California End of Life Option Act

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Agenda

- Prevalence
  - Physician Aid in Dying in the United States
  - Physician Aid in Dying in California
- California End of Life Option Act Deconstructed
- Other Practices Distinguished from Physician Aid in Dying
- The Requirements
- Ethical Considerations
- Position Statements

Death with Dignity in 2018: Policy Advocacy and Collaborations
The Law:
California End of Life Option Act

“This bill would enact the End of Life Option Act authorizing an adult who meets certain qualifications, and who has been determined by his or her attending physician to be suffering from a terminal disease, as defined, to make a request for a drug prescribed pursuant to these provisions for the purpose of ending his or her life.”

The law went into effect June 9, 2016.
Lessons from Oregon:
Criticisms of Oregon Death With Dignity Act

- Limited Data
- Data on Palliative Care Interventions are Incomplete
- Lack of Data on Psychiatric/Psychological Evaluations
- Insufficient Evidence of an Informed Decision

A CRITICAL ANALYSIS OF CRITICISMS OF THE DEATH WITH DIGNITY ACT
JAMES L. WERTH, JR., HOWARD WINEBERG, Death Studies, 29.1 - 27, 2005
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+ Other Practices Distinguished from Physician Aid in Dying

- **Euthanasia:**
  - Death caused by an intentionally lethal dose of medication ordered by a physician and administered by a physician or nurse.
  - **Voluntary:** with patient awareness and consent
  - **Involuntary:** without patient awareness or consent

- **Physician-assisted suicide:**
  - Death caused by an intentionally lethal dose of medication ordered by a physician and self-administered by a patient

+ Other Practices Distinguished from Physician Aid in Dying

- **Withholding/withdrawing life-sustaining treatments:**
  - an informed decision to refuse life-sustaining treatment,
  - the right of a competent adult patient to refuse life-sustaining treatments is supported by law.

- **Pain medication that may hasten death:**
  - A suffering patient may require dosages of pain medication that have side effects that may hasten death, such as impairing respiration
  - the ethical principle of double effect as the foundational ethical argument that offers justification that this action is acceptable
  - Since the primary goal and intention of administering these medications is to relieve suffering, the secondary outcome of potentially hastening death is recognized as an expected and acceptable side-effect in a terminally ill patient
Other Practices Distinguished from Physician Aid in Dying

- **Palliative sedation:**
  - The practice of sedating a terminally ill patient to the point of unconsciousness, due to intractable pain and suffering that has been refractory to traditional medical management.
  - Such patients are imminently dying, usually hours or days from death.
  - Often other life-sustaining interventions continue to be withheld (CPR, respirator, antibiotics, artificial nutrition and hydration, etc.) while the patient is sedated.
  - Palliative sedation may occur for a short period (respite from intractable pain) or the patient may be sedated until s/he dies.
  - In the rare instances when pain and suffering is refractory to treatment even with expert clinical management by pain and palliative care professionals, palliative sedation may legally and ethically be employed.

Voluntary Cessation of Eating and Drinking

- Legal alternative to PAD.
- Some terminally ill patients with decisional capacity will make this choice.

**End-of-Life Concerns in Oregon, USA**

<table>
<thead>
<tr>
<th>Concern</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Losing autonomy</td>
<td>91%</td>
</tr>
<tr>
<td>Less able to engage in activities</td>
<td>90%</td>
</tr>
<tr>
<td>Making life unbearable</td>
<td>76%</td>
</tr>
<tr>
<td>Loss of dignity</td>
<td>6%</td>
</tr>
<tr>
<td>Losing control of bodily functions</td>
<td>46%</td>
</tr>
<tr>
<td>Burden on family, friends, caregivers</td>
<td>44%</td>
</tr>
<tr>
<td>Inadequate pain control or concern about it</td>
<td>26%</td>
</tr>
<tr>
<td>Financial implications of treatment</td>
<td>8%</td>
</tr>
</tbody>
</table>
Criteria for Eligibility

- The individual has a terminal disease with a prognosis of less than 6 months.
- The individual must be at least eighteen years old with the capacity to make medical decisions.
- The individual has voluntarily expressed the wish to receive a prescription for an aid-in-dying drug.
- The individual is a resident of California and is able to establish residency.
- The individual makes 2 verbal requests (at least 15 days apart) and a written request on the form required by the Act.

Criteria for Eligibility

- The individual has the physical and mental ability to self-administer the aid-in-dying drug.
- The individual does not have impaired judgment due to a mental disorder.
- A request for a prescription for an aid-in-dying drug cannot be made on behalf of a patient. The request must be made directly by the individual diagnosed with the terminal disease.

California Requirements for Data

- The number of people for whom an aid-in-dying prescription was written.
- The number of known individuals who died each year for whom aid-in-dying prescriptions were written, and the cause of death of those individuals.
- Total number of aid-in-dying prescriptions written
- Number of people who died due to use of aid-in-dying drugs
- Number of those people who died who were enrolled in hospice or other palliative care programs at the time of death.
- Number of known deaths in California from using aid-in-dying drugs per 10,000 deaths in California.
- The number of physicians who wrote prescriptions for aid-in-dying drugs.
California Requirements for Data

Patient Demographics:
- Age at death.
- Education level.
- Race.
- Sex.
- Type of insurance, including whether or not they had insurance.
- Underlying illness.

California Data:
From January 1, 2017 through December 31, 2017

Figure 1: Summary of EOLA Prescriptions Written in 2017

2017 Prescriptions
177 individuals had prescriptions written in 2017

- 363 reported and died from the drug prescribed in 2017
- 96 did not report and died suddenly from unknown causes
- 5 individuals with unknown outcomes
Among those with malignant cancer as the underlying terminal disease—the largest group of individuals who utilized the Act—lung cancer accounted for 17.2 percent, breast cancer accounted for 11.5 percent, head and neck cancers comprised 10.9 percent, pancreatic cancer comprised 9.8 percent, and 8.2 percent had prostate cancer. Other malignant neoplasms accounted for the remaining 42.6 percent, as shown in Figure 3.

Table 1. Characteristics of the End of Life Option Act individuals who utilized the Act in 2017

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>108</td>
<td>43.5%</td>
</tr>
<tr>
<td>Black</td>
<td>31</td>
<td>11.7%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>15</td>
<td>5.6%</td>
</tr>
<tr>
<td>Asian</td>
<td>8</td>
<td>3.0%</td>
</tr>
<tr>
<td>American Indian</td>
<td>7</td>
<td>2.6%</td>
</tr>
<tr>
<td>Native Hawaiian</td>
<td>6</td>
<td>2.2%</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>3.6%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>138</td>
<td>50.0%</td>
</tr>
<tr>
<td>Female</td>
<td>132</td>
<td>46.8%</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>138</td>
<td>50.0%</td>
</tr>
<tr>
<td>Female</td>
<td>132</td>
<td>46.8%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No High School Diploma</td>
<td>11</td>
<td>4.0%</td>
</tr>
<tr>
<td>High School Diploma or General Education Completion</td>
<td>16</td>
<td>5.8%</td>
</tr>
<tr>
<td>Some College or Technical School</td>
<td>32</td>
<td>11.5%</td>
</tr>
<tr>
<td>2-Year College or Community College</td>
<td>10</td>
<td>3.6%</td>
</tr>
<tr>
<td>4-Year College or Bachelor Degree</td>
<td>23</td>
<td>8.3%</td>
</tr>
<tr>
<td>Master’s or Professional Degree</td>
<td>22</td>
<td>7.9%</td>
</tr>
<tr>
<td>Doctorate or Higher Degree</td>
<td>14</td>
<td>5.0%</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>189</td>
<td>67.0%</td>
</tr>
<tr>
<td>Married</td>
<td>83</td>
<td>30.0%</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>0.3%</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>0.3%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>2.1%</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>112</td>
<td>40.0%</td>
</tr>
<tr>
<td>Part-time</td>
<td>45</td>
<td>16.0%</td>
</tr>
<tr>
<td>Not employed</td>
<td>11</td>
<td>4.0%</td>
</tr>
<tr>
<td>Never</td>
<td>4</td>
<td>1.4%</td>
</tr>
<tr>
<td>Former</td>
<td>13</td>
<td>4.7%</td>
</tr>
<tr>
<td>Source of Life Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Security Benefits</td>
<td>1</td>
<td>0.3%</td>
</tr>
<tr>
<td>Medicare</td>
<td>53</td>
<td>18.3%</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
<td>6.3%</td>
</tr>
<tr>
<td>Not Enrolled</td>
<td>13</td>
<td>4.6%</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
<td>1.0%</td>
</tr>
</tbody>
</table>
“About 80 percent of private insurance companies have covered the cost of medication, including Blue Cross, Blue Shield, Kaiser Permanente, Sutter, many local health plans and all Medi-Cal plans.”

Preferred Medication

- **Cocktail**
  - Pre-Medication to Prevent Nausea/Vomiting
    - Reglan
    - Zofran
  - Optional Medication to Prevent Prolonged Death
    - Inderal (propranolol) – 200 mg
  - Life-ending Medication
    - Seconal (secobarbital) – 9 grams (90 capsules)
    - Mixed in water or other liquid to be ingested immediately and quickly

+ The End of Life Option Process

**The Attending Physician**

- The Law defines as:
  - The physician who has primary responsibility for the health care of an individual and treatment of the individual’s terminal disease.
- Responsible to assess that the patient meets the criteria for the End of Life Option Act.
- Receives the patient’s verbal request for the aid-in-dying drug.
The End of Life Option Process: Specifics

*Attending Physician*

- **Makes the initial determination of whether the patient is "qualified" to receive an aid-in-dying drug under the End of Life Option Act.**
- **Confirm that the patient is making an informed decision.**
- **Confirm that the patient’s request does not arise from coercion or undue influence.**

The End of Life Option Process:*

*Attending Physician*

- **Counsels the patient.**
- **Inform the patient that he or she may withdraw or rescind the request for an aid-in-dying drug at any time and in any manner.**
- **Offer the patient an opportunity to withdraw or rescind the request for an aid-in-dying drug before prescribing the drug.**

The End of Life Option Process

*The Consulting Physician*

- **The law defines as:**
  - A physician who is independent from the attending physician and who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding an individual’s terminal disease.
  - Responsible for confirming that the patient meets the criteria for eligibility for the End of Life Option Act.
The End of Life Option Process

The Attending Physician
- Patient returns at least 15 days after their 1st request to give their 2nd verbal request for the aid-in-dying drug and to give their written request to the Attending Physician.
- After this appointment, the Attending Physician can write the prescription.

Consulting Psychiatrist (as appropriate)
- Determines that the patient has capacity to make medical decisions and is not suffering from impaired judgment due to a mental disorder
- Patients only need to see a psychiatrist if the Attending or Consulting Physician requests the consultation.

Other safeguards:
- 2 witness must be present when patient signs written request
- At least one witness must not be related to the patient or be entitled to any inheritance
- At least one witness must not be employed by the facility where patient is receiving care
- The physician who prescribes the prescription cannot be related to the patient or stand to inherit anything
- An interpreter who assists cannot be related or be eligible for an inheritance
- Patients cannot be denied life or health insurance benefits based on participating in aid in dying
Common Arguments In Support Physician Aid in Dying:
Adapted from Bioethics Topics, Physician Aid in Dying, University of Washington School of Medicine

- Respect for autonomy:
  - Competent adults should have the right to choose the timing and manner of death.

- Justice:
  - Justice requires us to "treat like cases alike." Competent, terminally ill patients have the legal right to accept or refuse treatment that will prolong their deaths. For patients who are terminally ill but who are not dependent on life support, refusing treatment will not bring death quickly. To treat these patients equitably we should allow physician assisted death as it is their only option to hasten death. (The U.S. Supreme Court rejected this argument in Vacco v. Quill, 522 U.S. 793 (1997))

- Compassion:
  - PAD may be a compassionate response to unremitting suffering.

Common Arguments Against PAD:
Adapted from Bioethics Topics, Physician Aid in Dying, University of Washington School of Medicine

- Individual liberty vs. state interest:
  - Though society has a strong interest in preserving life, that interest lessens when a person is terminally ill and has a strong desire to end life. A complete prohibition against PAD excessively limits personal liberty.

- Honesty and transparency:
  - Some acknowledge that assisted death already occurs, albeit in secret. Legalization of PAD would promote open discussion and may promote better end-of-life care as patients and physicians could more directly address concerns and options.

- Protection of life:
  - Religious and secular traditions upholding the sanctity of human life would be diminished by PAD.

- Passive vs. active distinction:
  - PAD equates to killing (active) and is not morally justifiable.

- Protection of vulnerable groups:
  - Vulnerable populations, lacking access to quality care and support, may be pushed into assisted death and used as a cost containment strategy.

- Palliative Care and Hospice:
  - Better and more accessible care would reduce the need for PAD.
Common Arguments Against PAD:
from Bioethics Topics, Physician Aid in Dying, University of Washington School of Medicine

- **Professional integrity:**
  - Historical ethical traditions in medicine are strongly opposed to taking life. The overall concern is that linking PAD to the practice of medicine could harm both the integrity and the public's image of the profession.

- **Fallibility of the profession:**
  - The concern here is that physicians will make mistakes. Thus the State has an obligation to protect lives from these inevitable mistakes and to improve the quality of pain and symptom management at the end of life.

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**Position Statements**

- **AMA**
  - Opinion 2.211 - Physician-Assisted Suicide: "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"

- **CMA**
  - In May 2015, The California Medical Association removed longstanding opposition to physician aid-in-dying last May and took a neutral position on the End of Life Option Act, Senate Bill 128
  - "allows physicians to determine between themselves and patients whether they want to participate in the End of Life Option Act"

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**Position Statements**

- **American Academy of Hospice and Palliative Care**
  - "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...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.

*this position neither endorses nor opposes, but is intended to respect irreducible differences in values and deeply held positions*
Position Statements

- **American Society of Health-System Pharmacists**
  - supports the right of a pharmacist to participate or not in morally, religiously, or ethically troubling therapies.

- **ANA**
  - prohibits nurses' participation in assisted suicide and euthanasia
  - these acts are in direct violation of Code of Ethics for Nurses with Interpretive Statements (ANA, 2001; herein referred to as The Code), the ethical traditions and goals of the profession, and its covenant with society.
  - Nurses have an obligation to provide humane, comprehensive, and compassionate care that respects the rights of patients but upholds the standards of the profession in the presence of chronic, debilitating illness and at end-of-life.

Themes from California Statewide Convening Conference, September 2017

- Medical Aid in Dying still fraught with controversy and there continues to be a divide in perspectives about whether it should be offered and how it’s offered
- Perception that the media has largely reported only on the “successes”, demonstrating an inherent bias in favor of this type of “choreographed” dying
- Strong consensus, however, that any discussion about aid-in-dying serve as an invitation to discuss goals of treatment, palliative and hospice care
- Recognition there are adverse and strong emotional and psychological effects on physicians and other clinicians who are closely involved, that are not being addressed