The Oregon Death with Dignity Law: Patient, Family and Health Care Provider Views and Experiences

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Disclaimer

The views expressed in this presentation are those of the author and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.
Physician-Assisted Death (PAD) Laws in the U.S.

- Oregon Death with Dignity Act enacted in 1997
- Montana does not prosecute PAD for competent, terminally-ill patients by judicial decision
Structure of PAD Laws in U.S.

- Allow a physician to prescribe a lethal dosage of medication for a competent, terminally-ill patient for the purposes of self-administration
- Second physician consultant must confirm the patient has less than six months of life (in best judgment) and is competent
- Patient must be informed of all feasible alternatives including hospice care
- If the physician or consultant is concerned that the request is influenced by a mental disorder/depression, the patient must be evaluated by a mental health professional
- Physicians are not required to participate

All physicians who prescribe under PAD laws are required to notify a state legal entity and provide documentation that legal requirements are met

Sources of Evidence about PAD in Oregon

**Source of Evidence**

- **Oregon Health Division Reporting System**
  - **Strengths**
    - Comprehensive, includes all legal cases
    - High degree of confidence regarding demographic, disease and health care information
    - Continues to be updated yearly
    - PAD deaths can be compared to all other deaths in Oregon
    - Information directly from participants (patient, family)
    - Greater detail
    - Can be used for hypothesis testing
    - Can be used to generate new hypotheses
    - Vivid descriptions of participants and experiences
    - Can support quantitative data
  - **Limitations**
    - Lacks detail
    - Patients reasons for PAD reported through physician (secondary sources)

- **Research surveys**

- **Research Qualitative interviews**

- **Selection bias may limit generalizability**

- **Studies are now 10-20 years old**

- **Lacks generalizability**

- **Risk of bias**

- **Limited ability to compare/contrast**
Oregon Research Surveys

- 418 Oregon psychiatrists (1996)
- 625 Oregon psychologists (1999)
- 4000 eligible physicians (2000)
  - 5% had received a request for PAD
- 545 hospice nurses and social workers (2002)
  - 45% had cared for a requesting client
  - 30% had cared for a client who had received a lethal prescription
- 50 hospice chaplains (2005)—54% had worked with a requesting patient
- All surveys have response rates of over 65%
- Most surveys followed by qualitative interviews
Studies of Requesting Patients and Family Members’ Views and Experiences Around Requests for PAD

56 Oregonians who had explicitly requested PAD (2009)
- Measured depression (Structured Clinical Interview for DSM Disorders, Hospital Anxiety and Depression Scale), hopelessness, social support, burden to others, religiousness, reasons for request

95 family members of 83 Oregonians who requested PAD a mean of 14 months after death (2009)
- 59 had received a lethal medication
- 36 died by PAD
- Information on reasons loved one requested PAD, and family members experiences of complicated grief, depression, mental health care usage, effect of choices on grieving
- Qualitative open-ended interview with a subset of both patients and families
## Oregon Health Care Practitioners’ Attitudes Toward Oregon Death with Dignity Act (ODDA) or PAD

<table>
<thead>
<tr>
<th>Attitude toward ODDA or PAD</th>
<th>Generalist Physicians N=2641</th>
<th>Hospice Nurses N=307</th>
<th>Hospice Social Workers N=90</th>
<th>Hospice Chaplains N=50</th>
<th>Psychiatrists N=321</th>
<th>Psychologists N=423</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support</td>
<td>51%</td>
<td>48%</td>
<td>70%</td>
<td>40%</td>
<td>56%</td>
<td>78%</td>
</tr>
<tr>
<td>Neutral</td>
<td>17%</td>
<td>16%</td>
<td>16%</td>
<td>18%</td>
<td>44%</td>
<td>22%</td>
</tr>
<tr>
<td>Oppose</td>
<td>31%</td>
<td>36%</td>
<td>13%</td>
<td>42%</td>
<td>44%</td>
<td>22%</td>
</tr>
</tbody>
</table>
Physician Experiences with the ODDA (2000)

- Information received on 143 requests (of 2649 physician respondents)
- One in six requests for a lethal medication resulted in a prescription
- At the time of the first request
  - 32% of patients were receiving hospice
  - 76% had a life expectancy of less than six months
  - 59% in bed or chair over half their waking hours
- In 48% cases the physician implemented a substantive palliative intervention
  - 46% of Oregonians with substantive interventions changed their mind about PAD, compared to 15% of those without (P < .001)
- Physician more likely to prescribe if not in a small town, patient hospice enrolled and patient wanted control over death
- Less likely to prescribe if patient viewed self as burden or symptoms of depression

Ganzini et al, 2000
Actions of Health Care Practitioners

- 34% of physicians willing to prescribe
- Only 3% of hospice nurses and 14% of chaplains would actively oppose a client’s choice for PAD (62% of nurses neither support nor oppose, 34% of nurses support)
- 12% of hospice nurses and no chaplains would transfer a patient who received a lethal prescription
- 90% of patients who die by PAD are enrolled in hospice

## Importance of Religion

<table>
<thead>
<tr>
<th></th>
<th>Requesting Patients (N=56)</th>
<th>Hospice Nurses (N=397)</th>
<th>Caregivers of ALS/CA patients (N=189)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of religion in life (1-10 scale), mean (SD)</td>
<td>2.3 (3.1)</td>
<td>6.6 (3.6)</td>
<td>7.3 (3.2)</td>
</tr>
</tbody>
</table>
Spirituality and Attachment

- Compared 55 requesting patients and 39 terminally ill controls on depression, hopelessness, pain, attachment, support and spirituality.

- Low spirituality (meaning, purpose and hope) strongest predictor of PAD requests in multivariable analysis.
  - Also PAD requestors had higher hopelessness, depression, and dismissive attachment. No difference in pain or social support.

- Family members also rated patient attachment.
  - 56% of family rated requesting patient has having dismissive attachment.

Oldham et al, 2011; Smith et al, 2015
### Existential Reasons

<table>
<thead>
<tr>
<th>Physician Study</th>
<th>Hospice Nurses Study</th>
<th>Requesting Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=143&lt;sup&gt;1&lt;/sup&gt;</td>
<td>N=82&lt;sup&gt;2&lt;/sup&gt;</td>
<td>N=56&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Prevalence</strong></td>
<td><strong>Median (IQR)&lt;sup&gt;4&lt;/sup&gt;</strong></td>
<td><strong>Median (SD)</strong></td>
</tr>
<tr>
<td>Poor quality of life</td>
<td>55%</td>
<td>4 (4,5)</td>
</tr>
<tr>
<td>Poor quality of life in future</td>
<td>5 (4,5)</td>
<td></td>
</tr>
<tr>
<td>Ready to die</td>
<td>54%</td>
<td>5 (4,5)</td>
</tr>
<tr>
<td>Saw existence as pointless</td>
<td>47%</td>
<td>5 (3,5)</td>
</tr>
<tr>
<td>Life tasks completed</td>
<td>18%</td>
<td>3 (2,5)</td>
</tr>
</tbody>
</table>

<sup>1</sup> Patients who requested PAD  
<sup>2</sup> Hospice clients who received a lethal prescription. Score 1=not important, 5=very important  
<sup>3</sup> Patients who made an actual request. 1=not important, 5=very important  
<sup>4</sup> IQR-Interquartile range

### Role of Depression in Requests for PAD

<table>
<thead>
<tr>
<th>Depression</th>
<th>Physician Study&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Hospice Practitioners Survey&lt;sup&gt;2&lt;/sup&gt;</th>
<th>Requesting Patients Study&lt;sup&gt;3&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=143</td>
<td>N=82</td>
<td>N=58</td>
</tr>
<tr>
<td>Prevalence</td>
<td>20%</td>
<td>Median (IQR)&lt;sup&gt;4&lt;/sup&gt; 2 (1,3)</td>
<td>Median (IQR)&lt;sup&gt;4&lt;/sup&gt; 1 (1,2)</td>
</tr>
<tr>
<td>No. (%)</td>
<td></td>
<td></td>
<td>15 (24)</td>
</tr>
</tbody>
</table>

1. Patients who requested PAD
2. Hospice clients who received a lethal prescription. Score 1=not important, 5=very important
3. Patients who made an actual request. 1=not important, 5=very important
4. IQR-Interquartile range

Desire for Control, Independence, Dignity in Patients who Request or Receive a Lethal Prescription

<table>
<thead>
<tr>
<th></th>
<th>Physician Study N=143(^1)</th>
<th>Hospice Nurses Study N=82(^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prevalence</strong></td>
<td></td>
<td><strong>Median</strong></td>
</tr>
<tr>
<td>Wanted to die at home</td>
<td>28%</td>
<td>5</td>
</tr>
<tr>
<td>Fear of loss of independence</td>
<td>57%</td>
<td>4</td>
</tr>
<tr>
<td>Control circumstances of death</td>
<td>53%</td>
<td>5</td>
</tr>
<tr>
<td>Loss of dignity</td>
<td>42%</td>
<td>4</td>
</tr>
</tbody>
</table>

1 Patients who requested PAD  
2 Hospice clients who received a lethal prescription. Score 1=not important, 5=very important  
3 IQR-Interquartile range

Requesting Patients’ (N=56) Reasons: Independence, Control, Self-sufficiency

<table>
<thead>
<tr>
<th>Reason</th>
<th>Current State median (IQR)</th>
<th>Future State median (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of independence</td>
<td>5 (3,5)</td>
<td>5 (3,5)</td>
</tr>
<tr>
<td>Inability to care for self</td>
<td>1 (1,2)</td>
<td>5 (3,5)</td>
</tr>
<tr>
<td>Control circumstances of death</td>
<td>5 (4,5)</td>
<td></td>
</tr>
<tr>
<td>Not wanting to be cared for by others</td>
<td>3 (1,5)</td>
<td></td>
</tr>
<tr>
<td>Wanting to die at home</td>
<td>3 (1,5)</td>
<td></td>
</tr>
</tbody>
</table>

1 = not important, 5 = very important

_Ganzini et al 2009_
“… (Regarding several requests.) “But these were individuals who wanted control of their lives, and it was mostly control issues. And they sort of stated that right up front. It had nothing to do with the care that they were getting. And they would return to it and return to it and you could say, ‘Well you know we are doing all we can. And we are making this commitment to you. And we will try to take care of you.’ But you know they sort of fixated on ending their lives from the get go.”

“I think her big fear was loss of control. She wanted to control things right up to the end. She wanted to plan it. She wanted things to go the way she wanted it. And she didn’t want to wait. She did not want to take a chance at waiting until it would not be under her control any more. She was very in charge. But you know she was…most people like that can be little bit difficult to deal with and the like. She was not like that at all.”

Ganzini et al, 2003
“He was a very stable patient. He wasn’t someone who was in a lot of pain, physically. And he was the captain of his own boat. That’s how he had been his entire life. And he wanted to die a certain way. And he did it. I think he just wanted to have ultimate control.” (Hospice Nurse)

“So she was a control person. You know, we are talking big time control…You know, ‘I am in charge here.’ She sort of self-directed her medical care.”

Ganzini et al, 2003; Miller et al 2004
Independence/Self-sufficiency

“She had a very strong personality. She was very active and independent. This was a real important part of her life…Her own personal philosophy dictated that communication and self-determination are the most important things in her life.”

“He was a typical rural resident in the sense he is tough, macho, in control-of-himself-and-everything-else-kind of fellow.”

“He was a very strong-willed sort of patriarchal type of figure. He was a very independent soul.”

Ganzini et al, 2003
Hospice Nurses’ Views of How Family Caregivers of 82 Clients Who Receive a Lethal Prescription Differ From Other Hospice Clients’ Family Caregivers

- Found Positive Meaning in Caring for Family Member, N=73:
  - More Than Other Family Caregivers: 43%
  - About the Same as Other Family Caregivers: 41%
  - Less Than Other Family Caregivers: 16%

- Burdened by Caring for Ill Family Member, N=74:
  - More Than Other Family Caregivers: 11%
  - About the Same as Other Family Caregivers: 58%
  - Less Than Other Family Caregivers: 31%

- Burdened by Cost of Caring for Family Member, N=74:
  - More Than Other Family Caregivers: 3%
  - About the Same as Other Family Caregivers: 34%
  - Less Than Other Family Caregivers: 64%
# Mental Health Outcome for Family Members

<table>
<thead>
<tr>
<th></th>
<th>PAD Family Members (N=95)</th>
<th>Comparison Family Members (N=63)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Major Depressive Disorder, No. (%)</td>
<td>10 (10.5)</td>
<td>9 (14.3)</td>
<td>NS</td>
</tr>
<tr>
<td>Current Beck Depression Score, Mean (SD)</td>
<td>7.1 (5.9)</td>
<td>8.5 (7.8)</td>
<td>NS</td>
</tr>
<tr>
<td>Prolonged Grief, Mean (SD)</td>
<td>22.5 (7.4)</td>
<td>24.6 (8.8)</td>
<td>NS</td>
</tr>
<tr>
<td>Prolonged Grief Disorder, No. (%)</td>
<td>3 (3.2)</td>
<td>0 (0)</td>
<td>NS</td>
</tr>
</tbody>
</table>
## Family Member Views on Loved One’s Choices at the End of Life

<table>
<thead>
<tr>
<th>Family Member Views¹</th>
<th>Loved One Requested Aid in Dying (N=95)</th>
<th>Comparison Family Members (N=63)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was at peace with loved one’s end of life choices</td>
<td>3.8 (0.6)</td>
<td>3.7 (0.6)</td>
<td>0.37</td>
</tr>
<tr>
<td>Felt burdened by loved one’s care</td>
<td>1.5 (0.8)</td>
<td>1.4 (0.8)</td>
<td>0.58</td>
</tr>
<tr>
<td>Felt included in loved one’s decisions</td>
<td>3.6 (0.8)</td>
<td>3.5 (0.9)</td>
<td>0.44</td>
</tr>
<tr>
<td>Accepted loved one’s death</td>
<td>3.8 (0.5)</td>
<td>3.6 (0.7)</td>
<td>0.05</td>
</tr>
</tbody>
</table>

¹ 4-point scale with 1=not at all and 4=a great deal; mean (standard deviation)
Family Member Views on Loved One’s Choices at the End of Life

<table>
<thead>
<tr>
<th>Family Member Views¹</th>
<th>Loved One Requested PAD (N=95)</th>
<th>Comparison Family Members (N=63)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had regrets about how loved one died</td>
<td>1.9 (1.2)</td>
<td>2.2 (1.3)</td>
<td>0.13</td>
</tr>
<tr>
<td>Felt prepared for death</td>
<td>3.2 (1.0)</td>
<td>2.8 (1.2)</td>
<td>0.02</td>
</tr>
<tr>
<td>Wanted more opportunities to care for loved one</td>
<td>1.7 (1.0)</td>
<td>2.1 (1.3)</td>
<td>0.03</td>
</tr>
<tr>
<td>Was surprised at loved one’s end of life choices</td>
<td>1.4 (0.8)</td>
<td>1.3 (0.7)</td>
<td>0.40</td>
</tr>
</tbody>
</table>

¹ 4-point scale with 1=not at all and 4=a great deal; mean (standard deviation)
## Family Members’ Perceptions of Death among PAD Requestors

<table>
<thead>
<tr>
<th></th>
<th>Received Prescription</th>
<th>Did Not Receive Prescription</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regretted how loved one died¹</td>
<td>1.6 (1.0)</td>
<td>2.5 (1.2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Patients’ end of life preferences honored¹</td>
<td>3.9 (0.4)</td>
<td>3.2 (1.2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Caring for loved one was a burden¹</td>
<td>1.3 (0.6)</td>
<td>1.7 (0.9)</td>
<td>0.03</td>
</tr>
<tr>
<td>Rating of quality of life last 10 days²</td>
<td>4.2 (2.8)</td>
<td>2.9 (2.2)</td>
<td>0.03</td>
</tr>
</tbody>
</table>

1. 0=not at all, 4=great deal  
2. 0=terrible, 10=almost perfect  
Mean (standard deviation)
The primary reasons Oregonians request PAD are to increase sense of control and avoid dependence on others.

Patients are more motivated to request PAD because of worries about symptoms in the future, not symptoms they are experiencing at the time of the request.

Life long values and coping styles influence requests.

20-25% of requesting Oregonians have clinical depression, but it is unknown how this influences the request.

Pursuing PAD is not associated with increased risk of adverse mental health outcomes in family members.