End-of-Life Options Act: An Overview of the New Aid-in-Dying Law

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Disclosures

As part of the commercial guidelines, I am disclosing I have no affiliations or financial arrangements with any corporate organization relating to this presentation.

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Objectives and Outline of Presentation

- Background
- An Overview of the End of Life Option Act
- The Oregon Experience
- A Framework to facilitate
  - Institutional Decision Making
  - Personal Decision Making
- Response to Request for Aid in Dying
"I'm choosing to suffer less. To put myself and my family through less pain."
The world is a beautiful place, travel has been my greatest teacher, my close friends and folks are the greatest givers. I even have a ring of support around my bed as I type… Goodbye world. Spread good energy. Pay it forward!

Brittany Maynard
Maggie Karner, woman who challenged assisted suicide laws, has died from cancer

Maggie Karner, the woman who sent a video to Brittany Maynard, the assisted-suicide supporter who took her own life, has died from the same cancer that Maynard had.

On October 29, 2014, Karner bravely opened up to the nation about life with cancer, urging Maynard to choose life and spend precious time allowing those who love her to care for her. Both women were diagnosed with glioblastoma multiforme brain cancer and weren’t given much time to live. The weekend after Karner’s...
This week, he did an interview with New Jersey radio personality Bill Spadea, and he talked about why it’s insulting to people with terminal illnesses to call it “death with dignity” and to advocate for assisted suicide.

“I was told you don’t have an option. You can die dignified if you commit suicide. Whoa, wait a second. The whole terminology is flipping on its head. If you give up and you don’t fight, somehow you’re compassionate and dignified. But if you want to fight and you want to live, you lack compassion and dignity. To me it just doesn’t make sense. It’s kind of a reflection of where our society is.”

JJ Hanson

It’s All About Choice

• I would not tell anyone that he or she should choose death with dignity. My question is: Who has the right to tell me that I don’t deserve this choice? That I deserve to suffer for weeks or months in tremendous amounts of physical and emotional pain. Why should anyone have the right to make that choice for me? – Brittany Maynard

• The crux of the matter is whether the State of California should continue to make it a crime for a dying person to end his life, no matter how great his pain and suffering. My decision is personal, based on reflections on what I would want in the face of my own death. . . I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn’t deny that right to others. – Governor Jerry Brown, upon signing into law Assembly Bill 15, the End of Life Option Act, in October 2015
We Need our Patient’s Voices To Direct Medical Care

- Patients' preferences were not discussed and documented before a life-threatening crisis occurred.
  - nearly 8 in 10 Californians said that if they were seriously ill, they would want to speak with their doctor about end-of-life care, but fewer than 1 in 10 report having had such a conversation, including just 13% of those age 65 and older.

http://www.chcf.org/publications/2012/03/improving-care-eol#ixzz3YbgeVsTZ
Other Ways to Express Wishes

LIVING WILL
DO NOT put this person on artificial life support of any kind for any reason what so ever.
DO harvest reusable parts when he is dead, and then cremate all that remains.

Lee Su
Witness 1
Witness 2

DO NOT RESUSCITATE

CONSIDER
DNE
No CPR

the MIRACLE of SCIENCE with SOUL City of Hope
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.

Opinion 2.211 - Physician-Assisted Suicide
American Medical Association Code of Medical Ethics

The American College of Physicians–American Society of Internal Medicine (ACP–ASIM) does not support the legalization of physician-assisted suicide. The routine practice of physician-assisted suicide raises serious ethical and other concerns. Legalization would undermine the patient–physician relationship and the trust necessary to sustain it; alter the medical profession’s role in society; and endanger the value our society places on life, especially on the lives of disabled, incompetent, and vulnerable individuals. The ACP–ASIM remains thoroughly committed to improving care for patients at the end of life.

Position Paper on Physician-Assisted Suicide

The decision to participate in the End of Life Option Act is a very personal one between doctor and patient, which is why the California Medical Association has removed policy that outright objects to physicians aiding terminally ill patients in end of life options. We believe it is up to the individual physician and their patient to decide voluntarily whether the End of Life Option Act is something in which they want to engage.

CMA President Luther Cobb, MD
January 2016
Physicians and Aid in Dying

National survey of 2,000 practicing US physicians (members of AMA):

- Physician-Assisted Suicide:
  - 42% Had both a "religious and nonreligious objection" to physician-assisted suicide
  - 31% Had "no objection" to physician-assisted suicide
  - 21% Had a "nonreligious objection" to physician-assisted suicide
  - 5% Had a "religious objection" to physician-assisted suicide

- Terminal Sedation:
  - 82% Had "no objection" to terminal sedation
  - 9% Had both a "religious and nonreligious objection" to terminal sedation
  - 7% Had a "nonreligious objection" to terminal sedation
  - 2% Had a "religious objection" to terminal sedation
Physicians and Aid in Dying

➢ Withdrawal of Life Support:
  95% Had "no objection" to withdrawal of life support
  3% Had both a "religious and nonreligious objection" to withdrawal of life support
  1% Had a "nonreligious objection" to withdrawal of life support
  1% Had a "religious objection" to withdrawal of life support

➢ Physician Characteristics:
  79% of Asian doctors in the US object to physician-assisted suicide
  71% of Hispanic doctors in the US object to physician-assisted suicide
  67% of White doctors in the US object to physician-assisted suicide
  65% of Black doctors in the US object to physician-assisted suicide
79% of Catholic doctors object to physician-assisted suicide
79% of Muslim doctors object to physician-assisted suicide
75% of Protestant doctors object to physician-assisted suicide
74% of Hindu doctors object to physician-assisted suicide
54% of Jewish doctors object to physician-assisted suicide
39% of doctors with no religious affiliation object to physician-assisted suicide

American Journal of Hospice and Palliative Medicine, Apr./May 2008
Physicians and Aid in Dying

Survey of 3,299 oncologists (members of ASCO):

- **Support:**
  - 22.5% supported the use of physician-assisted suicide for a "terminally ill patient with unremitting pain"
  - 6.5% supported the use of euthanasia for a "terminally ill patient with unremitting pain"

- **Willingness:**
  - 15.6% were "personally willing to provide physician-assisted suicide for a patient in excruciating pain"
  - 2% were "personally willing to provide euthanasia for a patient in excruciating pain"
Physicians and Aid in Dying

- Patient Requests:
  56.2% "had requests" for physician-assisted suicide
  38.2% "had requests" for euthanasia during their career

- Clinical Practice:
  10.8% "had performed physician-assisted suicide" during their career
  3.7% "had performed euthanasia" during their career

Annals of Internal Medicine, Oct. 2000
Language is Important

Synonyms

- Physician Assisted Death
- Physician Assisted Dying
- Physician Assisted Suicide
- Voluntary Passive Euthanasia
- Aid in Dying *(preferred term)*
- Death with Dignity
- Right to Die

Suicide:

*Merriam-Webster*

1a: the act or an instance of taking one's own life voluntarily and intentionally especially by a person of years of discretion and of sound mind

b: ruin of one's own interests *<political suicide>*

c: *APOPTOSIS* *<cell suicide>*

“Physician-assisted dying isn’t suicide legally, morally or ethically. Patients already are dying and therefore are not choosing death over life but one form of death over another.”

—ED GOGOL, FINAL OPTIONS ILLINOIS
### What is NOT controversial in medical practice?

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Terminal Sedation (palliative sedation)</strong></td>
<td>sedating a terminally ill competent patient to the point of unconsciousness, then allowing the patient to die of her disease, starvation, or dehydration.</td>
</tr>
<tr>
<td><strong>Withholding/withdrawing life-sustaining treatments</strong></td>
<td>When a competent patient makes an informed decision to refuse life-sustaining treatment, there is virtual unanimity in state law and in the medical profession that this wish should be respected.</td>
</tr>
<tr>
<td><strong>Pain medication hastening death</strong></td>
<td>Often a terminally ill, suffering patient may require dosages of pain medication that impair respiration or have other effects that may hasten death. Doctrine of Double Effect-primary intent is to relieve suffering.</td>
</tr>
</tbody>
</table>
Advance Care Planning Conversations are also Not Controversial… Now Reimbursable

Billing and documentation Requirements:
- ACP may be performed on the same calendar dates as an E&M service
  - The time documented for the ACP must be separate and distinct from the E&M service time
  - Active management of the problem(s) is not undertaken during the ACP discussion
  
  ***Remember: don’t double dip on time***

- Both the services performed and the exact time required to complete this discussion must be documented
  - 99497 = First 30 minutes (must be minimum of 16 minutes in order to bill)
  - 99498 = each additional 30 minutes (must be minimum of 46 minutes total)

- May not report ACP on the same day as adult and pediatric critical care codes (in the same specialty)
What is controversial in medical practice?

<table>
<thead>
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</tr>
</thead>
<tbody>
<tr>
<td>Euthanasia</td>
<td>Euthanasia generally means that the physician would act directly, for instance by giving a lethal injection, to end the patient’s life.</td>
</tr>
<tr>
<td>Physician Assisted Death</td>
<td>Physician-assisted dying generally refers to a practice in which the physician provides a patient with a lethal dose of medication, upon the patient’s request, which the patient intends to use to end his or her own life.</td>
</tr>
</tbody>
</table>

https://www.deathwithdignity.org/learn/healthcare-providers/
Details of the California Aid in Dying Bill

- Initially Senate Bill 128
- Followed by AB X2 15 which was signed into law by Gov. Jerry Brown on October 5th, 2015
- In effect since June 9th, 2016

Physician participation is Voluntary!!

With permission from California Hospital Association
Qualified Individual-Criteria (California Aid in Dying)

- Adult (18 or older)
- Mental capacity
- Terminal disease (prognosis of 6 months or less)
- Resident of California
- 3 voluntary requests
- Physical/mental capacity to self-administer

With permission from California Hospital Association
Voluntary Requests (California Aid in Dying)

- Two oral requests made a minimum of 15 days apart AND
- One written request on required form; witnessed
- Request must be made **only by the patient**, directly to his/her Attending Physician
  - A designee, intermediary or surrogate decision maker cannot initiate the request for an aid-in-dying drug on behalf of the patient

With permission from California Hospital Association
The Attending Physician (California Aid in Dying)

– “The physician who has the primary responsibility for the health care of a patient and treatment of the patient’s terminal disease”

– Not a relative (by blood, marriage, registered domestic partnership, adoption) or entitled to a portion of the patient’s estate upon death

With permission from California Hospital Association
Responsibilities of the Attending Physician — Initial Determination (California Aid in Dying)

– Does the patient have the capacity to make medical decisions?
– If indication of mental disorder, mental health specialist assessment required
– Does the patient have a terminal disease?
  • “Incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, result in death within 6 months”

With permission from California Hospital Association
Making an Informed Decision (California Aid in Dying)

• To make an informed decision, the patient must be told by his/her Attending physician of:
  1. Diagnosis, prognosis
  2. Potential risks of taking drug
  3. Probable result of taking drug
  4. Possibility that patient may choose not to obtain the drug, or obtain it but not take it
  5. Alternatives or additional treatment opportunities, including comfort care, hospice, palliative care, pain control

With permission from California Hospital Association
Responsibilities of the Attending Physician (California Aid in Dying)

- Refer to consulting physician
- *Confirm no coercion or undue influence by questioning the patient alone*
- Counsel the patient about the importance of:
  - Having another person present during ingestion
  - Not ingesting in public place
  - Notifying next of kin of request for aid-in-dying drug (however, patient may decline)
  - Participating in a hospice program
  - Keeping drug in safe/secure location

With permission from California Hospital Association
Responsibilities of the Attending Physician (cont.)

- Attending Physician must also:
  1. Inform patient s/he can change mind at any time in any manner
  2. Offer patient opportunity to change mind before prescribing; the attending must do this directly himself or herself, not through an intermediary
  3. Verify, immediately before writing prescription, that patient is making an informed decision
  4. Confirm that all legal requirements are met
  5. Complete documentation, reporting requirements
  6. Give patient “Final Attestation” form (CHA Form 5-6) with instructions to complete

With permission from California Hospital Association
Responsibilities of the Mental Health Specialist (California Aid in Dying)

- A psychiatrist or licensed psychologist
- Not a relative or entitled to a portion of the patient’s estate upon death
- Consult is optional — at discretion of attending and consulting physicians

With permission from California Hospital Association
Responsibilities of the Consulting Physician
(California Aid in Dying)

1. Examine patient and relevant medical records
2. Confirm in writing: diagnosis, prognosis
3. Determine mental capacity; that patient is making a voluntary, informed decision
4. Refer to mental health specialist if indication of mental disorder
5. Complete “Consulting Physician Compliance Form” (CHA Form 5-8)

With permission from California Hospital Association
Responsibilities of the Mental Health Specialist (California Aid in Dying)

- A psychiatrist or licensed psychologist
- Not a relative or entitled to a portion of the patient’s estate upon death
- Consult is optional — at discretion of attending and consulting physicians

With permission from California Hospital Association
Responsibilities of the Mental Health Specialist (cont.)

1. Examine patient and relevant medical records (one or more visits)
2. Determine mental capacity; that patient is making a voluntary, informed decision
3. Determine that patient is not suffering from impaired judgment due to a mental disorder
4. Document
Responsibilities of the Qualified Individual (California Aid in Dying)

- Final Attestation for Aid-in-Dying Drug (CHA Form 5-6)
- Someone should give form to attending physician
- Don’t take drug in public place

With permission from California Hospital Association
Death Certificate

• What to list as cause of death?

  – The Oregon Department of Human Services recommends that the attending physician complete the death certificate with the underlying terminal condition(s) as the cause of death, and the manner of death as “natural”

    *The Oregon Death With Dignity Act: A Guidebook for Health Care Providers* 2008

  – Previously Oregon State Department recommended

    • “Drug overdose, legally prescribed,” or equivalent.
    • Terminal disease as the underlying cause
    • Manner of death is other

    CD Summary November 11, 1997; Vol. 46, No. 23
Insurer/Health Plan Provisions (California Aid in Dying)

- Ingesting aid-in-dying drug is not suicide
- Ingesting does not affect a life, health, or annuity policy
- Payor cannot offer info about aid-in-dying drug unless patient or attending physician asks
- Treatment denial cannot include info about aid-in-dying drugs

With permission from California Hospital Association
Declining to Inform a Patient (California Aid in Dying)

- A health care provider may decline to inform a patient about his/her rights under the End of Life Option Act
- A health care provider is not required to refer a patient to a physician who will participate
  - However, must provide medical records to patient who transfers care

Reminder: As a Physician, there is no obligation to participate or inform patients of this process

With permission from California Hospital Association
Where is Oregon since 1997?

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2015

Annual increase of 24.4%
Annual increase of 12.1%

Patient Characteristics

- **Age**
  - 78% were 65 or older

- **Ethnicity**
  - Most commonly white (93.1%)

- **Education**
  - Baccalaureate Degree (43.1%)

Terminal Diagnosis

- Cancer (72%)
- ALS (6.1%)
- Heart Disease (6.8%)

Place of Death

- Home (92.2%)
- Enrolled in Hospice in 92.2%

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Oregon Public Health Division

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>2015 (N=132)</th>
<th>1998-2014 (N=859)</th>
<th>Total (N=991)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Underlying illness</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Malignant neoplasms (%)</td>
<td>95 (72.0%)</td>
<td>667 (77.9%)</td>
<td>762 (77.1%)</td>
</tr>
<tr>
<td>Lung and bronchus (%)</td>
<td>23 (17.4%)</td>
<td>154 (18.0%)</td>
<td>177 (17.9%)</td>
</tr>
<tr>
<td>Breast (%)</td>
<td>9 (6.8%)</td>
<td>64 (7.5%)</td>
<td>73 (7.4%)</td>
</tr>
<tr>
<td>Colon (%)</td>
<td>7 (5.3%)</td>
<td>54 (6.3%)</td>
<td>61 (6.2%)</td>
</tr>
<tr>
<td>Pancreas (%)</td>
<td>7 (5.3%)</td>
<td>56 (6.5%)</td>
<td>63 (6.4%)</td>
</tr>
<tr>
<td>Prostate (%)</td>
<td>5 (3.8%)</td>
<td>35 (4.1%)</td>
<td>40 (4.0%)</td>
</tr>
<tr>
<td>Ovary (%)</td>
<td>3 (2.3%)</td>
<td>33 (3.9%)</td>
<td>36 (3.6%)</td>
</tr>
<tr>
<td>Other (%)</td>
<td>41 (31.1%)</td>
<td>271 (31.7%)</td>
<td>312 (31.6%)</td>
</tr>
<tr>
<td>Amyotrophic lateral sclerosis (%)</td>
<td>8 (6.1%)</td>
<td>71 (8.3%)</td>
<td>79 (8.0%)</td>
</tr>
<tr>
<td>Chronic lower respiratory disease (%)</td>
<td>6 (4.5%)</td>
<td>38 (4.4%)</td>
<td>44 (4.5%)</td>
</tr>
<tr>
<td>Heart disease (%)</td>
<td>9 (6.8%)</td>
<td>17 (2.0%)</td>
<td>26 (2.6%)</td>
</tr>
<tr>
<td>HIV/AIDS (%)</td>
<td>0 (0.0%)</td>
<td>9 (1.1%)</td>
<td>9 (0.9%)</td>
</tr>
<tr>
<td>Other illnesses (%)^2</td>
<td>14 (10.6%)</td>
<td>54 (6.3%)</td>
<td>68 (6.9%)</td>
</tr>
<tr>
<td><strong>Unknown</strong></td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
### Figure 3. Leading Sites of New Cancer Cases and Deaths – 2016 Estimates

<table>
<thead>
<tr>
<th>Male</th>
<th>Estimated New Cases</th>
<th>Female</th>
<th>Estimated New Cases</th>
<th>Male</th>
<th>Estimated Deaths</th>
<th>Female</th>
<th>Estimated Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>180,890 (21%)</td>
<td>Breast</td>
<td>246,660 (29%)</td>
<td>Lung &amp; bronchus</td>
<td>85,920 (27%)</td>
<td>Lung &amp; bronchus</td>
<td>72,160 (26%)</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
<td>117,920 (14%)</td>
<td>Lung &amp; bronchus</td>
<td>106,470 (13%)</td>
<td>Prostate</td>
<td>26,120 (8%)</td>
<td>Breast</td>
<td>40,450 (14%)</td>
</tr>
<tr>
<td>Colon &amp; rectum</td>
<td>70,820 (8%)</td>
<td>Colon &amp; rectum</td>
<td>63,670 (8%)</td>
<td>Colon &amp; rectum</td>
<td>26,020 (8%)</td>
<td>Colon &amp; rectum</td>
<td>23,170 (8%)</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>58,950 (7%)</td>
<td>Uterine corpus</td>
<td>60,050 (7%)</td>
<td>Uterine corpus</td>
<td>21,450 (7%)</td>
<td>Pancreas</td>
<td>20,330 (7%)</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>46,870 (6%)</td>
<td>Melanoma of the skin</td>
<td>49,350 (6%)</td>
<td>Melanoma of the skin</td>
<td>18,280 (6%)</td>
<td>Melanoma of the skin</td>
<td>14,240 (5%)</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>40,170 (5%)</td>
<td>Non-Hodgkin lymphoma</td>
<td>32,410 (4%)</td>
<td>Non-Hodgkin lymphoma</td>
<td>11,820 (4%)</td>
<td>Non-Hodgkin lymphoma</td>
<td>10,270 (4%)</td>
</tr>
<tr>
<td>Kidney &amp; renal pelvis</td>
<td>39,650 (5%)</td>
<td>Kidney &amp; renal pelvis</td>
<td>26,050 (3%)</td>
<td>Kidney &amp; renal pelvis</td>
<td>28,410 (3%)</td>
<td>Kidney &amp; renal pelvis</td>
<td>8,890 (3%)</td>
</tr>
<tr>
<td>Oral cavity &amp; pharynx</td>
<td>34,780 (4%)</td>
<td>Oral cavity &amp; pharynx</td>
<td>25,400 (3%)</td>
<td>Oral cavity &amp; pharynx</td>
<td>23,050 (3%)</td>
<td>Oral cavity &amp; pharynx</td>
<td>Unknown</td>
</tr>
<tr>
<td>Leukemia</td>
<td>34,090 (4%)</td>
<td>Leukemia</td>
<td>14,130 (4%)</td>
<td>Leukemia</td>
<td>12,720 (4%)</td>
<td>Leukemia</td>
<td>10,270 (4%)</td>
</tr>
<tr>
<td>Liver &amp; intrahepatic bile duct</td>
<td>28,410 (3%)</td>
<td>Liver &amp; intrahepatic bile duct</td>
<td>18,280 (6%)</td>
<td>Liver &amp; intrahepatic bile duct</td>
<td>11,820 (4%)</td>
<td>Liver &amp; intrahepatic bile duct</td>
<td>Unknown</td>
</tr>
<tr>
<td>All sites</td>
<td>841,390 (100%)</td>
<td>All sites</td>
<td>23,050 (3%)</td>
<td>All sites</td>
<td>314,290 (100%)</td>
<td>All sites</td>
<td>6,610 (2%)</td>
</tr>
</tbody>
</table>

Estimates are rounded to the nearest 10, and cases exclude basal cell and squamous cell skin cancers and in situ carcinoma except urinary bladder.

©2016, American Cancer Society, Inc., Surveillance Research

### Top reasons for requesting Aid in Dying?

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<th>Characteristics</th>
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<tbody>
<tr>
<td>Less able to engage in activities making life enjoyable (%)</td>
<td>127 (96.2)</td>
<td>758 (88.7)</td>
<td>885 (89.7)</td>
</tr>
<tr>
<td>Losing autonomy (%)</td>
<td>121 (92.4)</td>
<td>782 (91.5)</td>
<td>903 (91.6)</td>
</tr>
<tr>
<td>Loss of dignity (%)</td>
<td>98 (75.4)</td>
<td>579 (79.3)</td>
<td>677 (78.7)</td>
</tr>
<tr>
<td>Losing control of bodily functions (%)</td>
<td>46 (35.7)</td>
<td>428 (50.1)</td>
<td>474 (48.2)</td>
</tr>
<tr>
<td>Burden on family, friends/caregivers (%)</td>
<td>63 (48.1)</td>
<td>342 (40.0)</td>
<td>405 (41.1)</td>
</tr>
<tr>
<td>Inadequate pain control or concern about it (%)</td>
<td>37 (28.7)</td>
<td>211 (24.7)</td>
<td>248 (25.2)</td>
</tr>
<tr>
<td>Financial implications of treatment (%)</td>
<td>3 (2.3)</td>
<td>27 (3.2)</td>
<td>30 (3.1)</td>
</tr>
</tbody>
</table>
Provider Characteristics

- 106 physicians wrote 218 prescription (1-27 per provider)
- 5 patients referred for psychological/psychiatric eval
- Prescribing physicians present at time of death (10.8%)
- Other health care providers present at time of death (10%)

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<tr>
<td><strong>DWDA process</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referred for psychiatric evaluation (%)</td>
<td>5 (3.8)</td>
<td>47 (5.5)</td>
<td>52 (5.3)</td>
</tr>
<tr>
<td>Patient informed family of decision (%)</td>
<td>126 (95.5)</td>
<td>729 (93.2)</td>
<td>855 (93.5)</td>
</tr>
<tr>
<td>Patient died at</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home (patient, family or friend) (%)</td>
<td>118 (90.1)</td>
<td>810 (94.6)</td>
<td>928 (94.0)</td>
</tr>
<tr>
<td>Long term care, assisted living or foster care facility (%)</td>
<td>9 (6.9)</td>
<td>37 (4.3)</td>
<td>46 (4.7)</td>
</tr>
<tr>
<td>Hospital (%)</td>
<td>0 (0.0)</td>
<td>1 (0.1)</td>
<td>1 (0.1)</td>
</tr>
<tr>
<td>Other (%)</td>
<td>4 (3.1)</td>
<td>8 (0.9)</td>
<td>12 (1.2)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Lethal medication</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secobarbital (%)</td>
<td>114 (86.4)</td>
<td>466 (54.2)</td>
<td>580 (58.5)</td>
</tr>
<tr>
<td>Pentobarbital (%)</td>
<td>1 (0.8)</td>
<td>385 (44.8)</td>
<td>386 (39.0)</td>
</tr>
<tr>
<td>Phenobarbital/chloral hydrate/morphine sulfate mix (%)</td>
<td>16 (12.1)</td>
<td>0 (0.0)</td>
<td>16 (1.6)</td>
</tr>
<tr>
<td>Other (combination of above and/or morphine) (%)</td>
<td>1 (0.8)</td>
<td>8 (0.9)</td>
<td>9 (0.9)</td>
</tr>
</tbody>
</table>
What Medications are Used?

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Cost</th>
<th># of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secobarbital</td>
<td>9-10 gms</td>
<td>~$3700</td>
<td>&gt;2000</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>6 gms</td>
<td>~$150</td>
<td>~50</td>
</tr>
<tr>
<td>Morphine</td>
<td>1200mg</td>
<td>~$30(tab) - $60(solution)</td>
<td>~100</td>
</tr>
</tbody>
</table>

- Proper storage
- Co-administration with anti-emetics (Ondansetron/Metoclopramide), anti-anxiety/seizure (Lorazepam/Alprazolam), and/or anti-adrenergic (Propranolol)
- The time from ingestion to death ranged from two minutes to 4.5 days.

Institutional Response to the Aid-in-Dying Law
Some Institutional Considerations

- Consistency with City of Hope Mission/Vision/Values
  - Does participation in Aid-in-Dying activities create mixed messages for patients of City of Hope?
  - If COH does not offer aid-in-dying, will patients who qualify for this option perceive COH to have abandoned them in their time of need?

- Impact on Current Infrastructure and Operations: If aid-in-dying activities are permitted at COH’s Duarte campus and at the COH Community Practice sites, what additional resources are needed?

- Relations with Other Cancer Centers
  - City of Hope is an NCI-designated Comprehensive Cancer Center and a pioneer to whom other centers look for leadership and guidance.
  - The only NCCN center in states with Death with Dignity laws permitting aid-in-dying activities is Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance.
Other Institutional/Societal Concerns

• Medi-Cal is proposing to pay for Aid in Dying
  – Medi-Cal will pay for palliative care if revenue neutral

• Suicide Rates are on the rise
  – In 2014, 13 people out of every 100,000 took their own lives, compared with 10.5 per 100,000 in 1999. The suicide rate increased every year from 1999 to 2014 among both women and men and in every age group except those 75 and older.
  – Werther effect — “publicized cases of suicide can produce clusters of copycat cases, often disproportionately affecting young people, who frequently use the same method as the original case.”
  – Papageno effect --- “suggests that coverage of people with suicidal ideation who do not attempt suicide but instead find strategies that help them to cope with adversity is associated with decreased suicide rates.”
Does Aid in Dying Affect Non-Terminal Populations?

Southern Medical Journal

How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?

David Albert Jones, DPhil; David Paton, PhD

Disclosures


Fig. 1. Total suicide rates per 100,000 residents, PAS and non-PAS states, 1990–2013. Vermont is excluded because PAS was legalized in 2013 and no PASs were recorded in that year. Montana is excluded because PAS was decriminalized rather than legalized and as such, no data are collected on PAS. The vertical lines indicate the timing of the legalization of PAS in the two states. PAS, physician-assisted suicide.

Fig. 2. Nonassisted suicide rates per 100,000 residents, PAS and non-PAS states, 1990–2013. Vermont is excluded because PAS was legalized in 2013 and no PASs were recorded in that year. The vertical lines indicate the timing of the legalization/decriminalization of PAS in each state. PAS, physician-assisted suicide.
You asked for statistical data and research on suicide rates from the states that have passed assisted suicide legislation, before and after the legislation passed.

<table>
<thead>
<tr>
<th>Year</th>
<th>Oregon</th>
<th>Vermont</th>
<th>Washington</th>
<th>U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>15.67</td>
<td>14.97</td>
<td>14.21</td>
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<td>1991</td>
<td>15.44</td>
<td>16.15</td>
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<td>1993</td>
<td>15.00</td>
<td>15.99</td>
<td>13.48</td>
<td>12.04</td>
</tr>
<tr>
<td>1994</td>
<td>16.29</td>
<td>10.11</td>
<td>14.48</td>
<td>11.89</td>
</tr>
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<td>1995</td>
<td>15.44</td>
<td>12.07</td>
<td>14.64</td>
<td>11.79</td>
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<td>1996</td>
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<td>14.17</td>
<td>11.53</td>
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<td>1997</td>
<td>15.93</td>
<td>12.06</td>
<td>12.98</td>
<td>11.24</td>
</tr>
<tr>
<td>1998</td>
<td>16.03</td>
<td>14.05</td>
<td>12.29</td>
<td>11.12</td>
</tr>
<tr>
<td>1999</td>
<td>12.8/</td>
<td>10.30</td>
<td>14.16</td>
<td>10.48</td>
</tr>
<tr>
<td>2000</td>
<td>14.11</td>
<td>12.31</td>
<td>12.36</td>
<td>10.44</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Oregon</th>
<th>Vermont</th>
<th>Washington</th>
<th>U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>14.34</td>
<td>11.50</td>
<td>11.85</td>
<td>10.71</td>
</tr>
<tr>
<td>2003</td>
<td>15.16</td>
<td>12.99</td>
<td>13.03</td>
<td>10.77</td>
</tr>
<tr>
<td>2005</td>
<td>14.94</td>
<td>12.35</td>
<td>12.7</td>
<td>10.90</td>
</tr>
<tr>
<td>2006</td>
<td>15.28</td>
<td>12.25</td>
<td>12.2</td>
<td>10.97</td>
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<tr>
<td>2007</td>
<td>15.31</td>
<td>13.84</td>
<td>12.92</td>
<td>11.27</td>
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<td>2008</td>
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<td>14.24</td>
<td>13.05</td>
<td>11.60</td>
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<td>2009</td>
<td>15.18</td>
<td>12.77</td>
<td>13.3</td>
<td>11.75</td>
</tr>
<tr>
<td>2010</td>
<td>17.11</td>
<td>10.00</td>
<td>10.0</td>
<td>12.00</td>
</tr>
<tr>
<td>2011</td>
<td>–</td>
<td>14</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>2012</td>
<td>–</td>
<td>14.8</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

Table 1: Oregon, Vermont, Washington, and National Suicide Rates by Year
(Deaths per 100,000 people, age adjusted with 2000 as standard year)
Aid in Dying is Potentially one Aspect of a Comprehensive End of Life Program

What are your “prime directives?”

List prime directives:
1. Serve the public trust
2. Protect the innocent
3. Uphold the law

Right
- I don't know if it's right or wrong
- It's an individual choice, so what's the big deal

Wrong
- Depends on the situation
- As long as I don't get caught
The Hippocratic Oath Few (if Any) of Us Took

- The Oath of Hippocrates of Kos, 5th century BC:
- I swear by Apollo the physician, by Aesculapius, Hygeia, and Panacea, and I take to witness all the gods, all the goddesses, to keep according to my ability and judgment the following oath:
- To consider dear to me as my parents him who taught me this art; to live in common with him and if necessary to share my goods with him; to look upon his children as my own brothers, to teach them this art if they so desire without fee or written promise; to impart to my sons and the sons of the master who taught me and to the disciples who have enrolled themselves and have agreed to the rules of the profession, but to these alone, the precepts and the instruction. I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm to anyone. **To please no one will I prescribe a deadly drug, nor give advice which may cause his death.** Nor will I give a woman a pessary to procure abortion. But I will preserve the purity of my life and my art. I will not cut for stone, even for patients in whom the disease is manifest; I will leave this operation to be performed by specialists in this art. In every house where I come I will enter only for the good of my patients, keeping myself far from all intentional ill-doing and all seduction, and especially from the pleasures of love with women or with men, be they free or slaves. All that may come to my knowledge in the exercise of my profession or outside of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and never reveal. If I keep this oath faithfully, may I enjoy my life and practice my art, respected by all men and in all times; but if I swerve from it or violate it, may the reverse be my lot.

http://www.aapsonline.org/ethics/oaths.htm
## Interpretation of Do No Harm

<table>
<thead>
<tr>
<th>Arguments For</th>
<th>Arguments Against</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect for autonomy</td>
<td>Sanctity of life</td>
</tr>
<tr>
<td>Justice-treatment refusal allowed, may lead to suffering, so allow assisted death</td>
<td>Passive vs. Active- letting die vs killing</td>
</tr>
<tr>
<td>Compassion- addressing suffering, physical and existential, Aid in Dying increases control</td>
<td>Potential for abuse- insurance denial letters, limited availability of palliative care</td>
</tr>
<tr>
<td>Individual Liberty- ban excessively limits personal liberty</td>
<td>Professional integrity-Hippocratic Oath</td>
</tr>
<tr>
<td>Openness of discussion- assisted death occurs in secret with excess morphine drips, Aid in Dying allows an honest discussion</td>
<td>Fallibility of the profession</td>
</tr>
<tr>
<td></td>
<td>Subjective reasons logically justify Euthanasia and broadens the potential for abuse</td>
</tr>
</tbody>
</table>

**We need to support within our own moral, spiritual and ethical framework.**

https://www.deathwithdignity.org/learn/healthcare-providers/
Response to Requests for Aid in Dying

1. Clarify the request
2. Assess the underlying causes of the request
3. Affirm your commitment to care for the patient
4. Address the root causes of the request
5. Educate the patient and discuss legal alternatives
Step 1: Clarify the request

GIVE UP
At Some Point, Hanging In There
Just Makes You Look Like an Even Bigger Loser.
Step 1: Clarify the request

- A request for PAS may be the first expression of unrelieved suffering
- Provocative statements such as, “I hope you’ll help me die when it’s time” or “Please promise not to let me suffer,” asking for assurance of a way to escape suffering if it becomes unbearable
- Ask open-ended questions in a calm and non-judgmental manner
- Suicidal thoughts or plans?
Step 2: Assess underlying causes
Step 2: Assess underlying causes

**Physical Pain**
- Co-morbid causes
  - Caused by treatment
  - Caused by cancer

**Psychological**
- Anxiety
- Fear of suffering
- Depression
- Past experience of illness

**Social Status**
- Loss of role and social status
- Loss of job
- Financial concerns
- Worries about the future
- Dependency

**Spiritual Pain**
- Anger at fate/anger with God
- Loss of faith
- Finding meaning
- Fear of the unknown
This is Not a Decision in Isolation

**EFFICIENCY**

**International Comparison of Spending on Health, 1980–2009**

Average spending on health per capita ($US PPP*)

Total expenditures on health as percent of GDP

* PPP=Purchasing Power Parity.

Source: Commonwealth Fund National Scorecard on U.S. Health System Performance, 2011.
MedPac 2015

Chart 1-10. FFS program spending is highly concentrated in a small group of beneficiaries, 2011

- Medicare FFS spending is concentrated among a small number of beneficiaries. In 2011, the costliest 5 percent of beneficiaries accounted for 39 percent of annual Medicare FFS spending, and the costliest 25 percent accounted for 82 percent. By contrast, the least costly 50 percent of beneficiaries accounted for only 5 percent of FFS spending.

Note: FFS (fee-for-service). All data are for calendar year 2011. Analysis excludes beneficiaries with any group health enrollment during the year. “Percent of program spending” total may not sum to 100 percent due to rounding.

What can we Learn from the Paradigm of Pediatric Hematology?

![Graph showing event-free survival over years from diagnosis]

- Risk-adapted therapy (90's)
- Intensive therapy (80's)
- CNS preventative therapy (70's)
- Combination chemotherapy (60's)
- Single-agent chemotherapy (50's)

Years from diagnosis:

0 1 2 3 4 5 6

Event-free Survival (%): 100 80 60 40 20 0

Courtesy Pat Brown, Johns Hopkins
Money well spent - $1,947,084 in direct costs over 5 years of care
Money ill spent – Increasing healthcare spending producing no benefit to the patient.
Financial Toxicity

• Effect of out-of-pocket expenses on a patients economic status and quality of life
• Patients bear an increasing burden of cancer care costs
  – Average debt for patients treated for colorectal cancer is $26,860*
• Physicians are often oblivious to financial burden of proposed treatment regimens^
• Patients may elect to not receive high-cost regimens of marginal benefit, if advised of financial risk of treatment^

*JCO. 2011;29:954
^JCO. June 22, 2015
62% of US bankruptcy tied to medical debt

Medical bills push family to bankruptcy

Even those with insurance struggle to afford treatment

BY KATE SANTICH
Staff writer

The day their daughter was born should have been one of the happiest of Simon and Marsha Sutherland’s lives. Both previously married, they were having their first child together, a 6-pound, 10-ounce, dark-haired girl they would name Ellie Marguerite. But moments after Ellie made her entrance, doctors ordered her rushed to the Winnie Palmer neonatal intensive-care unit, fearing she’d had a seizure.

Ellie’s birth Aug. 30, 2005, began a 25-day, $74,000 stay in one of the most expensive places in any hospital. More daunting, it would launch a four-year journey of fear, hope, devotion and grief—a journey made all the more difficult by financial devastation.

Ultimately, it led two middle-class parents with good jobs, two major health-insurance policies and a house in suburbia into foreclosure and bankruptcy.

Though financial failures often have been blamed on careless consumer borrowing or the widespread layoffs of the recession, the Sutherlands’ financial story is strikingly common. A growing number of bankruptcies in Florida and nationwide are tied to medical bills, experts say.

Please turn to INSURE, 2A

Ellie died just shy of her fourth birthday.

Taking a toll

Report shows 62% of U.S. bankruptcies are tied to medical debt. Of the 8,850 medical-related bankruptcies filed so far this year in Florida, about one-third are in Broward and one-fourth are in Palm Beach County. 2A

Sun Sentinel (Broward County Edition)
Tuesday, August 9, 2011
Controlled Substance Utilization Review and Evaluation System

California’s Prescription Drug Monitoring Program

CURES 2.0 (Controlled Substance Utilization Review and Evaluation System) is a database of Schedule II, III, and IV controlled substance prescriptions dispensed in California serving the public health, regulatory oversight agencies, and law enforcement. CURES 2.0 is committed to the reduction of prescription drug abuse and diversion without affecting legitimate medical practice or patient care.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) and confidentiality and disclosure provisions of California law cover the information contained in CURES 2.0.

Access to CURES 2.0 is limited to licensed prescribers and licensed pharmacists strictly for patients in their direct care, and regulatory board staff and law enforcement personnel for official oversight or investigatory purposes.

CURES Registration Requirements

California law (Health and Safety Code Section 11651.1) requires all California licensed prescribers authorized to prescribe scheduled drugs to register for access to CURES 2.0 by July 1, 2016 or upon issuance of a Drug Enforcement Administration Controlled Substance Registration Certificate, whichever occurs later. California licensed pharmacists must register for access to CURES 2.0 by July 1, 2016, or upon issuance of a Board of Pharmacy Pharmacist License, whichever occurs later.

Prescriber and dispenser registration to access CURES 2.0 is simple and fully automated. Prescribers and dispensers can register to access CURES by clicking here.

Submission of Controlled Substance Data

California Health & Safety Code Section 11651(d) requires dispensing pharmacies, clinics, or other dispensers of Schedule II through IV controlled substances to provide specified dispensing information to the Department of Justice on a weekly basis in a format approved and accepted by the DOJ. Currently, the ASAP 2009 Version 4.1 format is accepted.

Important Notice:

Access to CURES 2.0 may be temporarily unavailable for up to 10 minutes for scheduled system maintenance on Monday, May 2, 2016 between 11:00pm – 11:10pm.
Injury Prevention & Control: Opioid Overdose

CDC Guideline for Prescribing Opioids for Chronic Pain

Improving the way opioids are prescribed through clinical practice guidelines can ensure patients have access to safer, more effective chronic pain treatment while reducing the number of people who misuse, abuse, or overdose from these drugs.

CDC developed and published the CDC Guideline for Prescribing Opioids for Chronic Pain to provide recommendations for the prescribing of opioid pain medication for patients 18 and older in primary care settings.

Recommendations focus on the use of opioids in treating chronic pain (pain lasting longer than 3 months or past the time of normal tissue healing) outside of active cancer treatment, palliative care, and end-of-life care.

What do you need to know?

Patients
Information and resources for patients

Health Care Providers
Overview of the guideline for providers

Resources
Fact sheets, clinical tools, and other materials related to the guideline
Doctor convicted of murder for patients' drug overdoses gets 30 years to life in prison

Dr. Hsiu-Ying "Lisa" Tseng was sentenced to 30 years to life in prison for the murders of three of her patients who fatally overdosed, making Tseng the first doctor to be convicted of murder in the United States for overprescribing drugs. (Irfan Khan / Los Angeles Times)

By Marisa Gerber • Contact Reporter
Step 3: Affirm your commitment

As a request for hastened death affects everyone who is close to the patient, a commitment to the patient also affirms a commitment to the family and those close to the patient.
Step 4: Address root causes
Step 4: Address root causes

Address fear of pain, other symptoms

- Reassure patients and families that pain ordinarily does not get suddenly worse as death approaches.
- Help them to understand the difference between pain and terminal delirium.
- Make a commitment to keep working to manage the symptoms until they are satisfactorily controlled. This is a critical piece for patients who may fear being told, “I’m sorry, there’s nothing more we can do.”
Post-Traumatic Growth

• “Have you ever considered that steel is iron plus fire; soil is rock plus crushing; linen is flax plus the comb that separates, and the flail that pounds, and the shuttle that weaves!” “Suffering, on the other hand, tends to plow up the surface of our lives to uncover the depths that provide greater strength of purpose and accomplishment. Only deeply plowed earth can yield bountiful harvests.”


• “This is the one thing that happened in my life that I needed to have happen, it was probably the best thing that ever happened to me. On the outside looking in that pretty hard to swallow, I’m sure, but hey, that’s the way I view it. If I hadn’t experienced this and lived through it, I likely wouldn't be here today because of my lifestyle previously--I was on a real self-destructive path. If I had it to do all over again I would want it to happen the same way. I would not want it not to happen.”

Figure 1: A Model of Posttraumatic Growth

From:
Posttraumatic Growth: Psychological Reconstruction in the Aftermath of Disaster
Richard G. Tedeschi, Ph.D.
Professor of Psychology, UNC Charlotte

The Miracle of Science with Soul
City of Hope
Step 5: Educate, discuss legal alternatives
Step 5: Educate, discuss legal alternatives

Randomized trial simultaneous standard cancer care with palliative care co-management from diagnosis versus control group receiving standard cancer care only:

• **Improved quality of life**
• **Reduced major depression**
• **Reduced ‘aggressiveness’** (less chemo < 14d before death, more likely to get hospice, less likely to be hospitalized in last month)
• **Improved survival** (11.6 mos. vs. 8.9 mos., p<0.02)


- Aggressive comfort measures
- Refuse or Withdraw treatment
- Declining oral intake
- Terminal / palliative sedation
Resources

- California Medical Assoc. – www.cmanet.org
- California Hospital Assoc. – www.calhealth.org
- Coalition for Compassionate Care – www.coalitionccc.org
- C-SPAN Congressional hearing
- NEJM Article on Death with Dignity Program at an NCCN Center
I'm back from training.

I got a big binder.

The training is already forgotten, but the binder will last forever.

A living monument to temporary knowledge!
Questions?

Contact information:
Finly Zachariah, MD
fzachariah@coh.org