Physician Assisted Dying in California

Outline of Talk

- Defining terms associated with Physician Aid in Dying (PAD)
- Ethics and debates surrounding PAD
- Overview of the End of Life Options Act
- How to respond to PAD requests
- How PAD is administered
- Questions to consider when responding to the law

Case Presentation

- 72 widowed woman with metastatic breast cancer tells her PMD that she “no longer wants to live.” She denies feeling depressed, and endorses fatigue, anorexia, insomnia, joint pain.
- She asks, “Have you heard of that new law? Will you help me use it when the time comes?”

What is physician aid-in-dying?

- physician provides a competent, terminally ill patient with a prescription for a lethal dose of medication, upon the patient's request, which the patient intends to use to end his or her own life.
- Physician Aid in Dying (PAD) versus Physician Assisted Suicide (PAS)
**PAD vs Euthanasia**

**Physician Aid in Dying (PAD)**
- Patient must self-administer drug
- Physician provides the medications, but the patient decides whether and when to ingest
- Legal in Oregon, Washington, Vermont, Montana, and soon California

**Euthanasia**
- Physician administers the medication or acts directly to end the patient’s life
- Illegal in every state in the US

**Other practices distinct from PAD**

**Withholding/withdrawing life-sustaining treatments:**
- A competent adult patient or their surrogate makes an informed decision to refuse life-sustaining treatment

**Pain medication that may hasten death:**
- A terminally ill, suffering patient may require doses of pain medications that cause side effect that may hasten death, such as impairing respiration
- Principle of double effect: Primary goal is relief of suffering, secondary outcome is recognizing that death may be potentially hastened.

**Palliative sedation:**
- Sedating a terminally ill patient to the point of unconsciousness
- Intractable pain and suffering refractory to medical management
- Imminently dying (hours to days)
- Other life-sustaining interventions held, “comfort care”

**Ethics and debates surrounding PAD**

**Did you (personally) oppose or support the End of Life Option Act**

A. Yes
B. No
C. Undecided

A: 70%
B: 14%
C: 16%
Why have people advocated for PAD?

- Brittany Maynard, 29 year old with terminal brain cancer who ended her life in Oregon and advocated for PAD
- Views that death is an process that is invariably painful and full of suffering.
- Inadequate access to palliative care

PAD and Patient Autonomy

- Societal trends that support individual autonomy and self-determination
- Societal backlash against overly aggressive care at the end of life
- Is PAD a societal attempt to regain control over death?
- Is more choice, rather than guidance and support or a more humanistic profession that fosters a “good death” the best?
Physician as Healer or Harmer?

- Ethical concerns included the physicians’ oath of non-maleficence
- “First do no harm” – overly aggressive treatments at the end of life, treatments that do more harm than good
- What is the role of physician as healer? What about the role to relieve suffering Commitment to holistic and spiritual healing? Guiding patients through death?

Concerns about PAD

- Vulnerable populations (disability, minority communities, elders, unbefriended, etc.)
  - fear of coercion and secondary gain
  - fear of being a burden as a motivation
- Legalizing PAD without having adequate palliative care resources can be seen as morally problematic

Changing norms

Long-term normative effects of PAD on social norms
- Perpetuates assumptions that death is an unbearably painful process
- Creates an ethical norm that death can be a easy solution to problems
- Influences perceptions of self-worth and the value of life, especially amongst disability community (i.e. ableism)
“Slippery Slope” Argument

• End of Life clinic in the Netherlands (second opinion clinic). In 2012, of 645 applications, 25% (162) approved
• Belgium has legalized PAD in children
• Depression qualifies for PAD in Netherlands

Do you practice in California?

A. Yes
B. No

Timeline of the EOL Option Act

• ABx2 15 was signed into law by Governor Jerry Brown on Oct 5, 2015
• Law to go into effect 90 days after the close of the special legislative session
• This session ended on March 10, 2016
• The law went into effect on June 9, 2016
1/5 of the US population now able to request PAD

<table>
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<th>Population (in millions)</th>
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<tbody>
<tr>
<td>United States</td>
<td>318.9</td>
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<tr>
<td>California</td>
<td>38.8</td>
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<tr>
<td>Washington</td>
<td>7.06</td>
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<td>1.02</td>
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<tr>
<td>Vermont</td>
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California as a Watershed

Who considers PAD in OR? (Tolle, 2014; OHA, 2015)
- 98% white
- 78% over 65 years old
- 43% had at least a college degree

End of Life Option Act

Allows terminally ill patients to request a drug that will end the patient’s life
- Must be 18 or older and a resident of California
- Must have a terminal disease with a prognosis of less than 6 months to live
- Must have the capacity to make decisions
- Not have impaired judgment due to a mental disorder
- Have the ability, mentally and physically, to take the drug independently
- Cannot be requested in advance directive, nor by surrogates

If a patient were to ask you for aid in dying, would you be willing to provide it?

A. Yes
B. No
C. Undecided

Survey Results:
- Yes: 41%
- No: 27%
- Undecided: 31%
Opting Out and Conscientious Objection

- Any provider can decline to participate for reasons of “conscience, morality, or ethics”
- Health care institutions can opt out
  - May not prohibit providers from providing diagnosis, prognosis, counseling, clinical options, or referral to a prescribing physician (except VA)

Moving Forward

- Law has passed, how can both sides come together to provide ethical care?
- Regardless of whether you support it, need to respond (not necessarily implement)
- This will mostly be an outpatient and hospice issue (90% of Oregon ingestions at home, 92% enrolled in hospice)

Do you have concerns about the law’s implementation?

A. Yes 42%
B. No 25%
C. Undecided 33%

Getting a request for PAD
Have you had a patient ask you for aid in dying?

A. Yes  
B. No

Have you had a patient ask you for aid in dying?

A. Yes  
B. No

How often do patients think about aid in dying?

10% of dying patients consider PAD

1% of those patients request PAD

1 in 10 of those who request ingest

Why do patients ask for aid in dying?

- Oregon 2015 data

What to do if you get a request?

How prepared do you feel you are to respond to the act?

A. Very prepared
B. Moderately prepared
C. Not very prepared
D. Completely underprepared

Supporting the patient

- Support the patient, reinforce commitment to finding an acceptable solution, regardless of your personal views
- Reflect on your personal views on PAD and death and how that might influence the way you communicate
- Respond empathetically to emotion

Slide courtesy of Laura Petrillo
Exploring the Request

- Clarify what is being asked before responding
- Explore reasons for the request
- Assess whether palliative care needs (i.e. pain and symptom control) are being adequately addressed
- Explore other reasons that may be contributing to unbearable suffering including family, spiritual or existential crisis. Take into account patient’s support system
- Evaluate for capacity and screen for depression or other mental health issues

Exploring the Request

- Assess understanding of diagnosis, prognosis and goals of care
- Assess whether palliative care needs (i.e. pain and symptom control) are being adequately addressed and intensify symptom management and treatable causes of suffering
- Discuss alternatives - Hospice referrals, social work referrals, etc.
- Help patient complete POLST, DNR or other appropriate advanced directive forms

What Patients Value

- Openness to discussing PAD, death, and dying
- They understand PAD is controversial so appreciate a physician who can transcend taboo and discuss it maturely and professionally
- Important to maintain therapeutic alliance and support patient regardless of whether clinician supports PAD

How is PAD Administered?
The Process

- Attending physician must determine prognosis and capacity
- Patient must make two oral requests at least 15 days apart directly to the same physician, as well as one written request
- Written request on a special form that is witnessed and signed by patient
- Must be done without anyone else present (except interpreter) to insure voluntariness

The Process

- The patient must then see a second physician (consulting physician) who can confirm diagnosis, prognosis, and capacity
- If either physician thinks the patient may have a mental disorder, they must also see a mental health specialist to ensure unimpaired judgment

The Process

- The patient and physician must discuss
  - How the drug will affect the patient, and that death might not come immediately
  - Realistic alternatives to PAD including hospice, PC and pain control
  - Whether the patient wants to withdraw the request
  - Whether the patient will notify next of kin, whether someone else will be present, or participate in hospice (none of these required)

The Process

- Prescription written
- Final Attestation: Patient must sign a form 48 hours before taking drug saying they took the drug voluntarily (new CA addition)
The Ingestion Process
(Orentlicher, 2015 JPM)

1. Antiemetic (zofran or metaclopramide) first administered
2. 45-60 mins they ingest 9g of a short-acting barbiturate (i.e. secobarbital or pentobarbital),
3. The powdered barbiturate is mixed with half a cup of water into a slurry
4. It should be ingested quickly within 30-120 seconds, otherwise they may fall asleep before ingesting the full dose
5. May drink juice or liquids but not fatty foods
6. In OR/WA, to maintain confidentiality, death certificate usually includes “respiratory failure” or the underlying terminal disease as immediate cause of death

Potential Complications
(Dunn, Tolle, 2008)

- Complications or technical problems in 10% (Netherlands)
- Delayed death (up to 48 hours)
- Regurgitation, nausea/vomiting
- May lead to EMS activation and ER visit
- Institutional response will need to include EMT/ED protocol

Barriers to PAD

- Lengthy process is physically, emotionally and mentally demanding.
- Secobarbital costs $3000 though private insurance and MediCal will cover
- Access of drug (i.e. not available at corner pharmacy). Pentobarbital not available in the US.
- Primary care physicians may not have experience in PAD nor palliative care

How PAD might affect you

- Moral distress likely to be a significant issue
- More challenging if patient appears “well”
- Recognize importance of interdisciplinary team. Work with your support staff including nurses, translators, social workers, chaplains, etc.
- Recognize that support staff will also need training and support
- Use support of palliative care consult if available at your institution
### Unanswered questions

- Should a PC consult be institutionally mandated? Ethics consult? Psych consult?
- Who should administer the drug and go through this process? The patient’s PMD/attending or a specially trained group? How do you ensure continuity and support?
- How would education and training occur?
- How would monitoring work?
- Will patients be permitted to take the drug on hospital grounds?
- How will institutions deal with individuals opting out?
- How will referrals work for institutions that have opted out? (i.e. VAMC, Catholic hospitals)
- Safe drug disposal?

### Case, revisited

- PMD explores request → learns quality of life significantly impacted by pain, fatigue
- PMD commits to supporting patient
- Refers to Symptom Management Service (SMS)
- Contacts a social worker to begin UCSF process of determining eligibility for End of Life Option Act

### Case, revisited

- Patient learns about options at SMS, gets help at home, decides to put End of Life Option Act process on hold until she has tried SMS suggestions
- Two years later, the patient died peacefully at home, on hospice. She had never reinitiated her request.

### Resources

- EOLARC website (Password: ethics)
  [http://www.eoloptionacttaskforce.org/resources.html](http://www.eoloptionacttaskforce.org/resources.html)
- UC Hastings EOL Option Act Fact Sheet:
- AAHPM Position Statement:
  [http://aaahpm.org/positions/padbrief](http://aaahpm.org/positions/padbrief)
- Coalition for Compassionate Care
- CAPC Fast Facts
  [http://www.mypcnnow.org/#blank/pbq3i](http://www.mypcnnow.org/#blank/pbq3i)
  [http://www.mypcnnow.org/#blank/q24s](http://www.mypcnnow.org/#blank/q24s)
- Oregon Death With Dignity Act Guidebook