the employer to transfer responsibility for the patient to another qualified health care professional.

8.4 Health care professionals may already have mechanisms in place that deal with staff and/or employee concerns that arise from the exploration or request for ODDA, the implementation of the Oregon Act, and/or case review. The professional may want to consider the utilization of existing resources, such as team meetings, staff support groups, ethics committees, or bereavement coordination to debrief cases which the staff believe need further discussion or intervention. Health care professionals might consider the development of new or different ways to address staff concerns.

8.5 The Oregon Act allows the patient to rescind the request for ODDA at any time. If after taking the prescribed medication the patient changes his/her mind, a health care professional who is present or called should take steps to initiate life-saving interventions.

8.6 A decision to initiate life-saving interventions will be based on professional judgment and on the available information about the patient's decisions regarding ODDA, advance directives and POLST.

8.7 A health care professional who is with the patient when he or she takes the medication should provide care and comfort to the patient and family. The Oregon Death with Dignity Act does not provide guidance on the degree of assistance with self-administration that may be given by another person. Nurses in particular have questions concerning this issue. The Oregon Act does not alter the existing standards and scope of practice of nurses in Oregon.

8.8 A health care professional that utilizes volunteers should develop policies and standards for the roles and responsibilities of the volunteer in relation to the Oregon Death with Dignity Act, and inform the volunteer of these guidelines in orientation. A health provider that employs personal care professionals or aides should develop policies and standards for the roles and responsibilities of the employee in relation to the Oregon Death with Dignity Act, and inform the employee of these guidelines in orientation.

8.9 The Oregon Act does not alter the existing standards or scope of practice for Licensed Clinical Social Workers or those working toward licensure in Oregon. Social workers should refer to the National Association of Social Workers (NASW) Code of Ethics and to the Policy Statement from NASW on End-of-Life Decisions, and the practice guide entitled NASW Standards for Social Work Practice in Palliative and End-of-Life Care.[17]

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Resources

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

9. Mental Health Consultation

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The Oregon Death with Dignity Act outlines a specific role for psychiatrists and psychologists. If the attending or consulting physician believes that the patient may be suffering from a "psychiatric or psychological disorder, or depression causing impaired judgment," a mental health evaluation is mandated. Either a licensed psychiatrist or licensed psychologist may perform the evaluation. Once the patient is referred, the attending physician may write a prescription under the Oregon Act only if the mental health professional assesses that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment. In addition, the mental health professional should evaluate if the person is "capable," that is, "has the ability to make and communicate health care decisions, including communication through persons familiar with the patient's manner of communication if those persons are available."[1] The mental health consultation as outlined in the Oregon Act, is a form of a capacity or competence evaluation, specifically focused on capacity to make the decision to hasten death by self-administering a lethal dose of medication. In the first ten years after enactment of the Oregon Death with Dignity Act, 11% of persons who died by a lethal dose of medication were evaluated by a mental health professional.[2] None of the 49 people who died by lethal prescription in 2007 were referred for a mental health evaluation.[3]

Mental health professionals may choose not to provide this type of consultation for conscientious reasons (see *Conscientious Practice*). In a survey of 290 U.S. forensic psychiatrists, 24% believed that psychiatric consultation for the purposes of determining competence for ingesting a lethal dose of medication was unethical.[4] Oregon psychiatrists and psychologists are divided on the ethical permissibility of the Oregon Death with Dignity Act. A 1995 survey of Oregon psychiatrists revealed that 56% support the implementation of the Oregon Act, but one third endorse that legal ingestion of a lethal dose of medication should never be permitted.[5] In a 1996 survey of Oregon psychologists, 78% supported enactment of the Oregon Death with Dignity Act.[6]

The American Psychological Association (APA) "Working Group on Physician Assisted Suicide" neither supports nor decries the Oregon Act, but encourages psychologists to be informed about policy and research related to the Oregon Act, to be aware of their own views and possible biases regarding eligibility for the option, and to be sensitized to possible social pressures that may contribute to the perception that vulnerable populations are more expendable. Psychologists are also advised to "fully explore alternative interventions (including hospice/palliative care, and other end-of-life options such as voluntarily stopping eating and drinking) for clients considering" this alternative.[7]

Mental health professionals' views on the ethical permissibility of the Oregon Act are likely to influence the standards used in diagnosing a mental disorder and determining whether the mental disorder causes impaired judgment. In the survey of U.S. forensic psychiatrists, those who were morally opposed to the Oregon Act were more likely to advocate a more stringent standard for evaluating competence and more likely to believe that depressive disorders would automatically render a patient incompetent to choose ingestion of a lethal dose of medication.[4] Oregon psychiatrists' and psychologists' positions on legalization of the Oregon Act influenced their willingness to evaluate patients who request a prescription under the Oregon Act and how they would follow up an evaluation. For example, 72% of psychiatrists opposed to the Oregon Act would refuse to perform this type of evaluation, compared to only 33% of those who favored the Act.[5] Despite majority support for legalization of the Oregon Act, only 36% of psychologists in Oregon were willing to perform these evaluations.[6] Interviews with physicians in Oregon who have received requests under the Oregon Act confirm their difficulties in finding a mental health professional to evaluate the patient, especially if a home visit is required (Ganzini, unpublished data). Most psychiatrists and psychologists who opposed the Oregon Act would work to prevent the patient from taking the medication to end his/her life, even if they found the patient competent. These data suggest that mental health professionals who are either strong proponents or opponents of this Oregon Act may have difficulty objectively evaluating patients and should consider declining. The mental health professional should disclose personal biases to the attending physician at the time of referral. The patient's therapist should not serve in this capacity, though he/she may provide invaluable insights to the mental health consultant.[8]

The Evaluation Process

The psychiatrist/psychologist should hold a valid Oregon license and have experience in psychiatric diagnosis, capacity evaluations, and evaluation of medically ill patients. Experience in working with dying patients in other settings may be helpful. Mental health professionals are qualified to evaluate capacity because of their expertise in diagnosing psychiatric disorders, examining mental status, and understanding irrational forces that influence decision-making. The consultation will usually include a record review, discussion with the referring physician, patient interview and assessment, and caregiver and family interviews (with the patient's consent). Eighty-six percent of patients who die by ingestion of medication under the Oregon Act are enrolled in hospice[2] and hospice practitioners may have important insights into potentially reversible conditions and mental state. If the mental health consultant perceives a conflict of interest, financial or otherwise, which might influence his/her decision-making, he/she should decline to perform the evaluation. Mental health professionals may decline to evaluate the patient or to even suggest colleagues who could evaluate the patient for conscientious reasons.

The evaluation should focus on assessing for mental disorders such as depression and delirium, the patient's decision-making capacity, and factors that limit decision-making capacity such as mental disorders, knowledge deficits, and coercion. Dementia may co-occur with a terminal illness. Mild dementia does not automatically disqualify a terminally ill person from Oregon's law; the evaluator must determine whether the patient retains capacity for medical decisions. The ability to understand the nature of the intervention, risks, and benefits of a prescription under the Oregon Act may be straightforward, but the ability to understand the risks and benefits and likelihood of success of alternative interventions can be difficult, especially for very ill patients, and should be a focus of the interview. Patients should be able to appreciate the information as shown by the ability not only to understand the facts but also to apply the information to his or her own situation.

The mental health professional is obligated to maximize the patient's ability to perform well on the examination.[9] The patient should be seen individually, as he/she may feel more comfortable talking about concerns such as being a burden to others. Many patients imagine an adversarial process. Rapport is important. Ill patients may tire easily. The examiner should be prepared to modify the examination based on the patient's tolerance. An extended evaluation may not always be feasible, depending on the patient's preferences, physical condition, limited time to live, financial constraints, and geographic location. Seeing the patient in his/her residence rather than the mental health professional's office may diminish the patient's exhaustion. Instruments such as the Geriatric Depression Scale,[10] the Folstein Mini-Mental State Examination,[11] or the Neurobehavioral Cognitive Status Examination[12] may be useful adjuncts to assess mood and cognition.

In the absence of a mental disorder, evidence of coercion or knowledge deficits, most patients will qualify for the Oregon Act. Attending physicians are unlikely to refer patients whom they know well or who are calm, lucid, and rational to a mental health professional. At the other end of the spectrum, physicians are likely to refer patients with severe depression or delirium for treatment, not a capacity evaluation. Cases in which some psychological symptoms are present and decision-making capacity is questionable or marginally compromised are the most likely to need referral. Although mental health professionals are skilled in diagnosing mental disorders, determining the role of a mental disorder such as depression on decision making is more difficult, even by expert assessment. In surveys of Oregon mental health professionals, only 6% of psychiatrists and psychologists were very confident that they could determine whether a mental disorder was influencing the judgment of a person requesting a prescription under the Oregon Act, if they only saw the patient once.[5,6] They were more confident about assessing decision-making capacity over an extended period of time.[5,6] In a study of 290 U.S. forensic psychiatrists, "58% indicated that the presence of a major depressive disorder should result in an automatic finding of incompetence for the purposes of obtaining assisted suicide".[4] As such, of the two components of the mental health assessment (presence of a mental disorder and determination of its influence) the greatest weight in determining eligibility for obtaining medication under the Oregon Act should be on whether or not a mental disorder such as depression can be diagnosed.[13]

The consulting mental health professional should feel free to communicate to the attending physician the standard he/she used for capacity and his/her degree of confidence regarding the determination of capacity.[4,5,14] Even if the evaluator cannot say with confidence whether the patient has or lacks decisional capacity, the attending physician will be able to use the information that the mental health professional provides. The consultant can suggest interventions to enhance capacity, ask to reevaluate the patient after treatment is provided, or recommend a second opinion from another mental health professional.[15] Once the patient is referred for a mental health evaluation, the attending physician may write a prescription for a lethal dose of medication only if the mental health professional can state that within his/her standards, the patient meets the criteria of the Oregon Death with Dignity Act.

Even when a mental disorder is absent and decision-making appears intact, psychotherapeutic interventions may relieve suffering. The mental health clinician's traditional role includes helping patients with coping and decision-making. As such, it is important for the mental health professional to understand the patient's overall situation and factors contributing to his/her request for medication with which to end life. These factors may include the patient's access to or attitudes about medical care, communication with the attending physician, his/her quality of life, belief system, life history, financial and family issues and experiences with deaths of others (see *Hospice, Palliative Care, and Comfort Care* and *Financial Issues*). The mental health consultant should explore with the patient the attitudes of family members or a decision to conceal the request for a prescription under the Oregon Act from the family (see *Family Needs and Concerns*). The mental health professional should also assess communication in the relationship between the attending physician and the patient.

The mental health consultant should support autonomous choice and attenuate the anguish of the dying process.[14] The patient may dread particular aspects of the future; struggle to find meaning in remaining life; feel guilt, low self-worth, anger, or worry about being a burden to others. Previous experiences with other dying persons may distort the patient's understanding of alternatives. Illness or personality may impede the patient's ability to think flexibly or to consider other alternatives. The request for a prescription under the Oregon Act may be an attempt to cope with loss of control and pending dependence on others.[16-19] The mental health consultant can help by reframing alternatives for the patient, exploring other methods for the patient to maintain control, and countering negative thinking.[17] The patient may question the mental health professional's motives, however, if the consultant puts too much emphasis on finding alternatives.[19]

Many patients may qualify under the Oregon Act yet still benefit from supportive counseling. The mental health consultant may choose to recommend individual supportive psychotherapy, family therapy, or referral to spiritual or other support services. Many of these services are available to those enrolled in hospice. If the mental health professional finds the patient competent and without a mental disorder that is influencing the desire to obtain a lethal dose of medication, refusal of further mental health treatment by the patient does not constitute a legal barrier to receiving a prescription for a lethal dose of medication.

Mental Disorders that may Influence Decision-Making

Mental disorders are the most common reasons why decision-making capacity is impaired, but not all psychiatric disorders automatically impair decision-making abilities. Disorders such as Alzheimer's disease occur in half of people over age 85 causing both difficulty in remembering the details of the illness and impairing the patient's ability to weigh risks and benefits and, applying the information to his/her own situation.[20,21] Studies of geriatricians, psychiatrists, and neurologists show high levels of disagreement among these professionals when assessing the ability of persons with mild Alzheimer's disease to make medical treatment decisions, though consistency can be improved when clinicians are made aware of applicable legal standards.[22,23] Some very physically ill patients will have mild cognitive impairments not meeting the criteria for dementia. These patients may not be impaired in their capacity to understand the risks and outcome of ingesting a lethal dose of medication or to recite the alternatives (e.g., hospice), but their ability to truly appreciate complicated palliative alternatives with their attendant uncertainties may be taxed.

Delirium is common in the final weeks of life, especially when high doses of opioids are needed to control pain.[24,25] Delirium is characterized by problems with attention, concentration, and memory. Delirium almost universally impairs decision-making capacity, and even when subtle can affect a patient's ability to see options clearly and make an informed decision and may lower inhibitions to ingesting a lethal dose of medication.[23] However, impairments in decision-making capacity due to delirium can wax and wane. Some patients will have suffered delirium during some portion of their treatment and may miss critical information regarding their disease. This lack of information can be overcome with patient education after the delirium has resolved.

Alcohol misuse may continue into the terminal period. Although the patient may meet the criteria under the Oregon Act for a prescription, he/she may impulsively ingest the medication. The attending physician should be advised of these concerns.

Depression is a common diagnosis among terminally ill patients desiring hastened death.[17,26-28] Oregon primary care physicians have appropriately expressed doubt about their ability to diagnose depression in these patients,[29] though in a recent survey of physicians who received requests, only 9% were uncertain if the patient had depression and no patient about whom the physician was uncertain received a prescription under the Oregon Act.[16] Even for mental health professionals, diagnosing a major depressive disorder in terminally ill persons can be difficult. What appear to be depressive vegetative symptoms such as weight loss and loss of energy may be due to the underlying disease in terminally ill patients. Mild psychological symptoms such as sadness, hopelessness, and difficulty experiencing pleasure may be realistic responses to a terminal prognosis and the limitations of severe medical illness. Unremitting low mood and anhedonia, despair, despondency, and pervasive low self-esteem are hallmarks of significant depression. Psychotherapy and medications are effective for treatment of depression in terminally ill persons. The patient's life expectancy and ability to tolerate antidepressant medications may limit treatment options. While psychostimulants are effective within several days of initiation, other medications take several weeks to be effective.[25]

Depression may impair patients' ability to understand their options, diminish the ability to appreciate the benefits of life, and magnify the burdens. Studies of elderly patients interested in life-sustaining medical treatment indicates that mild-moderate depression has little effect on patients' treatment decisions, but severe depression has a substantial effect.[28,30] A survey of Oregon physicians about their experiences with requests for prescriptions under the Oregon Act suggests that most proceed cautiously. Although 20% of patients who requested a prescription were depressed, none received a prescription from the surveyed physicians.[16] However, in a study of 58 individuals seeking a prescription under the Oregon Act, one in four were assessed to have major depressive disorder.[31] Of the 18 who received a lethal prescription, 15 (83%) had no evidence of a mood disorder, but three were diagnosed with major depression. All three died by lethal ingestion within two months of the research interview. This suggests that the practice of the Oregon Death with Dignity Act through 2006 did not include adequate assessment of all patients for mental health conditions that could impair judgment. Specifically, more vigilance and systematic examination for depression for these patients is needed.

Outside the context of terminal illness, the relationship between suicide and depression is very strong: some psychiatric disorder is present at the time of death in 90% of completed suicides.[13]

Treatment of psychiatric disorders in those who attempt suicide is very effective in abolishing suicidal ideation. This is the basis for our recommendation that patients who request a medication for the purpose of ending life be systematically screened for depression and referred for a mental health evaluation if screening indicates depression. Screening instruments that could be used include the *Patient Health Questionnaire-9* (*PHQ-9*), which is reliable, validated, and easy to administer. Further study is needed to determine whether depression treatment will alter desire for a prescription under the Oregon Act in terminally ill patients.

Guidelines

9.1 We strongly recommend that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the *PHQ-9. Other possible instruments could be used*. If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist.

9.2 Mental health professionals with strong personal biases for or against the Oregon Act should consider declining the consultation. Biases should be disclosed to the attending physician at the time of the referral.

9.3 The mental health consultant has two roles. The first, as outlined in the Oregon Death with Dignity Act, is to determine the patient's specific capacity to make the decision to hasten death by self-administering a lethal dose of medication. The second, a traditional role, is to evaluate for any remediable sources of suffering.

9.4 Mental health professionals may decline to participate in any aspect of the Oregon Act.

9.5 When a mental health consultant cannot make a determination of capacity with confidence, the consultant can suggest treatments, reevaluate, or recommend a second mental health evaluation.

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10. Pharmacists and Pharmacy-Related Issues

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The Oregon Death with Dignity Act presents a number of professional and ethical questions for pharmacists because the focus and the end point of the Oregon Act is the prescription for a lethal dose of medication that they may be asked to fill (see *Conscientious Practice* and *The Role of Other Health Care Professionals*). This chapter addresses some of the ethical challenges of pharmacists' participation in the Oregon Death with Dignity Act. Regardless of the details of any particular clinical situation, persons with terminal illness, their families, and their caregivers must be treated with the utmost of professional care, confidentiality and respect.

Information for Pharmacists

The Oregon Act states, "No health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the provision to a qualified patient of medication to end his or her life in a humane and dignified manner."[1] As defined by the Oregon Act, the term "health care provider" includes the pharmacist and a "health care facility." Pharmacists who choose to participate are encouraged to adopt policies and procedures for dispensing and medication counseling, as well as for the confidential handling of prescriptions and any required reporting forms for prescriptions written under the Oregon Act.

ORS 127.885, subsection 4.01 of the Oregon Act was amended in 1999 to provide that a health care facility may prohibit an employee from participating in the Oregon Act on the premises of the facility. Pharmacists must know their employers' policies regarding the Oregon Act. The Task Force encourages respect for the ethical positions of both individual pharmacists and of each health care facility. Pharmacists are bound by confidentiality requirements under Board of Pharmacy rules (OAR 855-041-0103) and all other legal and ethical standards for confidentiality of patients' health care information.

It is possible that a patient or family member may ask a pharmacist for information about the Oregon Death with Dignity Act. The pharmacist must be respectful of these inquiries. However, these patients should be referred to their attending physician to explore their questions and concerns in greater detail (see *The Meaning Behind the Patient's Request*).

The idea of participating in the Oregon Death with Dignity Act may evoke personal, moral and ethical questions for health care professionals (see *Conscientious Practice*). In deciding whether or not to participate, pharmacists need to examine their personal and professional ethics, and any policies of their employer related to the Act, so that they are prepared to meet their clinical, ethical and legal responsibilities in case they are asked to dispense a medication pursuant to the Oregon Act.

Resources exist that may assist the pharmacist. The *American Pharmaceutical Association* and *American Society of Health System Pharmacists* have published position statements outlining the professional responsibilities of a pharmacist when faced with moral, religious or ethical controversies. The *Oregon Board of Pharmacy* has issued a position statement describing pharmacists' professional responsibility when faced with a moral or ethical dilemma.

The Non-Participating Pharmacist

Many pharmacists choose not to participate in the Oregon Death with Dignity Act. If a non-participating pharmacist receives a request from a physician to dispense medication under the Oregon Act, he/she should immediately inform the physician of his/her decision to not participate. The non-participating pharmacist may refer the physician to a pharmacy or pharmacist who is willing to participate. However, the pharmacist is under no obligation to make such a referral. If the non-participating pharmacist does not know of a pharmacist who is willing to participate or chooses to not provide a referral, he/she should inform the attending physician.

A pharmacist who has declined to participate may be asked to furnish the patient's prescription records to the attending physician or participating pharmacist to assure appropriate continuity of care. The patient's medication history may be relevant, both in terms of continued pain and symptom management and in terms of any drug therapy that could impact the absorption, distribution or metabolism of the anticipated use of the lethal dose of medication. Pharmacists must maintain the privacy of patient records; however, when specifically requested, pharmacists must provide this information to a physician and/or another pharmacist who are actively involved in the patient's care.

The Participating Pharmacist

For pharmacists who are not precluded from participation by their employer and who choose to dispense medication pursuant to the Oregon Act, the professional, legal and regulatory standards that apply to all medication dispensing must be followed. Upon dispensing, pharmacists are required to review available patient information and each prescription drug order to assure therapeutic appropriateness. The pharmacist should consult with the physician if any questions arise regarding a prescription or a patient's drug therapy. In addition, pharmacists are required to provide information and counseling about the medication when dispensing any new medication or any refilled prescription that has a change in directions, dose, route of administration or conditions or circumstances that could impact the patient's current therapy. Medication counseling should include information on matters that a reasonable and prudent pharmacist would deem significant.

Medication counseling must be provided to the patient or the patient's agent orally and in person whenever practical. Patient counseling for medications to end life pursuant to the Oregon Act should be conducted in a private area, well away from other patients and pharmacy personnel, to assure confidentiality and comfort. The most effective patient counseling occurs in an atmosphere free of distractions. Oral counseling by the pharmacist is not required when the patient refuses or when the pharmacist determines that another form of counseling is more appropriate. Examples include when the medication is given to the physician who will personally provide the medication and counseling to the patient, when another health care professional would appropriately provide counseling, or when another form of counseling would be more appropriate (OAR 855-019-0230). The pharmacist may offer to provide medication counseling over the telephone for patients who are unable to pick up their own medication. Ultimately, the pharmacist must determine the most reasonable method to provide necessary information for the appropriate use of the medication in every circumstance. Pharmacies should have a policy or procedure in place for documenting patient-specific information and medication counseling.

OAR 333-009-0010(3), adopted by the Oregon Department of Human Services - Public Health Division in 1999 and amended in 2006, requires that any health care professional (pharmacist, physician, or health system), within 10 calendar days of dispensing medication pursuant to the Oregon Act, must file a copy of the Dispensing Record Form (see *Forms*) with the State Registrar, Center for Health Statistics, 800 NE Oregon Street, Suite 205, Portland, OR 97232 by mail or in person, or by facsimile at (971) 673-1201. Information to be reported must include the patient's name and date of birth; the prescribing physician's name and phone number; the dispensing health care provider's name, address, and phone number; the name and quantity of medications dispensed; the date the prescription was written; and the date the medication was dispensed.

Drug Information

There may be a misperception among the general public and some health care professionals that the ingestion of a lethal dose of medication will immediately cause death in every case. Experience under the Oregon Act indicates that the time from medication ingestion to death is variable. For most individuals, death occurs in less than four hours. According to the Oregon Department of Human Services[2], by the end of 2007, 341 patients have died under the terms of the law. Complications were reported for 20 patients. Of these, 19 involved regurgitation and none involved seizures. The median time between ingestion and unconsciousness was 5 minutes with a range of 1 to 38 minutes. The median time between ingestion and death was 25 minutes with a range of 1 minute to 48 hours. One patient (2007) lived 3 ½ days and one (2005) regained consciousness after ingesting the lethal dose of medication and then died 14 days later from his illness rather than from the medication. Emergency medical services were called for 4 patients, 3 to pronounce death and one to help a patient who had fallen.

As part of the decision-making process, patients need to talk with their attending physicians to plan for the possibility of unexpected outcomes, such as delayed death or other complications, when the patient self-administers the medication. If the patient has shared with family his/her wishes to take medication to end life, then the family should be included in these discussions. The patient and anyone else who will be present when the patient self-administers the medication must be informed of the probable time line of outcomes following ingestion. It must be explained that the medication may act more rapidly or more slowly than expected.[2,5]

Besides the information available in the DHS Annual Reports, some of the organizations listed under resources at the end of this chapter have developed recommendations for specific drug combinations and sequences of administration, which are available to physicians and pharmacists. Further information and reports from the Netherlands regarding specific drug combinations are also available.[8-10] The Task Force has not independently evaluated this information and does not advise on specific medications used under the Oregon Act.

Information for Physicians

When an attending physician writes a prescription for medication pursuant to the Oregon Act, personal communication with a pharmacist in order to determine his/her willingness to dispense it will help ensure confidentiality and avoid presentation of the prescription to a pharmacist unwilling or unable to participate. The Oregon Act and the Oregon Medical Board's administrative rule, OAR 847-015-0035, require this advance communication in order for the attending physician to personally issue the prescription to the pharmacist. This contact will also allow the attending physician and pharmacist to work together on medication-related details, allow them to confer regarding any questions about drug, dose, or route of administration, and to discuss patient medication counseling issues. It is an opportunity for the attending physician and the participating pharmacist to discuss how the medication will be prepared, picked up, or delivered. The pharmacist may help facilitate the process by delivering the medication to the physician's office or to the patient's home (see *Attending Physician and Consulting Physician*).

If the attending physician obtains the prescribed medication from the pharmacist and personally presents it to the patient, then the attending physician and patient can choose the date and time for medication delivery and arrange to have counseling provided in the privacy of the home or office. This will avoid possible concerns about lack of privacy or confidentiality in public areas of a pharmacy or hospital. In this scenario, the physician assumes responsibility for providing appropriate medication information to the patient and, with the patient's permission, family members. If the attending physician and patient desire, the pharmacist may be able to deliver the medication to the patient's home at an appropriate time.

A pharmacist who provides medications for the attending physician to present directly to the patient must assure that the attending physician is provided information on preparation, stability, storage, and any other information necessary to assure safety and efficacy. The attending physician should confer with the pharmacist regarding important issues about the specific drug or drug combination. The pharmacist should discuss any questions or concerns with the physician. The attending physician should assess the patient's knowledge of the medication and its proper use, the purpose and expected outcome of ingesting the medication, and the voluntary nature of taking the medication. The attending physician should also tell the patient: 1) how to safely and properly store the medication; 2) how to mix or prepare the medication; 3) that complications are possible; 4) what to do in the event of a complication and 5) disposal instructions in the event the medication is not taken. Special instructions might include sequence and timing when more than one medication is being prescribed. The attending physician should allow time and encourage the patient to ask questions. If the patient or caregiver picks up the medication at the pharmacy, the pharmacist should provide similar medication counseling to the patient or caregiver.

Physicians who have registered with the Oregon Medical Board to be dispensing physicians may personally prepare and dispense medications to their patients if they choose. Medications may be purchased from a licensed pharmacy, pharmaceutical wholesaler, or manufacturer. The Board's statutes and administrative rules found in ORS 677.089 and OAR 847-15-025 set guidelines for this practice.

Guidelines

10.1 Pharmacists, like other health care professionals, may choose to not participate, and are under no obligation to participate. If unwilling or unable to participate when asked by a physician, the pharmacist must inform the physician that they will not participate. The pharmacist must provide the pharmacy records upon request by the physician and may assist the physician in finding a willing pharmacist, but is under no obligation to do so.

10.2 It is the Oregon Board of Pharmacy's position that pharmacies must have policies and procedures in place to address employees' potential moral and ethical conflicts.

10.3 Pharmacists must be aware of and respect their employer's institutional policies regarding the Oregon Act before making any decision whether or not to participate.

10.4 Pharmacists need to assess their personal feelings and convictions about the Oregon Death with Dignity Act in order to appropriately respond to inquiries from physicians, patients, and others.

10.5 A participating pharmacist must be contacted by the physician prior to issuing a prescription under the Oregon Act. Attending physicians and pharmacists need to confer before a prescription is written to determine the pharmacist's willingness to participate and resolve other important details, such as drug preparation, stability and storage requirements, and patient medication counseling.

10.6 If the pharmacist has any question about the purpose or details of any prescription, it is his/her duty to confer with the prescriber and have those questions answered.

10.7 The attending physician may obtain the prescribed medication from the pharmacist and present it to the patient personally. The pharmacist can facilitate this by delivering the medication directly to the physician's office or to the patient's home.

10.8 The participating pharmacist should be prepared to discuss important pharmaceutical information and patient instructions with the physician. The attending physician assumes responsibility for advising on appropriate drug use when providing the medication directly to the patient.

10.9 Pharmacies should develop policies and procedures to ensure confidentiality for patients, physicians, and pharmacists in handling prescriptions issued pursuant to the provisions set forth in the Oregon Act.

10.10 The dispensing health care professional (pharmacist, physician, or health care facility) must report to the Oregon Department of Human Services within ten calendar days of dispensing a lethal dose of medication pursuant to the Oregon Act. The appropriate form can be found on the *DHS website*.

References

1. ORS 127.885 § 4.01(4).

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7. ORS 127.880 § 3.14.

8. Battin MP, Lipman AG, eds. Drug Use in Assisted Suicide and Euthanasia. Binghamton, NY: Pharmaceutical Press;1996.

9. Quill TE. Legal Regulation of Physician-Assisted Death — The Latest Report Cards N Engl J Med 356:1911, May 10, 2007 *Perspective*

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Resources

Oregon Hospice Association
P.O. Box 10796
Portland, OR 97297
888-229-2104
info@oregonhospice.org
http://www.oregonhospice.org

Compassion and Choices
PO Box 101810
Denver, CO 80251-1810
800-247-7421
info@compassionandchoices.org
www.compassionandchoices.org

Compassion and Choices of Oregon
P.O. Box 6404
Portland, OR 97228
(503) 525-1956
contact@compassionandchoices.org
www.compassionoforegon.org

Physicians for Compassionate Care Educational Foundation
P.O. Box 6042
Portland, OR 97228-6042
(503) 533-8154
www.pccef.org

Internet

A variety of Internet resources can be found via commonly available search engines.

Oregon Board of Pharmacy
Oregon Department of Human Services

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11. Emergency Department and Emergency Medical Services

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Many patients who come in contact with the emergency medical services (EMS) system or go to a hospital emergency department (ED) near the end of life may not desire potentially life-saving interventions. When a patient self-administers a lethal dose of medication as set forth in the Oregon Act, the EMS system or an ED may become involved if complications develop, if the ingestion does not result in death, or if the time between self-administration and death is longer than the patient and family expect. In the Netherlands, complications or technical problems with euthanasia, as practiced there, were found in about 10% of cases.[1] According to the seventh-year report (2004) from the Oregon Department of Human Services – Health Services, in none of the cases of the 208 persons who died using the Oregon Act was EMS called to intervene. Delayed deaths have been reported. One patient survived 48 hours following the ingestion of a medication prescribed under the Oregon Act and one patient regained consciousness after taking the medication.[2] Over the ten years of the Oregon Act, 20 of 341 patients had a complication, 19 of these regurgitating some of the medication.[3] Emergency medical services were called for 4 patients, 3 to pronounce death and one to help a patient who had fallen.

Thus, even with careful planning, it is possible that deaths which take longer than expected might lead to occasional ambulance calls and transport to emergency departments. Although it has been rare to date, emergency physicians may care for patients who are brought to the ED. When this happens, emergency physicians will be faced with making critical decisions. While always providing comfort measures, they need to consider the circumstances under which potentially life-sustaining procedures can be refused or withheld after self-administration of the lethal dose of medication by a terminally ill person. While the Oregon Act states that health care professionals may decline to provide a prescription for medication to end life, it does not address moral objection by emergency care professionals or how to handle a delayed death. (see *Liability and Negligence* and Appendix A, *The Oregon Death with Dignity Act*). A study of emergency physicians in Oregon found that the 69% supported the Oregon Act, but 19% believe it is immoral.[4] Similarly, a study of emergency medical technicians (EMTs) found that 68% supported the Oregon Act while 17% believed that withholding resuscitation for patients who had ingested the lethal dose of medication is immoral.[5]

Attending physicians have an obligation, therefore, to educate their patients and, when possible, those who will be with the patients, about what to expect if they or their family members call 9-1-1 or go to an emergency department. That response may vary from one EMS system to another, or in the ED, depending on the physician who is on duty. It is possible that patients will get more life-sustaining treatment than they desire. It is strongly recommended that physicians make written documentation of their patient's wishes available at the bedside and accessible to emergency personnel, including a Physician Orders for Life-Sustaining Treatment (*POLST*) form with a do-not-resuscitate (DNR) order (see Appendix C, *Advance Directives and Physician*

Orders for Life-Sustaining Treatment). POLST is widely recognized and honored by EMS in Oregon, Washington and many other states (see *POLST*).[6]

The Oregon Death with Dignity Act requires the patient to self-administer the lethal dose of medication. Problems with involvement of EMS and the emergency department can be avoided if the attending physician is present or readily available at the time the patient ingests the medication (see *Attending Physician and Consulting Physician* and *Family Needs and Concerns*).

The Oregon Act contains no guidance for providing information to other health care professionals, such as emergency personnel, about the wishes and plans of patients (see *The Role of Other Health Care Professionals*). This opens up the possibility that a patient could arrive in the ED or be treated and possibly transported by EMTs without adequate documentation of his/her wishes regarding life-sustaining treatment or without evidence of compliance with the Oregon Act. Without this information, it will be difficult for emergency professionals to make resuscitation decisions. This underscores the importance of having available appropriate end-of-life orders, such as the *POLST*.

Conflicts may occur between the policies of the institution and the conscience of an ED professional (see *Conscientious Practice*). The potential for conflict also arises if a physician alone decides for or against resuscitation when other members of the health care team have strong personal beliefs. Allowing for moral objections in practice in the ED is problematic because of the need for rapid resuscitation decisions. Most institutional policies regarding conscientious practice rely on the ability to substitute health care professionals from other units in the institutions, which often is not feasible on an urgent basis in the ED.

Hospitals and EDs need to develop policies and procedures about making treatment decisions for terminally ill patients who have self-administered a lethal dose of medication pursuant to the Oregon Act. These policies must address several areas of concern, including: a) circumstances, if any, under which the hospital would allow such a patient to die without potentially life-saving interventions; b) provision of comfort care in the ED to terminally ill patients who have self-administered medications pursuant to the Oregon Act; c) documentation required for honoring patient wishes about life-sustaining therapy; and d) procedures for honoring conscientious practice by staff who are unwilling to withhold resuscitation from a patient who has ingested a lethal dose of medication pursuant to the Oregon Act.

EMS systems should develop protocols that address how paramedics and EMTs should respond if called to the scene where a person has taken a lethal dose of medication pursuant to the Oregon Act (see Appendix F, *Sample EMS Protocol*). EMTs and paramedics treat patients based on written protocols from their physician supervisor or orders from a physician at a base station hospital. Supervising EMS physicians should develop protocols to provide direction to EMTs in making resuscitation decisions for a patient who has taken medication pursuant to the Oregon Act. In most cases, these complex decisions should involve on-line medical consultation. If they haven't already, EMS systems also should develop protocols for honoring patient preferences regarding potentially life-sustaining treatment at the end of life, including POLST and DNR orders in the out-of-hospital setting. If the patient dies, EMS involvement likely will result in notification of the Medical Examiner, who may pursue further investigation (see *Oregon Department of Human Services Reporting*).

Guidelines

11.1 Attending physicians should counsel their patients and family members or caregivers (with the patient's permission) about what to expect after the patient takes medication in compliance with the Oregon Act, including the probable length of time between administration and death and side effects of the medication. This counseling should include what to expect if they call 9-1-1 or go to an emergency department.

11.2 Attending physicians and patients should consider completing advance directives and the POLST, which include DNR orders, to provide written direction about patient wishes when the patient is later unable to express them (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*). Provisions need to be made to have these documents available should EMS be called to respond.

11.3 Hospitals and EDs need to develop policies and procedures for treating terminally ill patients who have taken medication pursuant to the Oregon Act. These policies must address the withholding of potentially life-saving interventions, the provision of comfort care, and procedures for conscientious practice by ED personnel.

11.4 EMS systems should develop protocols that address how paramedics and EMTs should respond if called to the scene of a terminally ill person who has ingested medication obtained under the Oregon Death with Dignity Act and how to honor patient preferences near the end of life, as documented by advance directives, the POLST form and other DNR orders (see Appendix F, *Sample EMS Protocol*).

References

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3. Oregon Department of Human Services. Tenth Annual Report on the Oregon Death with Dignity Act. March 2008. *http://oregon.gov/DHS/ph/pas/index.shtml*

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toward physician-assisted suicide Acad Emerg Med 1998, 5:912-918.

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12. Responding to Professional Non-Compliance

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The Oregon Death with Dignity Act establishes guidelines and safeguards described in Oregon statute ORS 127.800 to 127.890, 127.895, and127.897. Through this guidebook, we have identified appropriate professional standards in the broader care of terminally ill persons and specifically reviewed quality of care practices related to professional compliance with the Oregon Death with Dignity Act.

Participation in the Oregon Death with Dignity Act may involve (in addition to physicians) a variety of health professionals who hold state licenses. Physician assistants, nurses, nurse practitioners, psychologists, social workers, pharmacists, and emergency personnel are all licensed or certified professionals, and, while they cannot order a prescription under the Oregon Act, they may be involved in various other capacities with the Oregon Act from direct patient care to counseling (see *The Role of Other Health Professionals* and *Mental Health Consultation*). Licensing boards are responsible for regulating and disciplining health care professionals. To hold a state license is a privilege and confers upon the holder the obligation to practice in a competent, professional, and legal manner.

Throughout the Guidebook we have outlined some anticipated concerns for those participating in the Oregon Death with Dignity Act. No doubt others will arise. If a health care professional is aware of a physician or other health care provider who is non-compliant with the safeguards as outlined in the Oregon Act, or otherwise delivers significantly substandard care, he/she must report that individual to the appropriate licensing board. For example, if a physician provides a lethal dose of medication to a clearly incompetent patient or to a patient who is not terminally ill, or a nurse administers an injection with the intent to kill rather than for comfort, a report must be filed with the respective licensing board. Likewise, a physician who repeatedly provides grossly inadequate measures for comfort of their dying patients must also be reported.

This obligation to report is not new. Licensees must report to the appropriate licensing or certifying board those licensees who are medically incompetent, engage in unprofessional conduct, or have a physical or mental impairment that affects their ability to safely practice their profession. There is a legal requirement for health care professionals to report a fellow health care professional within their same discipline. Failure to report a fellow licensee may result in disciplinary action against the professional who knew of the inappropriate or illegal conduct. A professional in a different discipline may be ethically required to report to the appropriate board. Reporting to a physician group, insurance carrier, hospital, clinic, or an agency responsible for care may also be required. These groups should be consulted independently regarding reporting obligations. At the time a prescription under the Oregon Act is written, the prescribing physician is required to report information regarding the patient to the *Oregon Department of Human Services*. Failure to report in a timely fashion is considered non-compliance with the Oregon Act, and Department of Human Services will report to the appropriate licensing board.

For further information, see *Oregon Department of Human Services Reporting*.

If there are questions about a physician's or other health care provider's practice relative to appropriate comfort care or participation in the Oregon Act, the licensing board should be contacted. Since the goal of comfort care is to relieve pain and suffering, dying patients should receive sufficient dosages of appropriate medications. In particular, medications to relieve suffering should not be withheld on the basis of physiologic parameters when patients continue to experience pain. Opioids and other controlled substances should not be withheld because of fear of hastening death; however, it is essential to document the need for medication in the patient's medical record. Each board has an administrator and skilled medical professionals on staff to provide assistance.

Guidelines

12.1 Health professionals must report to the appropriate licensing and certifying board professionals who engage in medical incompetence or unprofessional conduct. Failure to report a licensee in the same profession may itself result in discipline against the license of the professional who knew of the illegal conduct.

12.2 If there is a concern about the conduct of a professional in another health care discipline, there is an ethical obligation to act. There may be a requirement for institutional or professional board reporting.

12.3 If a health professional has questions about the appropriateness of a practice relative to comfort care or participation in the Oregon Death with Dignity Act, he/she should consult the staff of the appropriate licensing board for guidance.

12.4 Physicians and other health care providers with prescriptive authority need to ensure that patients receive sufficient dosages of appropriate medications for the relief of pain and suffering. The Oregon Medical Board encourages physicians to employ skillful and compassionate pain control for dying patients. The Oregon Medical Board investigates allegations of under prescribing for pain in the same manner as over-prescribing.

12.5 Licensees should not report another professional to the licensing board simply because the other professional has cooperated with the request for a prescription under the Oregon Act. The Oregon Medical Board does not consider good faith compliance with the Oregon Act unprofessional conduct.

Resources

While not authorized to write or fill a prescription under the Oregon Death with Dignity Act, other health care providers may be involved and on occasion may have the need to report to the appropriate licensing board.

Oregon State Board of Clinical Social Workers
3218 Pringle Road SE, Ste 240
Salem, OR 97302-6310
(503) 378-5735
oregon.bcsw@state.or.us
http://www.bcsw.state.or.us/

Oregon Department of Human Services
Oregon Public Health Services
800 NE Oregon Street, Ste 930
Portland, OR 97232
(971) 673-1222
ohd.hr@state.or.us
http://oregon.gov/DHS/ph
http://www.oregon.gov/DHS/ph/pas/index.shtml
http://www.oregon.gov/DHS/ph/pas/pasforms.shtml

Oregon Medical Board (Physicians, Physician Assistants, EMT Scope of Practice)
1500 SW First Avenue, Ste 620
Portland, OR 97201-5826
(971) 673-2700
bme.info@state.or.us
http://www.oregon.gov/OMB/

Oregon State Board of Nursing (RNs, LPNs, CNAs, NPs)
17938 SW Upper Boones Ferry Rd.
Portland, OR 97224-7012
(971) 673-0685
oregon.bn.info@state.or.us
http://www.osbn.state.or.us/

Oregon Board of Pharmacy
425 State Office Building
800 NE Oregon Street #150
Portland, OR 97232
(971) 673-0001
pharmacy.board@state.or.us
http://www.pharmacy.state.or.us/

Oregon Board of Psychologist Examiners
3218 Pringle Road SE, Ste 130
Salem, OR 97302-6309
(503) 378-4154
oregon.bpe@state.or.us
http://www.obpe.state.or.us/

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13. Financial Issues

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Terminally ill patients may inquire about a prescription for a medication to end life for many reasons. With motivations ranging from pain or fear to philosophical or religious beliefs, each patient who expresses an interest in the Oregon Death with Dignity Act will do so for uniquely personal reasons (see *The Meaning Behind the Patient's Request*). This chapter discusses the health care professional's duty to ensure that real or perceived financial pressures do not inappropriately influence the patient's evaluation of all end-of-life options, including the request for a prescription under the Oregon Act.

For a growing number of Americans, financial issues are an important factor in medical decisions. More than one in ten Oregonians is uninsured, while many more are underinsured, particularly for end-of-life care. Hospice care is available to patients eligible for Medicare who elect hospice benefits and to patients eligible for the Oregon Health Plan. Most private Oregon insurers also offer coverage of hospice and home health services. Palliative and comfort care, however, commonly are left out. Some patients may have adequate health insurance, but lack the resources to pay for personal needs, in-home care, and other non-medical expenses associated with terminal illness and/or extended hospitalization. Payments for medications can also be a burden. While Medicare now offers a prescription benefit, it is important for beneficiaries to choose a plan that covers the medications they need. For those with severe pain, medications can be very expensive. The Task Force supports universal access to hospice and comfort care and encourages policy makers to allocate funding to assure access to comfort care for all terminally ill Oregonians.

Financial considerations have long played a role in end-of-life decision-making.[1] One study on the impact of illness on patients' families found that nearly a third of the families reported losing most of their savings or primary source of income as a result of a major illness.[2] Concerns about leaving family and loved ones in a perilous financial position following a terminal illness is one reason why many people complete advance directives and refuse life support.[3]

The Oregon Department of Human Services has reviewed data each year of the characteristics of patients who died after ingesting medication received under the Oregon Death with Dignity Act. Of the total of 341 ODDA patients, 63% had private insurance, 36% had Medicare or Medicaid, 1% had no insurance.[4] Nine (3%) patients mentioned financial implications of treatment as being an end-of-life concern. While experience with the Oregon Death with Dignity Act does not indicate that financial concerns are a primary motivator, health care professionals should be careful to identify patients who are considering a request for a prescription for a medication to end life as an answer to pressing financial concerns. Health care professionals can then more fully explore options with those patients.

Health care professionals should be aware of alternative sources of coverage for end-of-life care. The Oregon Health Plan (OHP) may be an option for low-income patients. OHP covers "comfort care," including hospice, in-home health services, pain management, and costs associated with the Oregon Death with Dignity Act. The federal Medicare program provides a prescription drug benefit and a hospice benefit, but does not cover a prescription under the Oregon Act. Federal funds may not be used to pay costs associated with the Oregon Act. HMOs may nonetheless elect to provide coverage of the Oregon Death with Dignity Act so long as coverage does not utilize federal funds, but not all have elected to do so. For more information on hospice, see *Hospice, Palliative Care, and Comfort Care.*

The potential impact of provider reimbursement on life support decisions is not a new issue. Some have long expressed concern that financial incentives in a fee-for-service mode encouraged excessive care, even beyond what the patient and/or family may have wanted. Changes in health care reimbursement practices have increased public concern about financial incentives that may influence patient care decisions in the other direction. Reimbursement methods can create actual or perceived conflicts for those caring for terminally ill patients with expensive, resource-intensive conditions. Patients and their families may fear that the quality of their care will be limited by the health care professional's financial considerations.

Conflict of interest refers to any situation in which an individual with responsibility for others might be influenced, consciously or subconsciously, by financial or personal factors that involve self-interest. End-of-life care is not the first context in which the conflict between a health care professional's patient care duties and personal financial interests has arisen. Because the dying process can be stressful, patients and families may experience heightened concern over real or perceived conflicts of interest. Those providing care to terminally ill patients must be particularly sensitive to this issue and remain willing to address it candidly should the need arise.

Guidelines

13.1 Any evidence that personal financial factors are underlying the patient's interest in a prescription for medication to end his/her life should be fully explored.

13.2 Physicians, hospitals, and others who may be perceived to have a direct or indirect financial interest in the care delivered to their patients should be sensitive to patient and family concerns about whether the financial interests impact care. Health care professionals must be willing to initiate an open discussion of these issues, including full disclosure of the provider's financial interest in the care provided to the patient, if and when the need arises.

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14. Oregon Department of Human Services Reporting

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The Oregon Death with Dignity Act allows terminally-ill Oregonians to self-administer a lethal dose of medication obtained with a physician's prescription. The law requires the Oregon Department of Human Services, Public Health Division, to collect information pertaining to compliance with the Oregon Act. These reporting requirements are essential for determining how many individuals receive prescriptions and ingest medications pursuant to the Oregon Act, and for assessing whether or not the safeguards built into the Oregon Act are being followed. In addition, the Oregon Department of Human Services must make available to the public an annual statistical report. The Department of Human Services' annual reports are available on the *Oregon Department of Human Services* web site and have been published as articles in the New England Journal of Medicine.[1-5] These reports offer insights into care of the dying and the impact of the Oregon Act in Oregon. While it is of paramount importance that accurate data be collected regarding implementation of the Oregon Act, the need for accurate data must be balanced with the concern for the confidentiality of patients and their health care professionals.

As specified in the Oregon Act, the Department of Human Services is required to "make rules to facilitate the collection of information regarding compliance with this Act" and to "annually review a sample of records maintained pursuant to this Act." The Department of Human Services adopted administrative rules in 1997, updated these rules in 1999 to reflect changes in the statute made during the 1999 legislative session, and updated them again in 2006.

The provisions of the administrative rules are described below (see *Oregon Department of Human Services Oregon Death with Dignity Act* site for a copy of the rules and the forms developed to assist physicians in documenting compliance with the requirements of the Oregon Act). The rules specify three reporting requirements. First, within seven calendar days of writing a prescription for medication to end the life of a qualified patient, the attending physician shall send the following completed, signed and dated documentation by mail to the State Registrar, Center for Health Statistics, 800 NE Oregon Street, Suite 205, Portland OR 97232, or by facsimile to (971) 673-1201: 1) The patient's completed written request for medication to end life; 2) one of the following reports prescribed by the Department: "Attending Physician's Compliance Form", or "Attending Physician's Compliance Short Form" accompanied by a copy of the relevant portions of the patient's medical record documenting all actions required by the Oregon Act; 3) "Consulting Physician's Compliance Form" prescribed by the Department; and 4) "Psychiatric/Psychological Consultant's Compliance Form" prescribed by the Department, if an evaluation was performed. Second, within 10 calendar days of a patient's ingestion of lethal medication obtained pursuant to the Oregon Act, or death from any other cause, the attending physician shall complete the "Oregon Death with Dignity Act Attending Physician Interview" form prescribed by the Department. Third, within 10 calendar days of dispensing medication pursuant to the Oregon Death with Dignity Act, the dispensing health care provider shall file a copy of the "Pharmacy Dispensing Record Form" prescribed by the Department with the State

Registrar, Center for Health Statistics, 800 NE Oregon St., Suite 205, Portland, OR 97232; or by facsimile to (971) 673-1201. Information to be reported to the Department shall include: (a) Patient's name and date of birth; (b) Prescribing physician's name and phone number; (c) Dispensing health care provider's name, address and phone number; (d) Medication dispensed and quantity; (e) Date the prescription was written; and (f) Date the medication was dispensed.

Attending physicians are encouraged to inform patients of the requirement that the Department of Human Services have access to data regarding implementation of the Oregon Act. They may wish to have the patient's written request for enacting the provisions of the statute include a statement of consent for release of medical records to the Department of Human Services. The patient and attending physician should discuss post-death arrangements as part of the overall plans. As discussed in the chapter, *Attending Physician and Consulting Physician*, the attending physician may want to be present at the time of death or make arrangements to be notified by the family immediately following the death. The attending physician could then notify the funeral home that this is an expected death and that he/she will be signing the death certificate. The death certificate will then be filed and processed according to routine procedures and the death will not go into the medical examiner's system. The Medical Examiner is required to investigate any death that is suspicious (i.e., not natural or expected).[6] In addition, if Emergency Medical Services (EMS) are present at the time of death the Medical Examiner will be called. Because medical examiner investigations allow for limited public disclosure,[7] the confidentiality of the patient cannot be assured in these instances. Additionally, family members may be questioned regarding the circumstances surrounding these deaths.

The death certificate originates in the mortician's office, and is sent to the physician to complete the cause of death information. The death certificate is then sent back to the mortician's office, which files it with the local health department. Finally, the death certificate is forwarded to the Department of Human Services, State Registrar for Vital Records. While the confidentiality of the death certificate can be assured once it has reached the local health department and the Department of Human Services, physicians must ensure confidentiality in the clinical setting. Because death certificates have multiple purposes, including settling the estate as well as for public health information, the Department of Human Services suggests physicians record the underlying terminal conditions as the cause of death and mark the manner of death "natural", rather than recording that the patient ingested a lethal dose of medication prescribed under the Oregon Death with Dignity Act. Death certificates should not be left on desktops or at nurses' stations. Health care professionals and institutions might consider implementing a policy of keeping all death certificates in envelopes marked "confidential" until they are formally filed.

Confidentiality is of paramount importance in ensuring compliance with this Oregon Act. The Oregon Act ensures that "information collected shall not be a public record and may not be made available for inspection by the public" (see *Liability and Negligence*). Thus, information regarding the identity of patients, health care professionals, and health care facilities obtained by the Department of Human Services with respect to compliance with the Oregon Act shall be confidential. Summary information released in Department of Human Services' annual reports will be aggregated to prevent identification of individuals, physicians, or health care professionals complying with the Oregon Act. Death certificates are also confidential: OAR 333-11-096 (1) states that the Department of Human Services "... shall not permit inspection of, or disclose information contained in ... death records, or issue a copy of ... any such record unless ... satisfied that the applicant has a direct and tangible interest in such record."

The Oregon Act does not assign enforcement authority to the Department of Human Services and is silent on what action the agency should take if non-compliance is encountered. When problems with documentation or reporting from physicians are encountered, the Department of Human Services will query those health care professionals for clarification. If the Department of Human Services encounters a violation of the Oregon Act, the individual committing the violation will be reported to the appropriate licensing board (see *Responding to Professional Non-Compliance*).

Guidelines

14.1 Physicians are advised to use the forms developed by the Oregon Department of Human Services as a good source of information about compliance with the Oregon Act (see *Oregon Department of Human Services Oregon Death with Dignity Act* site). These forms will serve to document compliance with the legislation and thus are a protective measure for physicians. The forms will ensure that the appropriate steps have been followed, facilitate record keeping, and limit the need for the Department of Human Services to have access to the actual medical record.

14.2 Attending physicians should inform their patients that they should let the physician know if they plan to take the prescription. Otherwise, the death may be investigated by the Medical Examiner. An investigation by the Medical Examiner may involve questioning family members about circumstances surrounding the death and confidentiality cannot be assured.

14.3 Physicians should inform their patients that the Oregon Department of Human Services will have access to forms (or medical records) that contain information regarding the patient's choice to pursue the Oregon Death with Dignity Act.

14.4 We encourage physicians to review their procedures to assure the confidentiality of death certificates.

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7. ORS 146.035(5).

Resources

Statutes and Rules: General public health authority (ORS 431.110 and ORS 431.120); confidentiality of special morbidity and mortality studies (ORS 432.060); death certificate rules (OAR 333-11-096).

Oregon Administrative Rules: 333-009-0000 through 333-009-0030 (see *Oregon Department of Human Services Oregon Death with Dignity Act* site).

Oregon Department of Human Services forms and annual reports *http://www.oregon.gov/DHS/ph/pas/ar-index.shtml*

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15. Liability and Negligence

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The following discussion and guidelines examine a range of potential legal pitfalls in the Oregon Death with Dignity Act[1] (the "Oregon Act") and the precautions that may be taken against them. The best defense against liability, however, is to make sure that patients receive appropriate care, that only qualified patients are supplied with medication to end life, and that only the limited assistance authorized by the Oregon Act is given. The Oregon Act does not permit active euthanasia, mercy killing, or lethal injection, no matter how compelling the circumstances.[2] It is essential to verify and document the terminally ill patient's basic qualifications: Oregon residence, at least 18 years of age, terminal illness, sufficient mental capacity, volition, an informed decision, and compliance with the procedure for oral and written requests.

The goal of minimizing liability may conflict with a provider's concept of ethical practice or the privacy of patients and other providers. In such circumstances, choices should be informed by an appreciation of the risks involved. This chapter points out a few of the most obvious potential conflicts between risk management and other values.

This chapter reflects the Oregon Act's focus on the obligations of attending and consulting physicians. However, many of the guidelines are equally applicable to health care providers generally.

The touchstone of the guidelines is documentation. The Oregon Act contains many new and unfamiliar procedural aspects. It is therefore critical, and in many cases obligatory, to document compliance with the Oregon Act.[3]

Identifying Existing Legal Resources and Obligations

The health care provider's first step should be to identify what legal or other resources are available in evaluating the decision to participate in the Oregon Act. Health care providers should contact the administrator of their group or plan to determine what assistance is available. If no such resource is available, then the physician should ask for a referral to a knowledgeable advisor.

Health care providers should review contracts, policies, and bylaws of the organizations and facilities with which they are currently affiliated. See "Contracts and Credentials," below. Agreements with other providers and with health plans may address the subject of the Oregon Act directly or indirectly. Policy documents or other contracts may be referred to but not included in these agreements. Copies of these referenced documents should be obtained.

The physician's group or clinic or its insurance representative should consult in advance and in writing with the malpractice insurance carrier to determine if it will confirm in writing coverage for damages and the costs of defense in a suit arising under the Oregon Act. Malpractice coverage typically contains an exclusion from coverage for intentional (as opposed to negligent) injury. The Oregon Act obviously contemplates acts intended to produce fatal consequences. When these acts fail to produce death but do produce injury to the patient, will this exclusion apply? Similarly, in cases where the prescription does produce death, but in a patient later determined not to have been qualified, how will the insurance carrier respond? Will the insurance carrier pay the costs of defending claims? To ensure coverage for such liabilities, answers to these questions should be obtained and documented before assisting patients under the Oregon Act.

It is advisable to determine in advance whether colleagues and employees, including allied staff, intend to exercise their right not to participate in activities authorized by the Oregon Act. The Oregon Act[4] prohibits a "health care provider" from taking disciplinary or punitive action against any person who refuses to participate.. "Health care provider" includes health care facilities.[5] It is clearly preferable to discuss and resolve the question of participation with other members of the care team before it arises as a result of a patient's request. Such discussions should respect provider privacy. It is important to remember that a person may participate or not on a case-by-case basis, regardless of previous consent to participation (see *Conscientious Practice*).

Responding to a Patient's Request Under the Oregon Act

Whether or not a provider chooses to participate, the patient's request for medication to end life triggers time-sensitive obligations under both the Oregon Act and the common law. On the one hand, a provider has a common law duty not to unreasonably delay treatment or abandon the patient. On the other hand, a prescription may be written under the Oregon Act only after a "waiting period" of at least 15 days.[6] It is important for the attending physician to document the date of the first oral request, respond promptly to the patient's request and document all responses.

Inquiries into the reasons for the patient's request should be made and the patient's responses explored and documented (see *The Meaning Behind a Patient's Request*). The provider should also determine and document the patient's mental state and any needs for more effective symptom management (see *Hospice, Palliative Care, and Comfort Care* and *Mental Health Consultation*).

If the attending physician decides not to participate, he/she promptly needs to provide the patient with a referral or a source of information about participating providers. The Oregon Act describes a legal medical practice, and the attending physician who declines to participate may not abandon the patient.[7] A timely referral to a participating provider or to a resource for information concerning participating providers should minimize claims of abandonment. The referral or the information provided to the patient should be documented.

Providers whose objection to the Oregon Act extends even to the provision of referrals or information must weigh their ethical concerns and the liability risks. At a minimum, however, the provider should not hinder in any way the transfer of care to a participating provider. Records must be transferred to the new attending physician.[8] Comfort care and other needed treatment should be provided in the interim.

Determining the Patient's Qualifications

Determining the patient's qualifications under the Oregon Act is the initial responsibility of the attending physician, and only the attending physician is authorized to dispense or prescribe medication under the Oregon Act.[9] The attending physician is primarily responsible for the patient's terminal care, and assumes responsibility for ensuring compliance with the Oregon Act by all health care providers involved prior to writing a prescription or dispensing medication.[10] When a patient is being treated by more than one physician, it is critical to identify who is the attending physician. The attending physician should document both oral and written communications to the care team, the patient, and the patient's family on this point.

The attending physician's first determination should be whether the patient meets the Oregon Act's nonmedical qualifications; that is, whether the patient is 18 years of age and an Oregon resident.[11] A long-standing physician-patient relationship is the best assurance of these basic qualifications. Regardless, all patients must be asked to "demonstrate" Oregon residency.[12] Oregon residency is not defined by the Oregon Act, but factors demonstrating residency include without limitation: an Oregon driver's license, Oregon voter registration, an Oregon tax return for the most recent tax year, and owning or leasing property in Oregon. Documentation of these and other Oregon connections should be obtained and a copy filed in the medical record.

The attending and consulting physicians must determine the patient's capability.[13] If, in the opinion of either physician, the patient may be suffering from a mental disorder or depression impairing judgment, a referral for an evaluation by a psychiatrist or psychologist is obligatory.[14] All such referrals should be documented. A copy of the psychiatrist's or psychologist's report must be filed in the patient's medical record.[15] The attending physician is responsible for ensuring that the report is filed in the medical record.[16]

The prudent attending physician will make a referral for psychiatric or psychological evaluation. The literature raises doubts about the ability of many physicians to diagnose a mental disorder or depression (see *Mental Health Consultation*).[17] Although the Oregon Act does not mandate referral in all cases, it will be the rare case when a referral is not legally prudent.

The attending physician should strongly consider referring the patient and family to an appropriate hospice program or others in their community who can provide social work and support services. Tending to the emotional needs of family members and to the communication between the care team and the family is helpful in avoiding liability claims (see *Family Needs and Concerns*).

The attending and consulting physicians must determine whether the patient is suffering from a "terminal disease;" *i.e.*, a disease which is "incurable and irreversible," and which will, "within reasonable medical judgment, produce death within six (6) months."[18] The attending and consulting physicians also must determine if the patient is "voluntarily" requesting assistance.[19] Both determinations require the exercise of professional judgment, and that judgment must be rigorously documented. Doubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication. A conservative approach to these decisions will provide greater legal protection.

The attending and consulting physicians should also take care to document an awareness of the patient's broader circumstances and a sensitivity to any indication that the patient's request is coerced or the product of the undue influence of friends, family, or others. Neither age nor disability alone are sufficient to qualify a patient under the Oregon Act.[20]

Timing, Documentation, and Rescission

The Oregon Act requires two oral requests and one written request by the patient before the prescription may be written.[21] The first oral request must be at least 15-days in advance of the prescription.[22] The second oral request must be at least 15-days after the initial oral request.[23] Thus, the shortest time permitted between the patient's initial oral request and the writing of a prescription is 15-days. Both oral requests must be documented in the medical record,[24] and such documentation should include the dates, times, and circumstances of the requests.

The written request must be made at least 48 hours in advance of the prescription.[25] The attending physician is responsible for ensuring that the written request is filed in the medical record,[26] and the date, time, and circumstances of the presentation of the written request should be documented. The written request must be properly witnessed by two persons, neither of whom may be the attending physician.[27] One witness must not be a relative by blood, marriage, or adoption, an heir, or an operator or employee of a health care facility where the person is a patient or resident.[28] If the person making the written request is an inpatient in a health care facility, one of the witnesses must be designated by the facility.[29]

The Oregon Act requires that the patient's written request conform substantially to the form of request set out in the Oregon Act.[30] The form provided in ORS 127.897 should be copied exactly and used without changes (see Appendix A, *The Oregon Death with Dignity Act*).

The Oregon Act appears to contemplate that the patient will not make a written request until after being examined by both the attending and consulting physicians.[31] This assumption is reflected in the form of written request specified by the Oregon Act: "I am suffering from __________, which my attending physician has determined is a terminal disease and which has been medically confirmed by a consulting physician."[32] Thus, the attending physician should obtain the written request only after the consulting physician has confirmed and documented the patient's terminal disease.

If other persons are present when an oral or written request for a prescription under the Oregon Act is made, their presence should be noted in the chart. It is advisable to have a consenting member of the care team otherwise aware of the patient's request for the prescription present at the time of the second oral request.

While the patient must be capable and make a request for a prescription in the specified manner, the patient's mental capability and proper procedure are irrelevant to a rescission of the request.[33]

Thus, the patient may rescind a request for a prescription at any time in any manner regardless of his/her mental state. Any indication that the patient wishes to rescind the request should be explored immediately, the resulting inquiry documented, and doubts resolved in favor of rescission. We also recommend the adoption of a protocol requiring other health care professionals to communicate the rescission immediately to the attending physician if he/she is not present.

The patient should be informed at the outset that a request for a prescription may be rescinded at any time in any manner regardless of the patient's mental state. The provision of this information should be carefully documented along with the information required for an informed decision.

The attending physician must offer the patient the opportunity to rescind at the time of the second oral request. A prescription may not be written otherwise.[34] Moreover, documentation of the opportunity given the patient to rescind is not just good practice, it is required by the Oregon Act.[35] If family members or other persons are present when the opportunity to rescind is offered, then their presence should be documented in the patient's medical record. We also recommend that a consenting member of the care team who is already privy to the patient's request be present when the opportunity to rescind is offered, and that such team member's presence be documented as well.

The Oregon Act requires the attending physician to recommend that the patient notify his or her next of kin of the patient's request for a prescription. (see *Family Needs and Concerns*).[36] The Act does not specify when the attending physician is to make this recommendation, but we suggest that it be done as soon as possible following the first oral request. After recommending that the patient notify his or her next of kin, the physician may not refuse to participate solely because the patient cannot or will not notify them.[37]

The Oregon Act also requires that the attending physician counsel the patient about the importance of having another person present when they take medication authorized by the Oregon Act and of not taking the medication in a public place.[38] The patient's estate is deemed liable under the Oregon Act for the costs incurred by governmental entities as a result of the patient taking medication in a public place, including attorney fees for enforcing such a claim.[39] The attending physician's communication of these facts to the patient should be documented in the medical record. To date, there have been no reports of deaths occurring in a public place.

An "Informed Decision" is More Than "Informed Consent"

Oregon's Informed Consent Law is familiar to providers.[40] It requires the physician to provide a general description to the patient of the nature of the procedure, and information about the risks involved, if any, and the viable alternatives, if any. The physician must also ask the patient if he/she wants a more detailed explanation of the procedure and its material risks and viable alternatives and then, if requested, provide an explanation satisfying the patient's concerns.

For there to be an "informed decision" under the Oregon Act, however, the patient must be fully informed regardless of whether a detailed explanation is requested.[41] The physician is not given the option of providing a general description and then asking the patient if more detail is desired.

The attending physician must provide that detail as a matter of course; without it, there is no "informed decision." Failure to satisfy the Oregon Act's specific "informed decision" requirements will expose the provider to civil liability and, potentially, criminal penalties.[42]

The Oregon Act requires specific information to be conveyed to the patient:

a. His/her medical diagnosis;

b. His/her prognosis;

c. The potential risks associated with taking the medication to be prescribed;

d. The probable result of taking the medication to be prescribed, and the possibility that, although most deaths occur within three hours, death may take longer:[43]

e. The feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.[44]

Like "informed consent," an "informed decision" under the Oregon Act involves the discussion of risks and alternatives. Note, however, that the Oregon Act specifically requires that the alternatives of comfort care, hospice care, and pain control must be discussed,[45] that the patient be informed of his/her diagnosis and prognosis, "the probable result" of taking the medication,[46] and the possibility that, "although most deaths occur within three hours, [the patient's] death may take longer."[47]

Documentation of an "informed decision" is required by the Oregon Act and is ultimately the responsibility of the attending physician.[48] Both the attending and consulting physician must document the communication of this information to the patient.[49] Informed consent is typically documented in the medical record with the notation "PARQ," for "Procedure, Alternatives, Risks, and Questions." An "informed decision" under the Oregon Act involves the communication of more information than is reflected by the notation "PARQ," and requires no less than a detailed discussion of all elements of the patient's "informed decision." The "PARQ" notation therefore will not document compliance with the Oregon Act. Compliance with "informed decision" requirements should be documented in considerably more detail; *i.e.*, Diagnosis, Prognosis, Risks, Results, and Alternatives (including comfort care, hospice care, and pain control). We also recommend that the patient be informed at the same time of the right to rescind a request for medication at any time for any reason, and that the provision of this information be documented. The presence of another member of the care team during the "informed decision" discussion is also recommended, and should be documented.

Immediately prior to writing the prescription, the attending physician must confirm that the patient is making an informed decision. Verification of the patient's "informed decision" immediately prior to dispensing medication or writing the prescription is both good practice and required by the Oregon Act.[50] The attending physician should provide and document the same information initially discussed with the patient.

Although not required by the Oregon Act, we recommend that as a part of the informed decision process the attending physician encourage the patient to execute an advance directive. An advance directive may be used to appoint a health care representative authorized to make end-of-life decisions for an unconscious or incapable patient, including the withdrawal of life support and tube feeding. The patient may also express his/her wishes directly with regard to these and other treatment decisions. If a patient takes medication prescribed under the Oregon Act but does not die, then the express directions of the patient or an authorized surrogate will serve to better effectuate the patient's wishes and to maximize the provider's legal protection (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*). The attending physician should document his/her recommendation to the patient regarding the execution of an advance directive. The attending physician also should inform the patient and family that if he/she is not in attendance at the time of death, or called immediately thereafter, or if emergency medical personnel are called to the scene, the death is likely to be investigated by the Medical Examiner. The attending physician should document the provision of this information.

Referrals and Consultations

The attending physician must refer the patient to a consulting physician who is qualified by specialty or experience to make a diagnosis and prognosis of the patient's terminal illness.[51] Judgments by the attending physician as to what experience qualifies a non-specialist to render such diagnosis and prognosis may be called into question. Geography and the availability of physicians willing to consult for purposes of the Oregon Act may make referrals to a consulting physician difficult and to a specialist impractical, particularly in rural areas. Nonetheless, involvement of a consulting physician is required under the Oregon Act. When possible, we recommend the use of a specialist as the surest means of establishing the qualifications of the consulting physician.

Even the appearance of financial conflicts of interest should be avoided. Referrals of managed care patients to other members of a physician's medical group or independent practice association (IPA), particularly in the case of capitated care, may give rise to accusations of financial self-interest in confirmations of terminal illness. Again, while referrals outside the physician's group may be impractical in some areas of the state, in-group referrals should be avoided when possible.

The Oregon Act's definition of "medically confirmed" makes clear that the consulting physician must review relevant medical records in confirming the patient's diagnosis and prognosis.[52] Arrangements for access to the patient's records should be made in advance of examination of the patient. The consulting physician should document the review of records as well as the patient's examination.

The Oregon Act requires the consulting physician to confirm in writing the attending physician's diagnosis and prognosis and verify the patient's capability, volition, and informed decision. Charting the results of the examination may not meet the consulting physician's obligations under the Oregon Act.[53] Separate written confirmation should be supplied to the attending physician. Such verification must be made a part of the patient's medical record.[54] The consulting physician's only sure means of verifying an "informed decision" is to provide the same information as the attending physician.[55] It is recommended that the consulting physician document the provision of the information necessary for an informed decision.

If the attending physician has not referred the patient for a psychiatric or psychological evaluation, then the consulting physician should strongly consider obtaining an evaluation of the patient's capability and the voluntariness of the request.

Dispensing or Prescribing Medication

The attending physician may provide medication under the Oregon Act in one of two ways: by dispensing directly to the patient or by writing a prescription.[56] Different procedures must be followed in each case.

An attending physician may dispense controlled substances directly to the patient only if registered as a dispensing physician with the Oregon Medical Board and certified by the Drug Enforcement Administration.[57] The patient's name, the kind and amount of medication dispensed, and the date it was dispensed must be entered in the controlled substance inventory log required by Oregon statute[58] and Oregon Medical Board rule.[59] The medication must be provided to the patient in a container complying with federal packaging requirements, unless a non-compliant container is requested by the patient, and labeled with the patient's name, the name and address of the attending physician, the date dispensed, the name of the drug, the quantity of drug per unit, directions for use, cautionary statements required by law, if any, and an expiration date.[60] A copy of the label or equivalent information, plus the dispensing physician's phone number and the total amount of medication dispensed, must be filed with the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR, 97232.[61]

Alternatively, an attending physician may write a prescription for medication under the Oregon Act.[62] Such prescription may be written, however, only if the patient consents in writing to the attending physician contacting a pharmacist and informing the pharmacist of the purpose of the prescription.[63] Further, the attending physician must deliver the prescription to the pharmacist personally or by mail.[64] The pharmacist may then dispense the medication to the patient, the attending physician, or an expressly identified agent of the patient, who may be the attending physician.[65] We recommend that, if an agent of the patient is to pick up the prescription, the attending physician identify such agent in writing for the pharmacist.

Three documents must be filed with the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR, 97232 at the time a prescription is written: the "Attending Physician Report and Medical Record Documentation," a copy of the patient's written request for medication under the Oregon Act, and a copy of the consulting physician's report (see Appendix B, *Oregon Department of Human Services Reporting Documents*).[66] In lieu of completing the Department of Human Services' reporting form, the attending physician may check a box at the beginning of the form indicating that relevant medical records will be made available for review by the Department of Human Services.[67] The patient's written authorization for such review should be obtained before the attending physician indicates that the patient's medical records will be made available.

Conscientious Practice

The Oregon Act makes clear that a health care provider may not be required under contract or otherwise to participate in activities authorized by the Oregon Act.[68] In order to avoid unknowing participation, the Oregon Act requires that, with the patient's written consent, the attending physician notify the pharmacist of the purpose of a prescription written pursuant to the Oregon Act.[69]

The Oregon Act also prohibits a health care provider from disciplining or penalizing "a person" who participates or refuses to participate.[70] Use of the term "person" indicates that this provision is intended to protect laypersons as well as health care providers. Although the Oregon Act does not expressly mention employees or applicants for employment, it is likely they also are protected by the Oregon Act.

Health care facilities and providers, particularly those in the public sector, must be aware of constitutional and statutory restrictions on employment policies. Given potential political or religious objections to the Oregon Act, employment criteria which penalize protected classes or speech on this basis may give rise to civil rights liabilities. Providers should consult with counsel before making preemployment inquiries or adverse employment decisions on the basis of employee views on the Oregon Act. Employers should make reasonable accommodations to the religious or sincerely held moral beliefs of employees. The substantial legal expense of defending a civil rights claim is often uninsurable.

Confidentiality and Privacy

Neither the Oregon Act nor any other Oregon statute makes special provision for the confidentiality of requests for medication under the Oregon Act. However, physician-patient communications, including those concerning the Oregon Act, are confidential under state law and federal administrative rules governing patient privacy.[71] While state and federal law generally permit the communication of patient information between providers for treatment purposes,[72] the best practice under the Oregon Act is to seek the patient's consent to disclosure of his/her request for medication before that information is provided to anyone, save for the information necessarily provided to the consulting physician under the Oregon Act. If the attending physician discloses patient information to persons outside the care team without the patient's consent, then he/she may be exposed to civil liability for invasion of the patient's privacy and breach of confidentiality.[73] Ethical considerations may require the attending physician to obtain patient consent.

Seeking the patient's consent to disclose information to other members of the care team is also important for quality care. Providers not informed of the patient's request may complicate or interfere with a qualified patient's wishes. The prudent attending physician will document efforts to seek the patient's consent and the patient's response.

The Oregon Act creates no legal obligation or privilege to inform others of the patient's request. If the patient refuses to consent to information-sharing with other providers, or requests nondisclosure, then the attending physician should accede to the patient's wishes and must document any restriction to which he/she has agreed.[74] The attending physician may still disclose the patient's request for medication to persons supervised, directly or indirectly, by the attending physician.[75] While the patient's right to privacy and confidentiality may conflict with the right of other providers to "opt out" of participation,[50] the attending physician's primary legal duty is to the patient. The attending physician's ethical duties to other providers are discussed in Chapter 8, *The Role of Other Health Care Professionals*.

Employees may have privacy interests in information regarding their participation in activities authorized by the Oregon Act. Such information is unquestionably sensitive and should not be disclosed to third parties without the employee's consent. Providers should take reasonable precautions to prevent the inadvertent disclosure of information concerning employee participation.

Contracts and Credentials

While the general rule is that health care providers may not be penalized for participating, or refusing to participate, in activity authorized by the Oregon Act, a health care provider may prohibit other health care providers from participation on its premises or within the course and scope of an employment or contract relationship. A "health care provider" includes pharmacists and "health care facilities."[76] Hospitals and long-term care facilities are generally thought to be included in the term "health care facility."[77]

"Participation" means acting as an attending or consulting physician or a psychiatric or psychological consultant.[78] However, providing information about the Oregon Act at the request of a patient or referring a patient to a physician willing to provide assistance under the Oregon Act is not considered "participation" which may be prohibited or sanctioned.[79]

The activities of pharmacists and health care facilities are not included within the definition of "participation" in ORS 127.800 to 127.897. It appears therefore that these two categories of health care providers are not subject to prohibitions against participation and may not be sanctioned for doing so. Nonetheless, the Task Force strongly endorses respect for the values of health care providers objecting to participation on their premises or by employees or contractors acting within the course and scope of their employment or engagement.

A health care provider can enforce a policy against participation only if it has provided advance notice of its policy in a separate written statement.[80] Providers accused of violating such a policy must be afforded whatever "due process" would otherwise be available to them before sanctions may be imposed.[81]

Potential sanctions vary with the context: Medical staff privileges or membership may be terminated for participation on the prohibiting provider's premises.[82] However, participation occurring solely within a physician's or other provider's private medical office may not be grounds for discipline, even if on the premises of the prohibiting provider.[83] Moreover, medical staff discipline under the Oregon Act is not reportable to the Oregon Medical Board and violation of facility policy on this point may not be the sole grounds for a report of unprofessional or dishonorable conduct to the Board.[84] A prohibiting provider may terminate leases and other property arrangements to sanction prohibited activity on its premises.[85] Contracts with employees and independent contractors may be terminated for participation on or off a prohibiting provider's premises if that participation occurs within the course and scope of the participant's employment or engagement.[86] However, employees and independent contractors may not be sanctioned for participation outside the course and scope of their employment or engagement.[87]

The enforceability and interpretation of certain contract provisions may be complicated or called into question by the Oregon Act. If a health care provider is in doubt about contractual obligations and rights with respect to the Oregon Act, then competent legal advice should be sought.

Contracts with health care plans or other providers often contain a promise to indemnify the other party. As a general rule, however, malpractice insurance does not cover indemnity for professional liabilities other than those arising from the professional's own fault. Providers should not agree to indemnify health plans or other providers for damages relating to conduct under the Oregon Act without first confirming insurance coverage of such liabilities by their malpractice carrier. Consultation with an attorney or malpractice insurance carrier is advised to determine if such liabilities will be covered. The attending physician should document both inquiries and responses on this issue.

A provider may not lawfully obtain a release of liability from a patient for care which falls below the standard of care or which is intentionally injurious. Such a release is void as against public policy. Providers may not condition participation under the Oregon Act on the patient providing a release from liability. Serious licensure and ethical violations may also arise from an attempt to obtain such a release.

Civil and Criminal Immunities

Providers enjoy civil and criminal immunity for conduct undertaken in "good faith compliance" with the Oregon Act.[88] It is unclear what "good faith" means in this context, or whether compliance deemed not in good faith is insufficient for immunity. In any event, scrupulous attention should be paid to the procedures and documentation demanded by the Oregon Act. Variation from the Oregon Act's requirements, no matter how well intentioned, may result in the loss of immunity and the possibility of review by the Oregon Medical Board.

The Oregon Act grants civil and criminal immunity only for conduct authorized by the Oregon Act.[89] As with any other medical service, "good faith" will not immunize the provider against civil liability for negligence in the delivery of patient care, including that authorized by the Oregon Act, or shield the provider from criminal penalties for intentional wrongdoing. The standard of care for patients receiving assistance under the Oregon Act is no lower than that applicable to any other patient.[90]

The Oregon Act makes it a Class A felony to exert "undue influence" on the patient to request medication or to revoke a rescission of such a request.[91] The term "undue influence" is not defined in the Oregon Act. "Undue influence" in other areas of law defies precise definition, with the courts using a case-by-case approach that takes into account the totality of circumstances. This lack of guidance is particularly troubling given the arguable duty of physicians under the Informed Consent statute to apprise terminally ill patients of the option legally available under the Oregon Act when discussing alternative courses of treatment or palliative care.[92] Thus, while the possibility of criminal prosecution argues forcefully for avoiding any basis upon which a charge of undue influence might be brought, including providing information regarding the Oregon Act, the failure to discuss this legally available alternative may create malpractice exposure. While there is risk in either course of action we recommend that discussions concerning the Oregon Act be initiated by patients.

Guidelines

15.1 The Task Force recommends contacting the administrator of the practice group or health plan to determine what legal or other resources are available in evaluating the decision to participate in conduct authorized by the Oregon Act.

15.2 A health care provider needs to review contracts, policies, and bylaws of the groups and organizations with which he/she is currently affiliated.

15.3 Groups, clinics, or insurance representatives should consult in advance and in writing with their malpractice insurance carriers to determine if they will confirm in writing that coverage for damages and the costs of a defense in a suit arising from the Oregon Act are available.

15.4 It is advisable to determine in advance whether colleagues and employees, including allied staff, intend to exercise their right not to participate.

15.5 Whether or not a health care provider chooses to participate, it is important to document the date and circumstances of patient requests for assistance under the Oregon Act and the provider's inquiry into the reasons for the request. The attending physician needs to respond promptly to the patient's request and document his/her response.

15.6 The attending physician who declines to participate in the provision of a prescription under the Oregon Act should promptly provide the patient with a referral or a source of information about participating providers and document the referral or resource provided.

15.7 The Task Force recommends that health care providers establish and document early on who is the "attending physician;" *i.e.*, the physician primarily responsible for the care of the patient and treatment of the patient's terminal disease. The attending physician is the only physician who may dispense or prescribe medication under the Oregon Act, and is responsible for ensuring compliance with the Oregon Act's requirements by the other health care providers involved.

15.8 An attending physician needs to determine first whether the patient is 18 years of age and an Oregon resident. Documentary proof of residency, such as an Oregon's driver's license, voter registration, recent tax return, or records of property interests in Oregon, should be obtained from the patient and copies filed in the medical record.

15.9 The Task Force recommends mental health consultation for any person desiring a prescription under the Oregon Act. Mental health counseling is especially recommended for patients who are not enrolled in hospice. (A psychosocial evaluation by a social worker is standard practice for patients enrolled in hospice).

15.10 Doubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication.

15.11 The shortest time permitted between the patient's initial oral request and the writing of a prescription is 15 days.

15.12 The statutory form, without changes, should be used for the written request. The statutory form specifies the qualifications of witnesses.

15.13 The written request for a prescription under the Oregon Act must be made at least 48 hours in advance of the prescription. The written request should be made only after the consulting physician has examined the patient and provided medical confirmation of the patient's prognosis, capability, and informed decision.

15.14 Medication may be dispensed directly by the attending physician to the patient only if the physician is registered as a dispensing physician with the Oregon Medical Board and the Drug Enforcement Administration. The medication must be properly recorded in the attending physician's controlled substances log and provided in a container properly labeled and, unless otherwise requested by the patient, compliant with federal container requirements. When the medication is dispensed, the attending physician must supply the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR 97232, with a copy of the log order and the physician's phone number and the total amount of medication dispensed.

15.14a A prescription for medication may be written by the attending physician in lieu of direct dispensing. However, the patient's written consent to disclose the purpose of the prescription to the pharmacist must first be obtained. After obtaining the patient's written consent, the physician must notify the pharmacist of the intended purpose of the prescription and deliver the prescription personally or by mail. The medication may be dispensed by the pharmacist to the attending physician, the patient, or a specified agent of the patient. If the medication is to be dispensed to a specified agent of the patient, then such agent should be identified by the physician to the pharmacist in writing.

15.15 When medication is either dispensed or prescribed, the attending physician must file the "Attending Physician Report and Medical Record Documentation" and a copy of the patient's written request for assistance under the Oregon Act. These are filed with the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR 97232. See the Oregon Department of Human Services website for *examples of the forms*.

15.16 In lieu of completing the Oregon Department of Human Service's reporting form, the attending physician may check a box at the beginning of the form indicating that relevant medical records will be made available for review by the Oregon Department of Human Service.

15.17 The presence of other persons at the time oral or written requests are made should be documented.

15.18 The patient may rescind a request for a prescription at any time in any manner regardless of his/her mental state. A protocol should be established by the health care provider for immediately reporting a rescission to the attending physician.

15.19 The attending physician should inform the patient of his/her right to rescind the request at the same time information is provided for the patient's informed decision. It is important to document this communication.

15.20 The attending physician must offer the patient the opportunity to rescind at the time of the second oral request. The offer to rescind and the patient's response must be carefully documented. The presence of other persons at the time the offer to rescind is made is recommended and should be documented.

15.21 The attending physician must recommend that the patient notify the patient's next of kin of the request, but the attending physician may not deny assistance under the Oregon Act on the basis of the patient's refusal or inability to notify next of kin. The attending physician should document the recommendation to the patient.

15.22 An "informed decision" by the patient requires that the patient be fully informed of the specified information regardless of whether a detailed explanation is requested.

15.23 The Oregon Act requires specific information to be conveyed to the patient:

a. His/her medical diagnosis;

b. His/her prognosis;

c. The potential risks associated with taking the medication to be prescribed;

d. The probable result of taking the medication to be prescribed, and the possibility that, although most deaths occur within three hours, death may take longer;

e. The feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.

15.24 The standard "Procedures, Alternatives, Risks, and Questions" (PARQ) chart notation is insufficient to document an "informed decision" under the Oregon Act. The provision of information concerning Diagnosis, Prognosis, Risks, Results, and Alternatives (including comfort care, hospice care and pain control) should be documented.

15.25 Immediately prior to writing the prescription or dispensing medication, the attending physician must verify that the patient is making an informed decision.

15.26 We recommend that the attending physician encourage the patient to execute an advance directive and document this advice in the chart.

15.27 The patient and family should be informed that if the attending physician is not in attendance at the time of death or called immediately thereafter, or if emergency medical services personnel are called in, the death may be investigated by the Medical Examiner. The attending physician should document the provision of this information.

15.27a The patient must be counseled on the importance of having another person present when the patient takes the medication, and of not taking the medication in a public place.

15.28 When possible, the attending physician should refer to consulting physicians who are specialists in the area called for by the patient's terminal disease, and avoid referrals of managed care patients to physicians with whom he/she has a financial relationship.

15.29 The consulting physician should document not only the examination of the patient but the examination of the patient's medical records, confirm in writing the patient's diagnosis and prognosis, and verify the patient's capability, volition, and informed decision.

15.30 If it has not already been done, the prudent consulting physician will refer the patient to a psychiatrist or psychologist to obtain confirmation of the patient's capability and the voluntariness of the request.

15.31 The consulting physician should provide the information necessary to the patient's informed decision.

15.32 The attending physician should obtain the patient's authorization to share relevant information regarding the patient's request for medication with other providers with a need to know. The request for authorization to disclose, and the patient's response, should be documented.

15.33 If the patient refuses to authorize information-sharing with other providers, or requests nondisclosure, then the attending physician should not disclose the patient's request for medication to anyone not supervised, directly or indirectly, by the attending physician. If medication is provided by means of a prescription, however, then the attending physician must obtain the patient's written consent to disclose to the dispensing pharmacist.

15.34 Health care providers may not discipline current or prospective employees for participating or not participating in conduct authorized by the Oregon Act and should protect information concerning employee participation.

15.35 Providers should consult with counsel before making preemployment inquiries or adverse employment decisions on the basis of employee views on the Oregon Act and make a reasonable effort to accommodate the religious or conscientious objections of employees to participation.

15.36 Medical staff privileges and membership may be suspended, revoked, or otherwise limited on the basis of participation on the premises of a health care facility that has provided adequate advance notice of its policy forbidding such participation. Medical staff discipline may not be imposed, however, for participation limited to a physician's or other provider's private medical office.

15.37 Provider agreements may not require participation in activities authorized by the Oregon Act.

15.38 Providers should not agree to indemnify health plans or other providers for damages relating to the Oregon Act without first confirming insurance coverage of such liabilities by their malpractice carrier.

15.39 Providers may not condition participation on the patient providing a release from liability.

15.40 Civil and criminal immunity requires adherence to the procedures and documentation prescribed by the Oregon Act. However, good faith compliance with the Oregon Act will not immunize providers from liability for professional negligence or intentional misconduct. The standard of care for treatment of patients under the Oregon Act is no lower than that required for treatment of other patients.

15.41 Avoid exerting any influence over the patient's decision to request medication or to revoke a rescission of such a request. Discussions concerning the Oregon Act should be initiated by patients.

References

1. ORS 127.800 - 127.897. The Oregon Death with Dignity Act is linked in *Appendix A*.

2. ORS 127.880, § 3.14.

3. See ORS 127.855, § 3.09, regarding mandatory documentation in the medical record.

4. ORS 127.885(2), § 4.01(2).

5. See ORS 127.800(6), § 1.01(6).

6. ORS 127.850, § 3.08.

7. ORS 127.885(7), § 4.01(7); ORS 127.890(3), § 4.01(3).

8. See ORS 127.885(4), § 4.01(4).

9. This conclusion is fairly implied by numerous provisions of the Oregon Act, e.g., ORS 127.815(1)(i) and (k), § 3.0l(1)(i) and (k); ORS 127.885(7), § 4.01(7); ORS 127.897, § 6.01.

10. ORS 127.815(1)(k), § 3.01(1)(k); 127.855(7), § 3.09(7). The Oregon Act actually refers only to the writing of a prescription; dispensing is not expressly mentioned. A fair reading of the Oregon Act suggests the attending physician's oversight responsibilities must be attested to prior either to dispensing or prescribing medication.

11. ORS 127.805(1), § 2.01(1).

12. ORS 127.815(l)(b), § 3.01(l)(b).

13. ORS 127.815(1)(a), § 3.01(l)(a); ORS 127.820, § 3.02.

14. ORS 127.825, § 3.03.

15. ORS 127.855(5), § 3.09(5).

16. ORS 127.815(1)(j), § 3.01(1)(j).

17. Lee ML, Nelson HD, Tilden VP, et al. Legalizing assisted suicide: views of physicians in Oregon. N Engl J Med. 1996;334:310-315.

18. ORS 127.815(1)(a), § 3.01(1)(a); ORS 127.800(12), § 1.01(12).

19. ORS 127.815(l)(a) and (d), § 3.01(1)(a) and (d); ORS 127.820, § 3.02.

20. ORS 127.805(2), § 2.01(2).

21. ORS 127.840, § 3.06.

22. ORS 127.850, § 3.08.

23. ORS 127.840, § 3.06.

24. ORS 127.855(l), § 3.09(l).

25. ORS 127.850, § 3.08.

26. ORS 127.815(1)(j), § 3.01(1)(j); ORS 127.855(2), 3.09(2).

27. ORS 127.897, § 6.01.

28. *Id.*

29. *Id.*

30. *Id.*

31. ORS 127.805(1), § 2.01(1).

32. ORS 127.897, § 6.01

33. ORS 127.845, § 3.07.

34. ORS 127.845, § 3.07.

35. ORS 127.855(6), § 3.09(6).

36. ORS 127.835, § 3.05.

37. *Id.*

38. ORS 127.815(1)(g), § 3.01(1)(g).

39. ORS 127.892.

40. ORS 677.097.

41. ORS 127.815(1)(c), § 3.01(1)(c).

42. ORS 127.885(1), § 4.01(l).

43. ORS 127.897, § 4.01.

44. ORS 127.815(1)(c), § 3.01(1)(c).

45. ORS 127.815(1)(c)(E), § 3.01(1)(c)(E).

46. ORS 127.815(1)(c)(A) and (D), § 3.01(1)(c)(A) and (D).

47. ORS 127.897, § 6.01.

48. ORS 127.815(1)(j) and (k), § 3.01(1)(j) and (k).

49. ORS 127.855(3) and (4), § 3.09(3) and (4).

50. ORS 127.815(1)(i), § 3.01(1)(i).

51. ORS 127.800(4), § 1.01(4); ORS 127.820, § 3.02.

52. ORS 127.800(8), § 1.01(8).

53. See ORS 127.820, § 3.02.

54. ORS 127.855(4), § 3.09(4).

55. ORS 127.815(1)(c), § 3.01(1)(c).

56. ORS 127.815(1)(L), § 3.01(1)(L).

57. ORS 127.815(1)(L)(A), § 3.01(1)(L)(A).

58. ORS 677.089.

59. OAR 847-015-0015.

60. ORS 677.089.

61. OAR 333-009-0010(2).

62. ORS 127.815(1)(L)(B), § 3.01(1)(L)(A).

63. ORS 127.815(1)(L)(B)(i), § 3.01(1)(L)(B)(i).

64. ORS 127.815(1)(L)(B)(ii), § 3.01(1)(L)(B)(ii).

65. *Id.*

66. OAR 333-009-0010(1)(a).

67. *Id.*

68. ORS 127.885(4), § 4.01(4).

69. ORS 127.815(1)(L)(B)(i); § 3.01(1)(L)(B)(i).

70. ORS 127.885(2), § 4.01(2).

71. 45 CFR. Parts 160, 162, and 164, implementing the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

72. 45 CFR § 164.506(a). The HIPAA rules also permit the provider to obtain consent for disclosures related to treatment. 45 CFR § 164.506(b).

73. 45 USC §§ 1320d-5 and 1320d-6.

74. 45 CFR § 164.530(j).

75. 45 CFR § 164.522(a)(B)(iii).

76. ORS 127.885(2), § 4.01(2).

77. ORS 127.800(6), § 1.01(6).

78. ORS 442.015(14).

79. ORS 127.885(5)(d)(B), § 4.01(5)(d)(B).

80. ORS 127.885(5)(d)(B)(ii) and (iii), § 4.01(5)(d)(B)(ii) and (iii).

81. ORS 127.885(5)(a), § 4.01(5)(a); ORS 127.885(5)(d)(A), § 4.01(5)(d)(A).

82. ORS 127.885(5)(c), § 4.01(5)(c).

83. ORS 127.885(5)(b)(A), § 4.01(5)(b)(A).

84. *Id.*

85. ORS 127.885(6), § 4.01(6).

86. ORS 127.885(5)(b)(B), § 4.01(5)(b)(B).

87. ORS 127.885(5)(b)(C), § 4.01(5)(b)(C).

88. ORS 127.885(5)(d)(B)(iv), § 4.01(5)(d)(B)(iv).

89. ORS 127.885(l), § 4.01(1); ORS 127.885(3), § 4.01(3).

90. ORS 127.885(l), § 4.01(1); ORS 127.890(3) and (4), § 4.02(3) and (4).

91. ORS 127.885(7), § 4.01(7).

92. ORS 127.890(2), § 4.02(2). Class A felonies carry a maximum penalty of 20 years imprisonment and/or $300,000 fine. ORS 161.605(l); 161.625(l)(a).

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

Appendix A. The Oregon Death with Dignity Act

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The State of Oregon provides for an initiative process through which laws may be adopted by a vote of the people. Oregon voters approved such an initiative, Measure 16, on November 8, 1994, and thereby enacted the Oregon "Death with Dignity Act." The statewide vote was 51% in favor and 49% opposed.

Implementation of the Oregon Act was enjoined on December 7, 1994, one day before the Oregon Act's effective date, by order of U.S. District Judge Michael Hogan. On August 3, 1995, Judge Hogan permanently enjoined implementation of the Oregon Act, finding that it violated the Equal Protection Clause of the U.S. Constitution. Lee v. State of Oregon, 819 F Supp 1429 (D Or 1995). The permanent injunction was appealed to the Ninth Circuit Court of Appeals, which ordered the injunction lifted, deciding that the plaintiffs lacked standing to challenge Oregon's law. Lee v. State of Oregon, 107 F3d 1382 (9th Cir. 1997). The plaintiffs' petition for review to the United States Supreme Court was denied on October 14, 1997.

On March 7, 1996, the Ninth Circuit issued an 8-3 decision in another case challenging a Washington State statute criminalizing conduct authorized by the Oregon Act. Compassion in Dying v. State of Washington, 79 F3d 790 (9th cir 1996). The Ninth Circuit overturned the Washington criminal statute and found a constitutional right to such conduct in the Due Process Clause of the U.S. Constitution. The court's opinion took the unusual step of criticizing Judge Hogan's decision, the subject of an entirely separate appeal, and expressly approved the safeguards contained in the Oregon Act.

On April 2, 1996, the federal Second Circuit Court of Appeals held that a New York criminal statute nearly identical to Washington State law was unconstitutional as applied to a terminally ill, competent adult in the final stages of illness. Quill v. Vacco, 80 F3d 716 (2d Cir. 1996). Unlike the Ninth Circuit in Compassion in Dying, the Quill court found no due process interest in conduct authorized by the Oregon Act. Instead, the Second Circuit concluded that New York's laws denied equal protection of the law to competent, terminally ill persons. The court found the law's distinction between the right to refuse or to withdraw life-sustaining treatment and the assistance of a physician to be irrational. Moreover, the court found no legitimate state interest in preserving life in the final stages of a terminal illness.

On June 26, 1997, the U.S. Supreme Court overturned both the Second and Ninth Circuit decisions: Washington v. Glucksberg, No. 96-110, and Vacco v. Quill, No. 95-1858. Glucksberg held that there is no constitutional right to conduct authorized by the Oregon Act under the Due Process Clause. The Court emphasized the limits of patient autonomy and rejected arguments for a constitutional interest in all decisions implicating intimate or deeply personal concerns. Quill held that competent, terminally ill patients are not denied equal protection of the law when physician assistance is prohibited by state law but the withdrawal or refusal of life-sustaining treatment is permitted. The Court endorsed professional and legal distinctions between "physician-assisted suicide" and withdrawal of life support or the "double effect" of aggressive palliative care. Although these cases addressed state laws criminalizing conduct authorized by the Oregon Act, the general approach of the court suggests that it will view state laws such as Oregon's Act, as presenting primarily political, rather than constitutional, issues.

The 1997 Oregon Legislature enacted HB 2954, which referred repeal of the Oregon Act to Oregon voters. The repeal effort was defeated on November 4, 1997, by a 60% to 40% margin.

The 1999 Oregon Legislature enacted SB 491, which amended the Oregon Act effective June 30, 1999. Among other changes, the 1999 amendments:

> a. strengthened the ability of health care facilities to prohibit conduct authorized by the Oregon Act on their premises, while also providing that loss of medical staff privileges or membership for violating such prohibition was not reportable to the Oregon Medical Board;
>
> b. required that physicians either dispense medication under the Oregon Act themselves, if properly registered as a dispensing physician with the Oregon Medical Board, or obtain the patient's written consent to inform the pharmacist of the purpose of the medication and deliver the prescription personally or by mail to the pharmacist;
>
> c. clarified the definitions of residency and medical decision-making capability; and
>
> d. authorized a claim by governmental entities against a deceased's estate for costs resulting from a person hastening death under the Oregon Act in a public place.

On November 6, 2001, U.S. Attorney General John Ashcroft issued an opinion that, if allowed to take effect, would have prohibited the use of controlled substances under the Oregon Death with Dignity Act. Attorney General Ashcroft's opinion interpreted the Controlled Substances Act to the effect that controlled substances could not be used with the intent of hastening death. The Task Force's concern was that the Attorney General's ruling may have had unintended consequences resulting in the under-treatment of pain.

In a statewide survey, some Oregon physicians reported that physicians often under-prescribe pain control medication for those who are dying. One of the reasons reported for this under-prescribing is fear of investigation by the Drug Enforcement Administration (DEA). Under the Attorney General's ruling position, the DEA could have investigated physicians who prescribed controlled substances under the Oregon Act.

On April 17, 2002, U.S. District Judge Robert Jones issued a permanent injunction against Attorney General Ashcroft's order, leaving legal practices under the Oregon Act (with controlled substances) in place. The U.S. Department of Justice immediately appealed from Judge Jones' order to the Ninth Circuit Court of Appeals.

On May 26, 2004, the Ninth Circuit Court of Appeals upheld the injunction granted by the District court. The Ninth Circuit held that the Attorney General's interpretation of the Controlled Substances Act of 1970 (CSA) impermissibly interfered with the state regulation of medical practice, contradicted the plain language of the CSA, and exceeded the authority granted to the Attorney General. Significantly, the Ninth Circuit held that the Attorney General's interpretation of the CSA was not entitled to deference for the reason that it conflicted with patent Congressional intent. The Ninth Circuit denied the Attorney General's request for rehearing on August 11, 2004.

The U.S. Supreme Court accepted review of the Ninth Circuit's decision on February 22, 2005, and heard oral argument on October 5, 2005. On January 17, 2006, the Court affirmed the Ninth Circuit's decision, concluding that the Attorney General had exceeded his authority in interpreting the federal Controlled Substances Act. By a 6 to 3 majority (Chief Justice Roberts and Justices Scalia and Thomas dissenting), the Court held that the Attorney General's interpretive authority did not extend to the criminalization of conduct authorized by state law. The Court further held that the Attorney General's interpretation of the statutory phrases "legitimate medical purpose" and "public interest" was not entitled to deference by the Court given the Attorney General's limited role under the Controlled Substances Act.

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Appendix B. Oregon Department of Human Services Reporting Documents

Written February 1998; Revised: October 2004; Reviewed March 2005, September 2007, December 2008

This Appendix provides links to the following information and documents:

1. *Forms* including:

    Patient Request Form
    Attending Physician Form
    Attending Physician Short Form
    Consulting Physician Form
    Psychiatrist/Psychologist Form
    Pharmacy Dispensing Record Form
    Reporting Physician Interview Form
    Chronology and Death Certificate Extract Form

2. *Legislation*

3. *Rules*

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Appendix C. Advance Directives and Physician Orders for Life-Sustaining Treatment

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

This appendix discusses Oregon's advance directive document and the Physician Orders for Life-Sustaining Treatment (POLST) document, which can be useful in clarifying and documenting treatment preferences for patients who are in their final months of life. These documents allow limits on life-sustaining treatment to be recorded, but do not speak directly to the Oregon Death with Dignity Act. Brief background information regarding these two instruments is described to help the health care professional in this important aspect of end-of-life care.

Advance Directive

The Oregon legislature adopted a revised advance directive law in 1993 [ORS 127.505-127.660]. The purpose of this document is to provide capable adult residents of Oregon a means to make known their preferences for life-sustaining treatments, including artificial fluids and nutrition. These preferences are elicited in the event of specific clinical conditions common at the end of life, including "close to death, permanently unconscious, advanced progressive illness, and extraordinary suffering." In addition, Oregonians can appoint a family member or friend to serve as their health care representative and to act as their agent in making health care decisions if they become incapable due to illness later. These decisions are based on the values of the individual who appoints the agent. An alternate health care representative can be appointed also in the event that the health care representative is unable to participate in the decision-making process. The health care professional who stimulates discussions regarding advance directives and the possibility of future impairment begins a process of communication with the patient and family members. These discussions can be of great benefit when considerations about the wise use of life-sustaining treatment occur in the future.

Despite the utility of written advance directives in clinical decisions, the availability of this helpful tool is frequently unknown and underutilized by patients and their families. The Task Force encourages health care professionals to stimulate advance planning for health care decisions.

For patients who have not appointed a health care representative, Oregon's advance directive statute defines the first of the following who can act as the representative: a guardian of the principal who is authorized to make health care decisions; the principal's spouse or domestic partner; an adult designated by the others on this list who can be located, if no person in this list objects to the designation; a majority of the adult children of the principal who can be located; either parent of the principal; a majority of the adult siblings of the principal who can be located with reasonable effort; any adult relative or adult friend.

Physician Orders for Life-Sustaining Treatment (POLST) and the National POLST Paradigm Initiative

In Oregon, Physician Orders for Life-Sustaining Treatment (POLST) are physician orders that are portable across different care settings. These orders are useful in common situations that most health care professionals encounter.

Have you ever cared for a patient whose wishes to limit life-sustaining treatment were not well documented on transfer? Here is a typical example we hear from colleagues:

A 78-year-old woman with advanced Alzheimer's disease was sent from a nursing home to the hospital with dehydration and respiratory distress. She has not recognized family members for over a year and is having some trouble swallowing. She had a do-not-resuscitate (DNR) order in the nursing home and her family and health care professionals had agreed to respect her prior wishes to focus on comfort and to forego tube feedings and other measures to extend her life. The family was most distraught to find the patient in the intensive care unit (ICU) intubated, restrained, and receiving tube feedings.

In addition to family concerns, emergency medical technicians (EMTs) have also been frustrated, feeling compelled to resuscitate hospice patients with end-stage AIDS or metastatic cancer who arrested during transport from home. Although these patients had DNR orders within their hospice programs, emergency personnel protocols precluded following these orders once the patient was under the care of emergency medical services (EMS).

To solve problems like these, the Center for Ethics in Health Care at Oregon Health and Science University in 1991 convened a multidisciplinary task force of 40 individuals representing such organizations as the Oregon Medical Association (OMA), statewide EMS, hospice, long-term care, and Senior and Disabled Services. In 1995, after four years of development and pilot testing, a document to record medical orders about patient wishes to limit life-sustaining treatment was developed for voluntary use statewide. The document is called Physician Orders for Life-Sustaining Treatment (POLST). It provides physicians, nurse practitioners and physician assistants a way to turn prior advance directive planning (oral or written) into action in a way the health care system can understand and respect. The bright pink document is now used in most Oregon communities. The POLST form allows the physician to record orders in four categories of life-sustaining treatment (cardiopulmonary resuscitation (CPR), other medical interventions, antibiotics, and artificially administered nutrition). It is possible (but probably unnecessary) for orders to be written for full code and all life-sustaining treatment. It is also possible to document medical orders that plan for comfort care, which for some will include an order not to transfer the patient except for comfort. The document does not allow comfort measures to be withheld (e.g., patients who can take food orally with assistance must be fed).

The POLST form is not designed to be completed by patients or family members; it is to be completed by health care professionals. The POLST orders are often completed by nurses or social workers in conversation with patients and their family members, but must be agreed to and signed by the attending physician, nurse practitioner or physician assistant to make the orders valid. The Oregon EMT Scope of Practice (OAR 847-35-0030) has been modified to both protect EMTs and require that these documents be followed. The language of the regulation is: "An Oregon-certified First Responder or EMT, acting through standing orders, shall respect the patient's wishes including life-sustaining treatments. Physician supervised First Responders and EMTs shall request and honor life-sustaining treatment orders executed by a physician, nurse practitioner or physician assistant if available. A patient with life-sustaining treatment orders always requires respect, comfort and hygienic care."

The Oregon Medical Board has defined rules for physicians and physician assistants regarding life-sustaining treatment orders (847-010-0110) as follows:

> 1) A physician or physician assistant licensed pursuant to ORS chapter 677 shall respect the patient's wishes including life-sustaining treatments. Consistent with the requirements of ORS chapter 127, a physician or physician assistant shall respect and honor life-sustaining treatment orders executed by a physician, physician assistant or nurse practitioner. The fact that a physician, physician assistant or nurse practitioner who executed a life-sustaining treatment order does not have admitting privileges at a hospital or health care facility where the patient is being treated does not remove the obligation under this section to honor the order. In keeping with ORS chapter 127, a physician or physician assistant shall not be subject to criminal prosecution, civil liability or professional discipline.
>
> 2) Should new information on the health of the patient become available the goals of treatment may change. Following discussion with the patient, or if incapable their surrogate, new orders regarding life-sustaining treatment should be written, dated and signed.

Numerous organizations in Oregon have endorsed the POLST document and encourage health care professionals to use it for their patients in hospice or long-term care to better document the wishes of those choosing to forego any aspect of life-sustaining treatment. If a terminally ill patient is considering the Oregon Death with Dignity Act, a concurrent wish for a DNR order can be recorded on the POLST form.

Similar physician order programs are developing in many states facilitated by the National POLST Paradigm Initiative Task Force. This organization is working to understand and develop policy, to help with standardization and implementation, and to coordinate research on POLST and POLST-like programs in other states. The overall goal is to help health care professionals honor patient wishes for end-of-life care.

If you would like additional information about POLST, please see the *POLST website* at *http://www.polst.org*, or email the *Center for Ethics in Health Care* or phone 503-494-3965 and ask for a free informational packet.

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Appendix D. The Final Months of Life: A Guide to Oregon Resources

The Final Months of Life: A Guide to Oregon Resources

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Appendix E. Oregon Medical Board Statement of Philosophy

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Oregon Medical Board

Current Statement of Philosophy on Pain Management
Approved April 16, 1999
Amended July 9, 2004

The Board of Medical Examiners (BME) urges the use of effective pain control for all patients, irrespective of the etiology of their pain. This includes, but is not limited to, postoperative pain, chronic pain of diverse etiology, and pain derived from malignancies. Physicians are encouraged to treat pain within the scope of their practice.

Studies have shown that as many as one-half of patients in pain are not given sufficient pain medication to control their pain in an optimal manner. There are three reasons for this failure to achieve adequate pain relief: 1) concern about causing addiction; 2) lack of knowledge about pain management techniques and pain medication pharmacology; and 3) fear of scrutiny and discipline by regulatory agencies. None of these factors, however, should preclude the physician from assuring that the patient has adequate pain control.

The treatment of post-operative pain requires aggressive management and frequent feedback from the patient regarding the adequacy of the pain control prescribed. The potential for addiction is very low when short courses of narcotics are used to treat post-operative pain.

Skillful pain management techniques, including oral, parenteral and, when available, regional pain management techniques can achieve maximum patient comfort and may reduce the total amount of narcotics required.

The BME encourages physicians to become well informed in acute post-operative pain management and to hone their skills in the latest techniques for control of these acute, self-limited episodes of pain caused by surgical procedures.

Management of the patient with chronic nonmalignant pain requires different techniques but a similar degree of skill. In 1995, the Oregon Legislative Assembly passed ORS 677.470-485, commonly referred to as the Intractable Pain Act. This act allows a physician to prescribe or administer controlled substances to a patient diagnosed with a condition causing intractable pain without fear of sanction from the Board of Medical Examiners, so long as that physician complies with the provisions of this statute.

Both this statute and its facilitating Oregon Administrative Rule (847-030-0015) assure that the patient with chronic nonmalignant intractable pain: 1), receives careful assessment, documentation, and management of the pain; 2), receives the assessment and recommendations of a physician specializing in the body area, system or organ perceived as the source of the pain; and 3), executes a signed material risk notice acknowledging receipt of information disclosing the material risks associated with the prescription or administration of controlled substances used in the course of his or her treatment.

Finally, physicians occasionally prescribe narcotics too sparingly for their terminally ill patients. The BME believes that physicians should make every effort to relieve the pain and suffering of their dying patients. This may require either intermittent or continued administration of large doses of narcotics, often well above those dosages that are considered usual in such references as the Physicians Desk Reference (PDR).

Since the goal of treatment is to relieve pain and suffering, dying patients should receive sufficient narcotic dosages to produce the maximal possible comfort. The physician should acknowledge that the natural dying process usually involves declining blood pressures, decreasing respirations and altered levels of consciousness. Narcotics should not be withheld on the basis of physiologic parameters when patients continue to experience pain.

Some physicians frequently express concerns that the use of narcotics in dying patients may hasten death through pneumonia or respiratory depression. For these reasons, at times physicians may have limited the use of narcotics in dying patients out of fear that they may be investigated for inappropriate prescribing or allegations of euthanasia.

The BME is concerned that such fear on the part of physicians may result in inadequate pain control and unnecessary suffering in terminally ill patients. The BME encourages physicians to employ skillful and compassionate pain control for dying patients and believes that relief from suffering remains the physician's primary obligation to dying patients.

Appropriate management of all of these types of pain is the treating physician's responsibility. The standard of care allows neither overtreatment nor undertreatment. As such, the Board will consider clearly documented undertreatment of pain to be a violation equal to overtreatment, and will investigate allegations in the same manner.

—Approved April 16, 1999

—Amended July 9, 2004

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Appendix F. Sample EMS Protocol

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

ADVANCE DIRECTIVES and DO NOT ATTEMPT RESUSCITATION ORDERS

PURPOSE:

This EMS system believes in respect for patient autonomy. The patient with decision-making capacity has the right to accept or refuse medical intervention. This includes the right to specify, in advance, patient preferences when the person is no longer able to communicate wishes.

PROCEDURE:

The EMS system shall honor POLST forms, Advance Directives and other Do Not Attempt Resuscitation (DNAR) orders under the following circumstances:

A. Do Not Attempt Resuscitation: In the pulseless and apneic patient who does not meet the criteria of the ***Death in the Field*** protocol, but is suspected to be a candidate for withholding resuscitation, BLS protocols will be followed until one of the following occurs:

1. The EMT sees a written DNAR, which should be honored, and resuscitation stopped.
2. The patient's physician is contacted and directs the EMTs not to continue resuscitation attempts.
3. The EMTs see a valid Advance Directive or Directive to Physician which directs them not to continue resuscitation.
4. The patient's attorney-in-fact (PAHC or DPAHC) directs the EMTs not to resuscitate the patient.
5. OLMC directs the EMTs not to continue resuscitation.
6. If a person, who is terminally ill, appears to have ingested medication under the provisions of the Oregon Death with Dignity Act (see section F below).

B. Advance Directives: DNAR orders only apply if the patient is in cardiopulmonary arrest. If the patient's PAHC, DPAHC, Directive to Physicians, or other Advance Directive is available to convey the patient's wishes, and the EMTs have seen a copy of the document, the EMTs must honor the treatment preferences as expressed.

C. Physician Orders for Life-Sustaining Treatment (POLST): If a POLST form is available, and it clearly expresses the patient's wishes and is signed by a physician, nurse practitioner or physician's assistant, EMTs shall honor the patient's treatment care preferences as documented in the EMS section of the POLST. [Cite: OAR 847-035-030 (7)] If an electronic registry is available and the POLST form is not immediately available, EMTs may also follow orders documented in the electronic POLST registry.

D. If there are questions regarding the validity, or enforceability, of the health care instruction, begin BLS treatment and contact OLMC.

E. It is always appropriate to provide comfort measures as indicated.

F. **Oregon Death with Dignity Act:** If a person who is terminally ill appears to have ingested medication under the provisions of the Oregon Death with Dignity Act, the EMT should:

1. Provide comfort care, as indicated.

2. Determine who called 9-1-1 and why (i.e., to control symptoms or because the person no longer wishes to end their life with the medication).

3. Establish the presence of DNAR orders and/or documentation that this was an action under the provisions of the Death with Dignity Act.

4. Contact OLMC.

5. Withhold resuscitation, if:

a. DNAR orders are present, and

b. There is evidence that this is within the provisions of the Death with Dignity Act, and

c. OLMC agrees.

DEFINITIONS:

A. **Do Not Attempt Resuscitation Order (DNAR):** An order written by a physician stating that **in the event of cardiopulmonary arrest**, cardiopulmonary resuscitation will not be administered. DNAR orders apply only if the patient is pulseless and apneic.

B. **Health Care Instruction:** A document executed by a person to indicate the person's instructions regarding health care decisions.

C. **Advance Directive:** A document that contains a health care instruction or a power of attorney for health care.

D. Living Will: A document that may confirm an Advance Directive or Directive to Physician informing her/him that if the patient has a terminal illness and death is imminent, the patient would not wish to be placed on artificial life support that will only prolong the process of dying. **In general, the traditional Living Will document alone is not helpful in the out-of-hospital setting because of its multiple restrictions and lack of clarity on when it should take effect.**

E. Attorney in Fact: An adult appointed to make health care decisions for a person.

F. Power of Attorney for Health Care (PAHC): Power of attorney document that authorizes an attorney-in-fact to make health care decisions for a person when the person is incapable.

G. Physician Orders for Life-Sustaining Treatment (POLST): The POLST is a voluntary form, which was developed to document and communicate patient treatment preferences across treatment settings.

1. It includes a section for documentation of DNAR orders and a section communicating patient preferences for EMS care.
2. While these forms are most often used to limit care, they may also indicate that the patient wants everything medically appropriate done.
3. **Read the form carefully!**
4. When signed by a physician (MD or DO), nurse practitioner or physician's assistant, the POLST is a medical order and EMTs are directed to honor it in their Scope of Practice.

5. If the POLST form is not immediately available, a POLST form as documented in the Electronic POLST Registry hosted at MRH (503 494-7333) may also be honored.

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Appendix G. Organizational Statements and Disclaimers

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Providence Health System - Oregon Region

The Providence Health & Services, Oregon Region, (PH&S) is proud to be a member of this Task Force. Through our membership, we have sought to bring our Mission and Values perspective to an important conversation about end-of-life care. Out of respect for the divergent points of views of the participants, this Task Force has sought to take a neutral stance on the issue of assisted suicide. As people of good will struggle with important moral issues, there is an appropriate place for a neutral discussion of issues that need to be addressed.

PHSOR, in fidelity to its Mission, core values and Catholic heritage, is not neutral on this issue. We firmly hold that excellence in end-of-life care does not include, and can be achieved without resort to, assisted-suicide. Healthcare providers associated with PHSOR should consult system policy for more information.

(Rev.) John F. Tuohey, Ph.D.
Director, Providence Center for Health Care Ethics
Chair, Applied Health Care Ethics

Department of Veterans Affairs

Department of Veterans Affairs (VA) patients will receive high quality and compassionate care. Dying patients will be provided with appropriate measures designed to relieve suffering and maximize comfort. In keeping with national VA policy, VA physicians may not provide a prescription for a lethal dose of medication to veterans who are patients in any VAMC. The VA Pharmacy may not fill a prescription for the purpose of providing a lethal dose of medication. The VA does support adequate relief of symptoms, however, even in the case where death may be hastened.

The Department of Veterans Affairs may not subject a part-time physician to censure, discipline, suspension or loss of privilege for participating or refusing to participate in the provisions of a lethal prescription to a veteran who is not an active VA patient and is seen outside normal VA duty hours. A VA physician may inform patients that physician-assisted dying is available elsewhere in the community.

Linda Ganzini, M.D.

Oregon Board of Pharmacy and Oregon State Pharmacy Association

The Task Force has not verified the accuracy of information contained in the references listed at the end of Chapter 10. Independent and patient-specific pharmaceutical advice should be sought to maximize the efficacy of medications prescribed by those participating under provisions of the Oregon Act. Information included in Chapter 10 has been presented by the authors and does not reflect the positions of the Oregon Board of Pharmacy or the Oregon State Pharmacy Association.

Joseph Schnabel, Pharm.D., R.Ph.

Gary Schnabel, R.N., R.Ph.

Health Law Section, Oregon State Bar Association

Chapter 15, Liability and Negligence, is intended solely for the educational use of the reader and is not intended as legal advice. Independent and specific legal advice is advisable to maximize the legal protection of those participating, or not participating, in conduct authorized by the Oregon Act.

Kelly Hagan, J.D.

Oregon Medical Board

The Oregon Medical Board participated on this Task Force, and like the Task Force, is neutral on the issue of assisted suicide. The information included in the Guidebook is presented by the authors and does not necessarily reflect the position of the Oregon Medical Board.

Kathleen Haley, Executive Director

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Appendix H. Definitions

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Because people at times are confused about the meaning of some of the terms used near the end of life, the following definitions are offered. These definitions are not meant to imply any ethical argument for or against any of the practices.

Doctrine of Double Effect: According to the doctrine of double effect, an action is justified as long as the intention is therapeutic, to relieve pain and suffering, even if there are foreseen but unintended consequences such as death. Based on this principle, medications are used and widely recognized for the purpose of relieving suffering in terminally ill patients even if those medications may hasten death. The concept of double effect originated in Jesuit theological thought and is widely endorsed by professional organizations.

Total Sedation ***(Sometimes called Terminal Sedation):*** Total sedation involves the use of sedative agents to make the patient unaware of symptoms that cannot be eliminated or satisfactorily controlled by the use of pain management, counseling, and other interventions that are clinically appropriate and acceptable to the patient. The most common method is IV infusion of barbiturates. Other agents and routes of administration potentially may be used. Life-sustaining interventions including artificial feeding and fluids may or may not be withheld.

Some people think that the term ***terminal sedation*** suggests that the sedative drugs are ending the patient's life and that they should only be used when a patient is actively dying. In order to avoid these implications the National Hospice and Palliative Care Organization recommends the term ***total sedation***.

Euthanasia: In the practice of euthanasia the physician or nurse practitioner (rather than patient) administers medication that hastens death. Euthanasia can be either voluntary or non-voluntary. Voluntary euthanasia would occur when a competent patient explicitly requests euthanasia. Non-voluntary euthanasia would occur when the patient is incapable of consenting due to mental impairment. Euthanasia is explicitly prohibited by the Oregon Death with Dignity Act and is illegal in all states.

The NEW ENGLAND JOURNAL of MEDICINE

SPECIAL ARTICLE

Implementing a Death with Dignity Program at a Comprehensive Cancer Center

Elizabeth Trice Loggers, M.D., Ph.D., Helene Starks, Ph.D., M.P.H.,
Moreen Shannon-Dudley, M.S.W., L.I.C.S.W., Anthony L. Back, M.D.,
Frederick R. Appelbaum, M.D., and F. Marc Stewart, M.D.

ABSTRACT

BACKGROUND

The majority of Death with Dignity participants in Washington State and Oregon have received a diagnosis of terminal cancer. As more states consider legislation regarding physician-assisted death, the experience of a comprehensive cancer center may be informative.

METHODS

We describe the implementation of a Death with Dignity program at Seattle Cancer Care Alliance, the site of care for the Fred Hutchinson–University of Washington Cancer Consortium, a comprehensive cancer center in Seattle that serves the Pacific Northwest. Institution-level data were compared with publicly available statewide data from Oregon and Washington.

RESULTS

A total of 114 patients inquired about our Death with Dignity program between March 5, 2009, and December 31, 2011. Of these, 44 (38.6%) did not pursue the program, and 30 (26.3%) initiated the process but either elected not to continue or died before completion. Of the 40 participants who, after counseling and upon request, received a prescription for a lethal dose of secobarbital (35.1% of the 114 patients who inquired about the program), all died, 24 after medication ingestion (60% of those obtaining prescriptions). The participants at our center accounted for 15.7% of all participants in the Death with Dignity program in Washington (255 persons) and were typically white, male, and well educated. The most common reasons for participation were loss of autonomy (97.2%), inability to engage in enjoyable activities (88.9%), and loss of dignity (75.0%). Eleven participants lived for more than 6 months after prescription receipt. Qualitatively, patients and families were grateful to receive the lethal prescription, whether it was used or not.

CONCLUSIONS

Overall, our Death with Dignity program has been well accepted by patients and clinicians.

From the Fred Hutchinson Cancer Research Center (E.T.L., F.R.A., F.M.S.), Group Health Research Institute (E.T.L.), Seattle Cancer Care Alliance (E.T.L., M.S.-D., A.L.B., F.R.A., F.M.S.), and the University of Washington (E.T.L., H.S., A.L.B., F.R.A., F.M.S.) — all in Seattle. Address reprint requests to Dr. Loggers at 825 Eastlake Ave. E., Seattle, WA 98109, or at eloggers@seattlecca.org.

N Engl J Med 2013;368:1417-24.
DOI: 10.1056/NEJMsa1213398

IN 1997, OREGON BECAME THE FIRST STATE in the United States to pass legislation that offered a "physician-assisted" approach to dying for adults with poor short-term prognoses.[1] The Washington State legislature followed Oregon more than a decade later, passing an almost identical law, the Washington Death with Dignity Act, in November 2008.[2] Under the law, competent adults residing in Washington who have a life expectancy of 6 months or less because of a diagnosed medical condition may request and self-administer lethal medication prescribed by a physician (Table 1).

As of December 2011, a total of 255 patients had participated in the Washington Death with Dignity program.[3] Of those participants, approximately 78% (and 81% of the 596 Oregonians) had cancer as their underlying terminal diagnosis. Although several articles have touched on the experiences of patients with cancer, family members, and physicians regarding Death with Dignity programs in the two states,[4-18] none have addressed institutional responses to the laws. Given ongoing efforts to introduce similar legislation in other states (including Hawaii, Pennsylvania, and Vermont),[17,19-21] increasing numbers of health care institutions may be faced with the questions of whether, and how, to respond to requests for assisted dying. Because this legislation has a disproportionate effect on patients with cancer and their families, the response of a comprehensive cancer center may be particularly instructive.

Table 1. **Essential Elements and Safeguards of the Washington State Death with Dignity Law.**

- The patient must make both an initial oral and written request
- After the initial oral request, the patient must wait 15 days to make a second oral request
- Before prescribing the lethal medication, the prescribing physician must:
  - Make an initial determination of the terminal nature of the disease
  - Determine the patient's competency and the voluntary nature of the request, with referral to a state-licensed psychiatrist or psychologist, if necessary, to ensure competency and the absence of a mental health disorder causing impaired judgment
  - Confirm Washington State residency (defined as possession of a Washington State driver's license, registration to vote, or evidence of lease or ownership of property in Washington State)
  - Assess informed consent on the basis of the patient's awareness of the medical diagnosis, the prognosis, the risks of the medication, the result of the medication (death), and the alternatives (palliative care, hospice, and pain control)
  - Recommend that the patient notify next of kin, have someone present at ingestion, and not take the medication in a public place
- The consulting physician confirms the diagnosis, the patient's competency, and the voluntary nature of the request
- At the time of prescribing, the prescribing physician must:
  - Offer the patient an opportunity to rescind the request
  - Verify that the patient is making an informed decision at the time of prescription
  - Deliver the prescription directly to the pharmacist
- The pharmacist dispenses the medication directly to the patient or an identified agent of the patient

Seattle Cancer Care Alliance is the outpatient site of care for patients with cancer from the Fred Hutchinson Cancer Research Center, the University of Washington, and Seattle Children's, all in Seattle, and is the only National Cancer Institute–designated comprehensive cancer center serving the Washington, Wyoming, Alaska, Montana, and Idaho region. In response to the Washington law, Seattle Cancer Care Alliance developed a Death with Dignity program, adapted from the existing programs in Oregon. This article describes the implementation and results of our Death with Dignity program, designed to adhere to legal regulations, maintain safety, and ensure the quality of patient care.

METHODS

POLICY DEVELOPMENT

After considerable internal debate, Seattle Cancer Care Alliance instituted a Death with Dignity policy (see the Supplementary Appendix, available with the full text of this article at NEJM.org), which was written by the medical director and approved by a simple majority of Medical Executive Committee members, as is consistent with all our clinical policies. In addition, we created informational packets for patients, physicians, and patient advocates (described further below) for use during the process (available on request from the corresponding author). The policy and its implementation addressed basic aspects of the program as well as issues that were more controversial. For example, Seattle Cancer Care Alliance does not accept new patients solely for the purpose of accessing our Death with Dignity program. Instead, patients are referred to Compassion and Choices of Washington, a local affiliate of a national patient-advocacy organization that provides education and support for those pursuing physician-assisted death. Although this is not part of the formal policy, we do not post information pertaining to Death with Dignity legislation or our program in public spaces, effectively requiring patients to initiate requests or their physicians to raise the topic. In addition, we require that participants sign an agreement not to take the lethal prescription in a public area or manner — a more restrictive measure than that in the law, which only recommends this to participants.

Finally, no staff or faculty members are compelled to participate in the program. To determine how many clinicians might be willing to participate, we conducted a confidential survey in March 2009, asking clinicians whether they would be willing to act as either a prescribing or a consulting clinician. The survey followed an institution-wide educational program outlining the provisions of the law and the planned program at Seattle Cancer Care Alliance. Of 200 physicians surveyed, 81 responded (40.5%, a typical response rate for a general survey with no follow-up), with 29 physicians willing to act as a prescribing or consulting physician (35.8%), 21 willing to act as a consulting physician only (25.9%), and 31 unwilling to participate or undecided about participation (38.3%). The small cadre of willing physicians was thought to be sufficient to support implementation.

IMPLEMENTATION OF THE DEATH WITH DIGNITY PROGRAM

After clinician or patient referral to the Death with Dignity program, each potential participant is assigned a patient advocate (hereafter referred to as advocate), one of three (of six) licensed social workers employed by Seattle Cancer Care Alliance. The advocate assists patients, family members, pharmacists, and physicians throughout the multistep process, while prospectively tracking compliance with required documentation submitted to the Washington Department of Health. The advocate describes the Death with Dignity process and the alternatives (specifically, palliative care and hospice, with these services offered as additions to, or in lieu of, Death with Dignity). The advocate then assesses the patient's rationale for and interest in further participation. In nearly all cases, family members are present.

If the patient elects to participate in the Death with Dignity program, the advocate conducts a preliminary chart review to confirm documentation of the terminal prognosis or, if absent, to request that the attending physician document the prognosis explicitly. The advocate then determines whether the attending physician will act as the prescribing physician. If not, the advocate identifies a prescribing physician and a consulting physician from the list of willing providers, preferentially choosing physicians who specialize in the type of cancer that the patient has. (General care of the patient is not transferred to the prescribing or consulting physician, unless the patient requests this.) The advocate then formally documents the patient's request for assistance with dying and provides the patient with written information that describes the program (including a timeline of the required requests, assessments, and waiting periods), which must be signed by the patient. The advocate also verifies that the patient is a Washington resident and completes a psychosocial assessment. At Seattle Cancer Care Alliance, social workers provide the first line of psychological evaluation for all patients, regardless of whether or not they are participating in the Death with Dignity program, using interview-based techniques and standardized assessments (e.g., the Patient Health Questionnaire 9 and the Generalized Anxiety Disorder 7 questionnaire). Although physicians retain the responsibility to evaluate patients for depression and decision-making capacity, advocates make these assessments as part of their standard practice. Advocates refer patients to the Psychiatry and Psychology Service if there is any history of, or positive screening for, a mental health disorder or impaired decision-making capacity.

The advocate then collects copies of the Physician Order for Life-Sustaining Treatment (a form that delineates the patient's preferences for interventions such as mechanical ventilation or resuscitation) and health care directives, assisting in their completion if desired; arranges for a clinician to be present at the time of medication ingestion, if requested (this is rare); provides advice regarding the securing and disposal of unused medication; provides grief support and legacy support (e.g., help in preparing letters or videos by which to be remembered) through periodic calls or visits; and requests that the family inform us when the patient ingests the medication, so that we can provide assistance in the case of complications, offer bereavement support, and aid the prescribing physician in completing the required after-death reporting forms. Advocates participate in two in-person meetings with the patient and family on average (range, one to four); we have not assessed our use of telephone follow-up.

The patient (and family) meets sequentially with the prescribing clinician and the consulting clinician to review the medical diagnosis, prognosis, risks of medication, and alternatives (including palliative and hospice care and specialized care for pain). After the mandatory waiting period of 15 days, if all requirements are met, a written prescription is given to our retail pharmacy. The pharmacist schedules a private room to meet with the patient (and family) in order to discuss preparation of the drug for ingestion, potential side effects, and the use of antiemetic therapy (ondansetron is routinely prescribed). Because of the lack of availability of pentobarbital, we currently use secobarbital, although 16.9% and 36.1% of Death with Dignity participants in Washington and Oregon, respectively, received pentobarbital.

Checklists and medical charts are randomly audited annually by the director of supportive care and specialty clinics. We have had 100% compliance with the completion of mandated forms and processes, with the exception of one unintentional failure to observe the full waiting period early in our program.

RESULTS

CHARACTERISTICS OF PATIENTS AT SEATTLE CANCER CARE ALLIANCE

Data on patients who have participated in the Death with Dignity program at Seattle Cancer Care Alliance are presented in Table 2, along with comparable data publicly reported by Washington and Oregon for all Death with Dignity participants from March 5, 2009, through December 31, 2011, and from January 1, 1998, through December 31, 2011, respectively.[1,2] During the former period, 114 patients inquired about our Death with Dignity program. Of those, 44 patients (38.6%) did not pursue Death with Dignity further or were deemed ineligible. We have refused participation to only 1 patient, who expressed an unwillingness to ingest the medication privately. Thirty patients (26.3%) initiated the process by making a first oral request but either elected not to pursue Death with Dignity or died before completing the process (average time from first oral request to death, 16.6 weeks [range, 2.3 to 97.1]). Our patients seldom contact Compassion and Choices without also discussing this with their physician (Miller R, Compassion and Choices of Washington: personal communication).

Forty patients (35.1% of all those who made an initial inquiry) received prescriptions for lethal medication; all 40 have died, 24 (60.0% of those receiving prescriptions) after ingesting the medication. The 40 patients who died represent 15.7% of the 255 Washington State Death with Dignity participants. Although we do not formally track patient deaths, Death with Dignity participants account for 0.02% of annual deaths among patients at Seattle Cancer Center Alliance, on the basis of recent estimates. Most participants were white, male, and college-educated, characteristics that are consistent with the statewide Washington and Oregon data. Seattle Cancer Care Alliance participants may be more likely than overall Washington participants to be working, given the higher percentage of persons with both private and Medicare insurance in our patient population. Participants typically have known their oncologist for 8 months. At the time of the initial request, 54.2% of our Death with Dignity participants are enrolled in hospice; Seattle Cancer Care Alliance has not formally tracked hospice enrollment at the time of death. However, 80.9% of patients in Washington State and 89.7% of those in Oregon are enrolled in hospice at the time of death.

No unexpected complications have occurred; however, one patient died a day after taking the medication, with the protracted process causing distress on the part of family members and clinicians (similar cases have occurred in Washington State in general and in Oregon). We have not received any complaints from family members or caregivers regarding our process or the manner of death. Anecdotally, families describe the death as peaceful (even when death has taken longer than the average of approximately 35 minutes). In addition, both patients and families frequently express gratitude after the patient receives the prescription, regardless of whether it is ever filled or ingested, typically referencing an important sense of control in an uncertain situation. Eleven participants lived longer than the expected 6 months. Of these, nine died after ingesting the lethal prescription an average of 7.4 weeks (range, 0.1 to 18.9) beyond the 6-month cutoff.

The most common reasons given by patients

Table 2. **Characteristics of Death with Dignity Participants at Seattle Cancer Care Alliance, as Compared with Participants in All of Washington State and in Oregon.***

Characteristic	Seattle Cancer Care Alliance	Washington State	Oregon
Medication dispensed — no.	40	255	935†
Died — no./total no. (%)	40/40 (100)	241/255 (94.5)	NA‡
After ingesting medication	24/40 (60.0)	157/241 (65.1)	596/935 (63.7)
Died at home	20/24 (83.3)	145/155 (93.5)	562/596 (94.3)
Enrolled in hospice at time of initial request	13/24 (54.2)		
Enrolled in hospice at time of initial request or death		127/153 (83.0)	522/582 (89.7)
Age			
18–64 yr — no./total no. (%)	14/40 (35.0)	67/213 (31.5)	187/596 (31.4)
65–84 yr — no./total no. (%)	23/40 (57.5)	114/213 (53.5)	409/596 (68.6)
≥85 yr — no./total no. (%)	3/40 (7.5)	32/213 (15.0)	71/596 (11.9)
Range — yr	42–91	41–101	25–96
Male sex — no./total no. (%)	22/40 (55.0)	111/213 (52.1)	308/596 (51.7)
Non-Hispanic white — no./total no. (%)	29/40 (72.5)	180/189 (95.2)	579/593 (97.6)
Married — no./total no. (%)	22/40 (55.0)	90/189 (47.6)	271/593 (45.7)
High-school diploma or higher level of education — no./total no. (%)	39/40 (97.5)	177/188 (94.1)	551/591 (93.2)
Residence east of the Cascade Mountains — no./total no. (%)	1/40 (2.5)	12/213 (5.6)	43/593 (7.3)
Insurance status — no./total no. (%)			
Private insurance	12/40 (30.0)	63/182 (34.6)	382/577 (66.2)
Medicare, Medicaid, or other public insurance	13/40 (32.5)	84/182 (46.2)	185/577 (32.1)
Combination of private and public insurance	11/40 (27.5)	30/182 (16.5)	NA‡
None	4/40 (10.0)	5/182 (2.7)	10/577 (1.7)
Diagnosis — no./total no. (%)			
Cancer	24/24 (100)	166/213 (77.9)	480/596 (80.5)
Neurodegenerative disease		22/213 (10.3)	44/596 (7.4)
Respiratory disease (including COPD)		9/213 (4.2)	25/596 (4.2)
Heart disease		10/213 (4.7)	10/596 (1.7)
Other or unknown		6/213 (2.8)	37/596 (6.2)

* Data for Seattle Cancer Care Alliance and Washington State are complete from March 5, 2009, through February 29, 2012, for patients prescribed medication through December 31, 2011. Data for Oregon are complete from January 1, 1998, through February 29, 2012, for patients prescribed medication through December 31, 2011. Washington State does not release data for research purposes. Annual reports are released, but data from those reports are not updated in subsequent years. Therefore, data can be missing because the data were not reported on required forms, the data were reported as unknown, or forms were not available at the time of finalizing the annual report. COPD denotes chronic obstructive pulmonary disease, and NA not available.

† Oregon tracks prescriptions written, not those dispensed (as is done in Washington).

‡ The total number of deaths and data on combined public and private insurance coverage are not tracked in Oregon.

for wanting to participate in Death with Dignity were loss of autonomy (97.2%), inability to engage in enjoyable activities (88.9%), and loss of dignity (75.0%) (Table 3). Eight of 36 participants (22.2%) reported uncontrolled pain or concerns of future pain (as compared with 34.7% and 22.6% of Washington State and Oregon participants, respectively). None of the patients who inquired about Death with Dignity and were found to have either current or previous depression or decisional incapacity elected to move forward with the process. Among patients who have pursued Death with Dignity, no participants were deemed to require mental health

Table 3. **Aspects of Death with Dignity Experience for Participants Receiving Care at Seattle Cancer Care Alliance, as Compared with Participants in All of Washington State and in Oregon.***

Variable	Seattle Cancer Care Alliance	Washington State	Oregon
End-of-life concerns — no./total no. (%)			
Loss of autonomy	35/36 (97.2)	183/202 (90.6)	538/592 (90.9)
Inability to engage in enjoyable activities	32/36 (88.9)	179/202 (88.6)	523/592 (88.3)
Loss of dignity	27/36 (75.0)	151/202 (74.8)	386/592 (65.2)
Loss of control of bodily functions	10/36 (27.8)	105/202 (52.0)	318/592 (53.7)
Burden on family, friends, or caregivers	8/36 (22.2)	78/202 (38.6)	214/592 (36.1)
Inadequate pain control or concern about it	8/36 (22.2)	70/202 (34.7)	134/592 (22.6)
Financial implications of treatment	0/36	8/202 (4.0)	15/592 (2.5)
Patient informed family of decision — no./total no. (%)	32/40 (80.0)	189/202 (93.6)	493/522 (94.4)†
Duration of patient–physician relationship — wk			
Median	33	14	12
Range	4–637	3–1404	0–1905
Time from ingestion of medication to death — min‡			
Median	35	45	25
Range	15–1680	5–1800	1–104
Health care provider present at time of ingestion — no./total no. (%)§			
Prescribing physician		7/157 (4.5)	100/526 (19.0)
Other provider, prescribing physician not present		80/157 (51.0)	231/526 (43.9)
No provider		52/157 (33.1)	72/526 (13.7)
Unknown	24/24 (100)	18/157 (11.5)	123/526 (23.4)

* Data for Seattle Cancer Care Alliance and Washington State are from March 5, 2009, through February 29, 2012. Data for Oregon are from January 1, 1998, through February 29, 2012.

† In Oregon, whether the patient informed the family of the decision was recorded beginning in 2001. Since then, 21 of 522 patients (4.0%) have chosen not to inform their families, and 8 patients (1.5%) have had no family to inform. Data were missing for 1 patient in 2002, for 2 in 2005, and for 1 in 2009.

‡ Washington State presents the data in categories (1 to 90 minutes, ≥91 minutes, or unknown), with the range of times. To approximate the median, the middle of the most common category for the 3 years was selected.

§ The data shown are for 2009 through 2011 in Washington State and for 2001 through 2011 in Oregon. Information about the presence of a health care provider or volunteer, in the absence of the prescribing physician, was first collected in 2001 in Oregon. The procedure in Oregon was revised in mid-2010 to standardize reporting on the follow-up questionnaire. With the new procedure, information about the time of death and the circumstances surrounding death is recorded only when the physician or another health care provider is present at the time of death. This change resulted in a larger number of patients for whom the information was unknown, beginning in 2010.

evaluation for depression or decisional incapacity (as compared with 10 of 209 patients [4.8%] in Washington State and 40 of 596 patients [6.7%] in Oregon).

DISCUSSION

Our Death with Dignity program has been well accepted by patients, families, and staff. We attribute this to the professionalism of our advocates, the great care taken by our prescribing and consulting clinicians when interacting with patients and families, the low profile of the Death with Dignity program overall, and the willingness of the Seattle Cancer Care Alliance leadership to allow considerable debate before the program was developed. A few clinicians who were initially strongly opposed to the Death with Dignity program subsequently expressed their willingness to participate as consulting or prescribing clinicians, which further supports acceptance of the program.

The reasons for participation in our program reflect concern about autonomy, dignity, and functional status rather than disease-related symptoms or depression, findings that are consistent with the literature.[9] Patients, caregivers, and family members have frequently expressed gratitude after the patient obtained the prescription, regardless of whether it was ever filled or ingested, typically referencing an important sense of control in an uncertain situation. However, we continue to identify and address process and quality issues. For example, although consistent with the broader reported experience in Washington and Oregon, the eight reports of uncontrolled pain or fear of future symptoms at the time of the initial request for Death with Dignity deserve attention. Seattle Cancer Care Alliance provides specialized care for pain and palliative care services in the outpatient setting. Both services have nurse practitioners and physicians who provide care in the oncology clinic. Clinicians (social workers, nurses, and physicians) can directly refer patients to either service; however, these services have been invoked infrequently for Death with Dignity participants (perhaps because the participants typically do not have symptoms at the time of the request).[9] Regardless, palliative care consultations will be offered as a matter of policy to all Death with Dignity participants going forward. It is our hope that this will also encourage earlier enrollment in hospice.

Opponents of Death with Dignity legislation have raised the concern that it might disproportionately affect vulnerable populations (e.g., racial or ethnic minorities and lower-income populations). The Oregon experience does not support this concern.[21] Nor do we have evidence that our population differs from the broader Washington State population on the basis of U.S. Census data.[22] Also consistent with the literature is the finding that only a small subset of patients who are initially interested in Death with Dignity go on to pursue this option.[23] Some patients do not complete the process owing to rapidly deteriorating performance status or death, and others live longer than the estimated 6 months, findings that represent opportunities to improve both prognostication and communication. However, we have purposefully not informed prescribing and consulting physicians when Death with Dignity participants live longer than 6 months, because of the concern that such feedback may unintentionally delay prognostic conversations until clinicians are certain of the timing, thereby reinforcing the more persistent and likely problem of communicating the prognosis (too) late in the course of illness.

In conclusion, our Death with Dignity program both allows patients with cancer who wish to consider this option to do so within the context of their ongoing care and accommodates variation in clinicians' willingness to participate. The program ensures that patients (and families) are aware of all the options for high-quality end-of-life care, including palliative and hospice care, with the opportunity to have any concerns or fears addressed, while also meeting state requirements.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

We thank Barbara Glidewell, M.B.S., C.E.C., former patient relations director, ombudsman, and assistant professor, Oregon Health and Science University (OHSU), and Linda Ganzini, M.D., M.P.H., professor of psychiatry and medicine, OHSU, for their consultation and expertise early in the formation of our Death with Dignity program; Danika Kubota for her administrative assistance; and the University of Washington Palliative Care Center of Excellence for its support.

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