Oregon’s Death with Dignity Act: Data to Inform Policy & Research

Katrina Hedberg, MD, MPH
Health Officer & State Epidemiologist

February 13, 2018
OR Death with Dignity Act

- **Citizens' initiative:** passed 1994, 1997
- **Allows:** qualified terminally-ill patients to end their lives with legally-prescribed medications
- **Outlines:** process / requirements for patients; physicians; pharmacists; *up to the point the prescription is written*
- **Requires:** Oregon Health Authority to monitor compliance; issue annual report
Talk Overview

• Statutory requirements
• Data collection Process
  • Monitoring / reporting system
  • Compliance
  • Context: reasons for request, circumstances surrounding death
• 20 year experience
• Data issues for consideration
Patient Requirements

- Oregon resident; > 18 years old
- "Capable" - make / communicate health care decisions
- Terminal illness prognosis <6 mths
- Request voluntary
Prescription Process

- 2 verbal requests: 15-day waiting period
- 1 written request: 2 witnesses
- Prescribing & consulting MDs
  - confirm diagnosis / prognosis
  - determine patient is "capable"
- Psych evaluation if appropriate
- Patient informed of alternatives
Public Health Division: Monitoring and Compliance

• Data from mandatory reporting:
  – Process in administrative rule
  – After the prescription is written
  – Met law requirements: dates of requests, diagnosis, prognosis
  – Medications prescribed

• Non-compliance reported to licensing board

• Data from death certificates
  – Demographics, education level, underlying illness
Data for Policy / Research

- Data from post-death follow-up reports
- How many people die from medications?
- Reasons for requesting DWDA:
  - “existential”, end-of-life care access, pain control, financial concerns
- DWDA process:
  - time to death, complications
Oregon’s 20-year Experience

prescriptions written

DWDA deaths


0 50 100 150 200 250
DWDA Deaths by Age
Median = 72 yrs
## DWDA by Education

<table>
<thead>
<tr>
<th>Education Level</th>
<th>DWDA Percent</th>
<th>Rate per 10,000 deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; High school</td>
<td>6%</td>
<td>16.0</td>
</tr>
<tr>
<td>HS graduate</td>
<td>22%</td>
<td>28.5</td>
</tr>
<tr>
<td>Some college</td>
<td>26%</td>
<td>65.6</td>
</tr>
<tr>
<td>Bachelor’s deg</td>
<td>24%</td>
<td>128.3</td>
</tr>
<tr>
<td>Graduate deg</td>
<td>22%</td>
<td>190.9</td>
</tr>
<tr>
<td>Underlying Dis</td>
<td>DWDA</td>
<td>Rate</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Cancer</td>
<td>77%</td>
<td>65.5</td>
</tr>
<tr>
<td>ALS</td>
<td>8%</td>
<td>439.3</td>
</tr>
<tr>
<td>Respiratory Dz</td>
<td>5%</td>
<td>14.4</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>2%</td>
<td>7.9</td>
</tr>
<tr>
<td>HIV/ AIDS</td>
<td>1%</td>
<td>141.4</td>
</tr>
</tbody>
</table>
Physician Participation

- **2000*-2017:**
  - 374 physicians wrote prescriptions (range: 1-85)

- **1997-2017**
  - 22 physicians reported to Oregon Medical Board
  - Reasons: Incorrect documentation; incomplete written consent; lack of two witnesses; not complying with waiting periods
  - OMB response: Found all MD’s to be acting in “good faith compliance” with law

*first year data tracked*
DWDA Process

- Referred for psych eval: 59 (5%)
- Hospice: 976 (88%)
- Location of death:
  - Home: 1093 (93%)
  - Assisted living: 53 (5%)
- Ingestion to death:
  - Median (range): 25 min (1 min-104 hrs)
- Seven people regained consciousness
## End-of-Life Concerns

- Losing autonomy: 1070 (91%)
- Unable to participate: 1054 (89%)
- Loss of dignity*: 802 (68%)
- Loss bodily control: 546 (46%)
- Burden on family: 503 (43%)
- Inadequate pain control: 308 (26%)
- Financial concerns: 41 (3.5%)

* After 2003
Data Collection Issues

• Reason for data
  – Monitoring, compliance, research

• Data collection method
  – Required reports, death certificates, special studies

• Source of Information
  – Providers, families, volunteers (secondary sources)
  – Patients (primary source)

• Balance
  – Confidentiality, transparency, regulatory
Elements Not Included in DWDA

- **Patient evaluation:**
  - Reasons for request denial; depression evaluation; psychological autopsy
- **Process between written prescription and death**
  - Decision-making; re-evaluation of patient competency
- **At time of death:**
  - Who needs to be present at death; reporting of circumstances and complications
- **After death:** No required patient follow up
Improvements in Data

• Role of government
  – Monitoring, compliance
  – Role of external stakeholders: Task Force to Improve Care of Terminally-ill Oregonians
  – Barriers to access/reporting

• Role of academia/researchers
  – Why differences in SES of patients who participate
  – End-of-life care research; range of practices; shared decision-making; needed family supports
  – Medical ethics; doctor-patient relationship
Questions?