The Washington Death with Dignity Act: A First Year Perspective

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Disclosures

• Anne Koepsell is a principal with Koepsell Consulting, Inc.

• Robb Miller has nothing to disclose.

Objectives

• Identify the eligibility criteria for Death With Dignity Act (DWDA) as defined in law in Washington
• Restate the key characteristics of individuals who utilized DWDA to end their lives
• Discuss pertinent policies and procedures
• Identify the role of Compassion & Choices of Washington (C&C) in the DWDA process
• Discuss challenges and problems for hospice and C&C

About Compassion & Choices of Washington (C&C)

• Washington affiliate of the national organization, Compassion & Choices, which was created by the unification of End of Life Choices (formerly the Hemlock Society) and Compassion In Dying in 2005
• C&C was formed by the 2005 unification of End of Life Choices of WA State (founded 1988) and Compassion In Dying (founded 1993)
• Nonprofit that advocates for patient-centered, end-of-life care, advance planning and expanded choice at the end of life, including upholding patients' rights to the DWDA
• Provides free client support services to qualified patients whether they wish to use the DWDA or not
• Created the coalition that passed I-1000

About C&C

• Believes that hospice is an essential component of excellent end-of-life care
• Has referred hundreds of patients to hospice
• Supports Washington’s POLST program
• Advocates for the right to aid in dying, not for patients to use life-ending medication
• Believes no patient should elect to use the DWDA due to undertreated pain, unmanaged symptoms, or a lack of adequate medical or palliative care
• Does not support, or advocate for, euthanasia.
• Lobbied with WSHPCO during the 2010 legislative session to preserve the Medicaid hospice benefit

C&C’s Role in the DWDA Process

• Ensure client is aware of and understands all alternatives
• Ensure client receives optimal palliative care (hospice)
• Referrals re: participating physicians
• Guide clients and physicians through the process
• Medical expertise/medical director
• Refer prescribing physician to participating pharmacy
• Personal presence at the time of death
Oregon, Washington, and Montana: States with Death With Dignity

- Oregon statute implemented October 1997
- Washington statute implemented March 2009
- Montana – District Court Case allows DWD December 2008

History of Death With Dignity in Washington

Two unsuccessful efforts, one initiative and one judicial, before passage in 2008:
- 1991: Citizen’s Initiative 119 (to legislature) failed, 54% – 46%
- 1997: US Supreme Court Case Glucksberg v. Washington (filed by Compassion in Dying)
- 2008: Citizen’s Initiative 1000 (to people) passed 58% - 42%, voter turnout = 85% of registered voters

I-1000 Passed in all but 9 Counties

Death With Dignity Provisions

- Allows terminally-ill adults to request a prescription for life-ending medication which must be self-administered
- Ending life is not suicide or assisted suicide under Oregon or Washington statutes
- Death certificate lists underlying disease as cause of death
- No effect on life insurance, annuities, etc.

Death With Dignity Provisions

- Is opt-in, not opt-out
  - “Only willing health care providers shall participate…”
- Allows institution to prohibit employees from participating, with certain limitations
- Definition of “Participation” does not include discussing or referring
- Physicians, patients, and others acting in good faith have civil and criminal immunity

The DWDA does not

- Permit any form of euthanasia (lethal injection)
- Apply to patients with dementia or Alzheimer’s
- Apply to patients with intractable or incurable illnesses that are not terminal (e.g., Parkinson’s)
- Lower the standard of care at the end of life
- Have a negative impact on end-of-life care
Eligibility Criteria

- Resident
- 18 years old
- “Capable”
  - Able to make and communicate health care decisions
- Terminally ill with a prognosis of 6 months or less to live
- Request must be voluntary
- Patient must be able to self-administer

Residency Requirement

- Factors demonstrating Washington state residency include but are not limited to:
  - Possession of a Washington State driver's license
  - Registration to vote in Washington
  - Evidence that the person owns or leases property in Washington

Prescription Process

- 2 oral requests separated by a 15-day waiting period
- 1 written request witnessed by 2 people (elaborate re: witnesses)
- Waiting periods are concurrent, not consecutive.
- Prescribing & consulting physicians must
  - Confirm diagnosis and prognosis
  - Determine patient is "capable"
  - Consider mental health referral and refer to participating WA State licensed psychologist or psychiatrist, when warranted
- Patient informed of alternatives

Who Uses Death With Dignity? 2009

Patient Demographics in Oregon and Washington

<table>
<thead>
<tr>
<th></th>
<th>OR</th>
<th>WA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>55-84 yrs</td>
<td>48-95 yrs</td>
</tr>
<tr>
<td>Race</td>
<td>98%</td>
<td>98%</td>
</tr>
<tr>
<td>Education</td>
<td>48.3%</td>
<td>39%</td>
</tr>
<tr>
<td>Disease</td>
<td>79.7%</td>
<td>79%</td>
</tr>
<tr>
<td>Death</td>
<td>98.3%</td>
<td>94%</td>
</tr>
<tr>
<td>Hospice Use</td>
<td>91.5%</td>
<td>72%</td>
</tr>
<tr>
<td>Insured</td>
<td>98.7%</td>
<td>89%</td>
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</table>

Patient Concerns

2009 Oregon and Washington

<table>
<thead>
<tr>
<th>Concern</th>
<th>OR</th>
<th>WA</th>
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</thead>
<tbody>
<tr>
<td>Loss of autonomy</td>
<td>96.6%</td>
<td>100%</td>
</tr>
<tr>
<td>Loss of dignity</td>
<td>91.5%</td>
<td>82%</td>
</tr>
<tr>
<td>Decreasing ability to participate in activities that made life enjoyable</td>
<td>86.4%</td>
<td>91%</td>
</tr>
<tr>
<td>Losing control of bodily functions</td>
<td>52.5%</td>
<td>41%</td>
</tr>
<tr>
<td>Burden on family, friends/caregivers</td>
<td>25.4%</td>
<td>23%</td>
</tr>
<tr>
<td>Inadequate pain control or concern about</td>
<td>10.2%</td>
<td>25%</td>
</tr>
<tr>
<td>Financial implications of treatment</td>
<td>1.7%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Death Statistics

2009 Oregon and Washington*

<table>
<thead>
<tr>
<th>Category</th>
<th>OR</th>
<th>WA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescriptions written/dispensed</td>
<td>95</td>
<td>63</td>
</tr>
<tr>
<td>DWD Deaths</td>
<td>59</td>
<td>36</td>
</tr>
<tr>
<td>Prescribing Physicians</td>
<td>55</td>
<td>53</td>
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</tbody>
</table>

* Based on 10 months of data (law became effective on 3/5/09)
C&C’s 2009 DWD Data
(vs. DOH’s, when applicable)

• On hospice at time of death: 84% (DOH = 72%)
• Self-identified as religious: 45%
• Had health insurance: 96% (DOH = 89%)
• Longtime belief in having control of death: 92%
• Average duration of C&C volunteer/client relationship for case closed in 2009: 310 days
• DOH duration of physician-patient relationship:
  - 3 - 24 weeks = 23; 25 - 51 weeks = 4; 1 year or more = 17; range = 3 weeks – 27 years

2009 DWD Data

• Average time between ingestion and death w/o a C&C volunteer present: 345 minutes (5.75 hours)
• Average time between ingestion and death with a C&C volunteer present: 27 minutes
• Median time between ingestion and death for all C&C deaths: 30 minutes
• DOH time between ingestion and death:
  - 1 - 90 minutes = 25; 91 or more minutes = 5; unknown = 5; range = 9 minutes – 28 hours)

Oregon DWDA Statistics 2009

• 95 prescriptions were written
• 59 deaths
  - 53 patients took the medication
  - 6 patients with earlier prescriptions died in 2009
  - 30 patients died of their underlying disease
  - 12 were alive at the end of 2009
• Death With Dignity deaths are less than .019% of Oregon deaths (19.3 deaths per 10,000 total deaths)
• Once in hospice, 7 of 10 people who consider using Oregon’s law change their minds because their quality of life is acceptable to the end

Washington DWDA Statistics 2009

• Attending physician required to file form within 30 days of writing
• Pharmacist files additional report at time of dispensing
• 65 prescriptions were written
• 63 individuals had medication dispensed
• 47 individuals have died
  - 36 died after ingesting the medication
  - 7 died without having ingested the medication
  - 4 ingestion status is unknown

2010 Washington DWDA Forms Received by the DOH (as of 9/15/10, source: http://www.doh.wa.gov/dwda/forms/)

<table>
<thead>
<tr>
<th>DOH Publication Number</th>
<th>Form Name</th>
<th>2009</th>
<th>2010</th>
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<tbody>
<tr>
<td>422-063</td>
<td>Written Request for Medication to End My Life in a Humane and Dignified Manner form</td>
<td>64</td>
<td>65</td>
</tr>
<tr>
<td>422-064</td>
<td>Attending Physician’s Compliance form</td>
<td>66</td>
<td>66</td>
</tr>
<tr>
<td>422-065</td>
<td>Consulting Physician’s Compliance form</td>
<td>67</td>
<td>66</td>
</tr>
<tr>
<td>422-066</td>
<td>Psychiatric/Psychological Consultant’s Compliance form</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>422-067</td>
<td>Pharmacy Dispensing Record form</td>
<td>63</td>
<td>54</td>
</tr>
<tr>
<td>422-068</td>
<td>Attending Physician’s After Death Reporting form</td>
<td>42</td>
<td>54</td>
</tr>
</tbody>
</table>
Policies to Consider

- Level of organizational involvement
- Informed Consent
- Conscientious Objection clauses
- Staff training
- Staff retraining
- Management of complaints
- Referring patients
- Professional ethics

Level of Involvement

- Embrace (Fully participate)
  - Designate social worker to facilitate DWD referrals
  - Medical Directors write prescription
  - Staff present at time of implementation
- Educate/Support
  - Facilitate referral to support organization
  - May or may not be present at implementation
- Distance
  - Refer to appropriate support organization
- Oppose
  - Prohibit discussion about option and referrals to other organizations

Informed Consent

- Patient right to accurate information
- Patient right to non-judgmental care
- Support of patient self-determination
- Patient made aware of level of organization involvement at time of hospice admission

Conscientious Objection

- Develop policy and process for staff to
  - Invoke
  - Transition of care
- Train staff on how to have the conversation that is patient centered, not provider centered

Staff Training

- Train on organization policies
- Be sensitive to conflict presented
- Role play having the conversations
- Provide in-service by support organization
- Create environment of open dialogue
- Continuing education
- Request presentation from C&C

Implementation Issues

- Steep learning curve in first years after implementation
- Create supportive communication process when:
  - Patient raises issue
  - Staff invokes conscientious objection
- Be proactive in determining if patients are making requests
Management of Complaints

- Seek out information from staff on requests
- Ask how the conversation went
- Identify when it could have been handled more appropriately
- Intervene if necessary

Management of Complaints

- Washington experience
  - 50% patient complaints (7) about hospice during first 3 months
  - All were around patient feeling judged, demeaned, ignored or experiencing unwanted interventions when making request for DWD information
  - Several patients revoked hospice
  - Several switched to another hospice
  - Hospice management was unaware of complaints
  - Complaints came to WSHPCO from C&C
- Retrain, retrain, retrain

Hospice concerns re: C&C

- Initially instructed patients not to reveal their intention to use the DWDA
- Concerns or beliefs that “promotes suicide” rather right to use the DWDA
- Unprepared for death of patient
- Confidentiality issues re: mutual patient/client
- Difficulty referring due to C&C due to lack of familiarity or prior experience

C&C concerns re: hospice

- Lack of policies or policies that don’t honor patient autonomy re: DWD
- Not referring patients, or prohibitions about referring patient, to C&C
- Confidentiality issues re: mutual client/patient
- Confidentiality issues re: participating physicians
- Patients delaying admission due to reimbursement issue
- Lack of reimbursement for participating physicians
- Perception of what constitutes patient-centered care
- Clients’ perceptions that hospice is anti-DWD or will undermine their choice
- In-patient hospice prohibitions re: DWD death on premises

Solutions

- Patient-Centered Communication between C&C and hospice
- Presentations/Continuing Education between C&C and hospice
- Policies
- Time and Experience
- Advocacy Within Systems
- Written Releases (Confidentiality)

Resources

- http://www.wshpco.org
  - Washington State Hospice and Palliative Care Organization
  - Compassion & Choices of Washington’s Death With Dignity Act webpage
- http://www.wsha.org/page.cfm?ID=0302
  - Washington State Hospital Association’s Death With Dignity Act webpage
Resources

- http://www.doh.wa.gov/dwda/
  - Washington State Department of Health, Center for Health Statistics’ Death With Dignity Act webpage
  - Oregon Department of Human Services, Public Health Division, Death With Dignity Act webpage
  - The Oregon Death With Dignity Act: A Guidebook for Health Care Professionals

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A Recent Study of Interest

Hospice and Physician-Assisted Death: Collaboration, Compliance, and Complicity
by Courtney S. Campbell and Jessica C. Cox

An examination of fifty-five Oregon hospices reveals that both legal and moral questions prevent hospices from collaborating fully with physician-assisted death.