Patient Centered Care: Translating Patient's' Wishes into Federal and State Policy

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Agenda

• About C&C
• Public Opinion About End of Life Care
• State Policy: Medical Aid in Dying
• Federal Policy: Policy Solutions & Policy Landscape
About Compassion & Choices
C&C Programming

- Federal Advocacy
- State Advocacy
- Legal Advocacy
- National Programs
- End of Life Resource Center
Public Opinion Around End of Life Care & Choice
Eight out of Ten Believe that Doctors Should Discuss End-of-life Care with their Patients

Do you think doctors should discuss end-of-life care issues with their patients, or not?

Kaiser Family Foundation Survey, September 2015
Large Majority Says They Would Feel Very Comfortable Talking About End-Of-Life Care With Spouse, Ranking Above Others

How comfortable would you be talking about your own end-of-life medical wishes with each of the following?

<table>
<thead>
<tr>
<th></th>
<th>Very comfortable</th>
<th>Somewhat comfortable</th>
<th>Not too comfortable</th>
<th>Not at all comfortable</th>
<th>Doesn’t apply (Vol.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your spouse/partner*</td>
<td>83%</td>
<td></td>
<td>10%</td>
<td>3%</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>A doctor or other health care provider</td>
<td>57%</td>
<td>27%</td>
<td>6%</td>
<td>9%</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Your children</td>
<td>55%</td>
<td>19%</td>
<td>8%</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>Your close friends</td>
<td>51%</td>
<td>26%</td>
<td>10%</td>
<td>11%</td>
<td>1%</td>
</tr>
<tr>
<td>Your parents</td>
<td>51%</td>
<td>15%</td>
<td>4%</td>
<td>8%</td>
<td>21%</td>
</tr>
<tr>
<td>A minister, priest, or other religious or spiritual advisor</td>
<td>50%</td>
<td>21%</td>
<td>8%</td>
<td>18%</td>
<td>3%</td>
</tr>
<tr>
<td>Other family members</td>
<td>48%</td>
<td>29%</td>
<td>10%</td>
<td>11%</td>
<td>2%</td>
</tr>
<tr>
<td>A mental health counselor or therapist</td>
<td>46%</td>
<td>26%</td>
<td>10%</td>
<td>16%</td>
<td>1%</td>
</tr>
</tbody>
</table>

**"Your spouse/partner" was only asked of those who said they are married or living with a partner.
NOTE: Don’t know/Refused responses not shown.
SOURCE: Kaiser Family Foundation Health Tracking Poll (conducted September 17-23, 2015)
Fewer than Two out of Every Ten Have Actually Had a Conversation with their Doctor

Have you ever had a conversation with your doctor or other health care provider about your wishes for your care at the end of your life, or not?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>17</td>
<td>83</td>
</tr>
<tr>
<td>18-49</td>
<td>12</td>
<td>87</td>
</tr>
<tr>
<td>50-64</td>
<td>19</td>
<td>81</td>
</tr>
<tr>
<td>65-74</td>
<td>23</td>
<td>76</td>
</tr>
<tr>
<td>75+</td>
<td>34</td>
<td>66</td>
</tr>
</tbody>
</table>

Kaiser Family Foundation Survey, September 2015
Only One out of Every Three Have Participated in a Discussion with a Health Care Provider About Another Family Member’s wishes

Have you ever participated in a discussion with a doctor or other health care provider about another family member’s wishes for their care at the end of their life, or not?

Kaiser Family Foundation Survey, September 2015
Three In Four Americans Does Not Have An Advanced Directive: The numbers Improve Considerably Among Seniors

American Journal of Preventive Medicine, January 2014
One out of every four Americans has acknowledged receiving unwanted or excessive medical treatments.

“You’ve got six months, but with aggressive treatment we can help make that seem much longer.”
Two out of Five Primary Care Physicians acknowledge Overtreatment Exists

What Level of Treatment Are the Patients in Your Own Practice Receiving?

Data from JAMA Internal Medicine

Compassion & Choices
Nine out of Ten People are Confident They Will Receive The Type of Medical Treatment They Want at The End of Life

How confident or unconfident do you feel that doctors and hospitals will...
- give you only the medical treatment you want if you become seriously ill?
- follow your parent(s) wishes and instructions for the types of medical treatment he/she would and would not want if he/she if he/she became seriously ill?

<table>
<thead>
<tr>
<th>Category</th>
<th>Confident</th>
<th>Unconfident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Own Treatment</td>
<td>87</td>
<td>13</td>
</tr>
<tr>
<td>Elderly Own Treatment</td>
<td>89</td>
<td>11</td>
</tr>
<tr>
<td>Parent’s Treatment</td>
<td>92</td>
<td>8</td>
</tr>
</tbody>
</table>
Yet Seven out of Ten People Haven’t Asked Their Proxy To Perform the Role

Would you say you have someone who you trust will be by your side and make medical decisions for you should you become more seriously ill, but who you haven’t officially or legally asked to do so? Who will be by your side?

- Best Friend: 9
- Sibling: 18
- Child: 52
- Spouse: 67
<table>
<thead>
<tr>
<th>Early Assumptions</th>
<th>Research Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s about the relationship between patient and proxy</td>
<td>It’s about the entire family or “inner circle”</td>
</tr>
<tr>
<td>We could engage at the time of the terminal diagnosis</td>
<td>Terminal is in the eye of the beholder. End of life often not recognized until the very end.</td>
</tr>
<tr>
<td>People who experienced a “bad death” of a parent may be a key target audience</td>
<td>Previous experiences don’t appear to affect how people prepare</td>
</tr>
<tr>
<td>We need to sugar coat this stuff to get anyone to do it</td>
<td>People are clamoring for ways to show support to parents</td>
</tr>
</tbody>
</table>
Translating Patients Wishes at the State Level: Medical Aid in Dying
What Is Medical Aid in Dying?

A safe and trusted medical practice in which a terminally ill, mentally capable person who has a prognosis of six months or less to live, has the option to request from their doctor a prescription for medication which he or she can choose to self-ingest to end unbearable suffering and to die peacefully.
Gallup National Poll

When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?

1996-1999 WORDING: When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should be allowed by law to assist the patient to commit suicide if the patient requests it, or not?
Medical Aid in Dying in the Polls
State Polling Results

Compassion & Choices
A Story of Medical Aid in Dying
Percentage of Change in Support

May, 2015 Gallup Poll
Patient - Centered Care

Translating Patients Wishes at the State Level: Medical Aid in Dying

DAVID R. GRUBE MD
NATIONAL MEDICAL DIRECTOR
COMPASSION & CHOICES
THE ART OF MEDICINE

To cure sometimes,
to relieve often,
to comfort always…

(OSLER or HIPPOCRATES)
Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it.

Atul Gawande MD

Being Mortal
... in spite of all of the stunning and remarkable advances in medicine over the last 40 years, physicians cannot always prevent or heal physical or mental suffering.
“Well, good news! We think we got it all!”
End of Life

~ 63% of patients do not die at home
~ 17% of patients die in a long term care facility
~ 30% of patients spend last 10 days of life in ICU
~ 34% of patients have significant pain/suffering in last month of life (50% of these are undertreated!)

sources: NIH website; APA website
32 people questioned
76% supported AID, including 82% of Democrats, 79% of Independents and 67% of Republicans

Support levels of at least 69% were registered across all other demographic categories — gender, education, income and age. Among age groups, support was weakest among 18- to 19-year-olds (70%) and stronger among older groups: 86% among those in their 40s, 79% among those in their 50s, and 81% among those over 65.
• 54% of primary care physicians support MAiD
  ~ 21K participants (PCP’s: MD’s DO’s)
  Increased from 46% in 2010
  Source: MEDSCAPE ETHICS REPORT 2014
• ~ 70% of citizens support MAiD
  ~ 50% of citizens (in same poll) support PAS
  Source: GALLOP MAY 2014
Medical Aid in Dying - USA

- Oregon – 1997
- Washington – 2009
- Vermont – 2013
- California – 2015
- Montana (court orders) - 2009
Medical Aid In Dying (AID)

- ~ 25 States now considering legislation or have law suits pending
- Canada, February 2016: The Canadian Supreme Court ruled that individuals have a right to aid in dying under certain circumstances and gave Provincial Canadian lawmakers 12 months to craft rules to protect patients and physicians who choose to exercise their rights under the law.
The Law:

Death with Dignity

ORS 127.800-897
ORS 127.800 - .897
Death With Dignity Act (DWD)

• An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 - 127.897.
ORS 127.800 – 897
“Death With Dignity:”
caveats...

• Dignity is defined by the dying patient. (Dignity is not defined by the doctor, the hospice nurse, legislators, ethicists, etc.)

• A person with a terminal illness may have a dignified death in many ways:
  – Choosing all or some treatments
  – Choosing no treatments
  – Choosing to have control of the timing of death
ORS.127
Patient Requirements

• A patient must be:
  – 18 or older
  – Oregon citizen
  – Capable
    • Able to make and communicate health care decisions (w/o psychiatric problems)
  – Acting on own volition
  – Diagnosed w/ terminal illness
    • Prognosis of less than six months to live
ORS.127
Physician Components

• Two physicians
  #1: Prescribing (need not be attending)
  #2: Consulting
  – Referral if psychiatric diagnosis uncovered
  – Both must affirm patient eligibility

(Not PA / NP / DC / ND)
Attending (Prescribing) Physician Responsibilities

• Two oral requests from patient
  (not necessarily in person)
  – At least 15 days apart
• Written request (after both doctors’ evaluation)
  – Signed by two witnesses
• Prescription may not be written until 48 hours after second oral request
Physician responsibilities

• Inform patient of feasible alternatives:
  – Hospice Care / Palliative Care / Pain Control

• Must request (but may not require) patient notify next of kin of Rx request
Physician Responsibilities

• Both Prescribing and Consulting Physicians must complete Dept. of Human Services’ (DHS) forms
• Attending Physician must inform DHS only if prescription is written
• Pharmacy must be informed of intended use of medication (1999)
• Follow-up form within 10 days of patient’s death
ORS.127
Patient’s rights

• The choice of DWD cannot affect status of health or life insurance
• DWD does not constitute suicide, mercy killing, or homicide under the law (…127.880)
• Death certificate will list terminal diagnosis (e.g., lung cancer)
Statistics
(ORE. PUBLIC HEALTH DIV. ANNUAL REPORT 2/2016)

• **2015:**
  - 218 DWDA prescriptions written
  - **132** DWDA deaths (61%)
  - \( (2014 = 155 / 105) \) (67%)

• **Since 1997:**
  - **1,545** DWDA prescriptions written
  - **991** DWDA deaths (64%)
  - \( (38.6/10,000 \text{ deaths}) \)
Time of death from ingestion varied from 5 minutes to 34 hours
  – No cases of ‘awakening’
  – 27 (of 218) had MD or hospice RN in attendance

No referrals to OMB for failure to comply with DWDA requirements

106 physicians wrote prescriptions

5 referral for psychiatric evaluation
DWDA prescription recipients and deaths by year, Oregon, 1998-2016

*As of January 27, 2016*
Demographics of DWD Patients (2015)

- Median age: 73 years old
- Caucasian (93.1%)
- Well-educated (43% had at least a baccalaureate degree)
- Cancer diagnosis: 72% (prev. years 77.9%)
  - CHF 6.8%, ALS 6.2%, COPD
- 90.1% died at home and 92.2% were under hospice care
End of Life Concerns of DWDA Patients

• Loss of autonomy (92.4%)
• Decreasing ability to participate in activities that make life enjoyable (96.2%)
• Loss of dignity (75.4%)
• Losing control of bodily functions (48.2%)
• Burden on family/care givers (41.1%)
• Inadequate pain control or concerns (25.2%)
The choice of medical aid in dying is not a failure of hospice or palliative care

• “Jenny”
• Vaginal cancer (surgery/radiation/chemotherapy)
• Recto-vaginal and cysto-vaginal fistulas
  – Constant discharge (indignities)
  – Pain
  – Flu symptoms
• Hospice referral (Palliative care team)
• Husband not initially supportive of planned death
• Jenny always thinking of others….
Some unexpected consequences...

- EOLC (Hospice, Palliative Care) has improved and more fully utilized than ever before
- Patients remain free of or immune from coercive forces; no evidence of abuse for vulnerable populations (ex: disabled)
- Very few patients opt for DWD; only 2/3 who receive prescriptions take them
- Lethal drugs are without additional complications
- No “slippery slope”
“Of note, Oregon was in the highest quartile of hospice use as well as in the lowest quartile of potentially concerning pattern of hospice use.

... it is possible that the Oregon Death with Dignity Act has resulted in or at least reflects more open conversation and careful evaluation of end-of-life options, more appropriate palliative care training of physicians, and more efforts to reduce barriers to access to hospice care and has thus increased hospice referrals and reduced potentially concerning patterns of hospice use in the state.”
An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 - 127.897.
Language matters

• The “suicide” question:

  Definition of suicide:
  - the taking (sic) of one’s own life

• A dying patient’s life is already taken

• “Words are like scalpels. They can remove the disease; or if used improperly they can permanently scar.”
Suicidal patients have:

• CO-MORBIDITY
  – Major depressive disorder
  – Post-traumatic stress disorder
  – Borderline personality disorder
  – Bi-polar disorder (I & II)
  – Substance abuse/Addictive personality trait, etc.

DWD patients have no psychiatric diagnosis (i.e. they want to live but they cannot)
<table>
<thead>
<tr>
<th>Aid in Dying</th>
<th>Suicide</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Terminal diagnosis</td>
<td>• Not terminal</td>
</tr>
<tr>
<td>• Mental capacity</td>
<td>• Mental health diagnosis</td>
</tr>
<tr>
<td>• Patient wants to live</td>
<td>• Patient wants to die</td>
</tr>
<tr>
<td>• Planned with family</td>
<td>• Often impulsive / alone</td>
</tr>
<tr>
<td>• Death is gentle</td>
<td>• Death may be violent</td>
</tr>
<tr>
<td>• Normal grieving</td>
<td>• Abnormal grief</td>
</tr>
<tr>
<td></td>
<td>– (What could we have done?)</td>
</tr>
</tbody>
</table>
Suicide...... Aid in Dying

• ORS 127.880:

127.880 s.3.14. Construction of Act. Nothing in ORS 127.800 to 127.897 shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing or active euthanasia. Actions taken in accordance with ORS 127.800 to 127.897 shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law. [1995 c.3 s.3.14]
“The Falling Man, and others like him, didn’t have a real choice to live or die—they only had a choice in which way they died: smoke and fire, or by falling.

For their children to have to walk through life saying, “my dad committed suicide” is less than fair and completely untrue—they didn’t choose to die (the very definition of suicide), they just chose how they died.”

Benjamin L. Corey / Patheos Nov. 4, 2014
Ethics and AiD

Aid in Dying
The Ultimate Argument
The Clear Ethical Case for Physician Assisted Death

Right or Wrong?
Belief or Reason?
Speculation or Experience?
Dialogue or Force?
Ethical or Unethical?
Danger or Protection?

Suicide or Hastening Death?
Liberty or Control?
Criminal or Legal?
Rational or Irrational?
Allowing to Die or Killing?
Life or Death?

Byron Chell
Potential Barriers

• **Patient**
  – Resources
  – Finding a physician
  – The “protections” under the law
  – Family support

• **Provider**
  – Lack of education
  – Personal beliefs
  – Restrictive covenants

• **Institutional**
  – Pharmacy
  – Religious affiliation
Conclusions

• **DEATH** is **not the enemy**
  
  “I have often thought upon death, and find it the least of all evils.” - FRANCIS BACON

• **SUFFERING** is the enemy
  
  • Inadequately or uncontrolled pain
  • Unrecognized or untreated depression/grieving
  • Iatrogenic conditions (technology) which unnecessarily prolong life
  • Loss of patient autonomy/dignity
Conclusions

DWD “is not primarily about physicians or their self image; it’s about patients – specifically patients for whom healing is no longer possible.”

M Angell MD  WP  November 2, 2014
Conclusions

• Medical aid in dying is not a reflection of poor or “failed” end-of-life care (hospice/palliative care programs)
• Medical aid in dying does not cause more people to die; it allows fewer to suffer.
• Medical aid in dying is now a standard of care in various US States and Canada
• Medical aid in dying is not suicide.
Conclusions

“We give patients the right to hasten their deaths by refusing dialysis, mechanical ventilation, antibiotics, or any other life-sustaining treatment. Why deny them what is essentially the same choice?”

M Angell MD  WP  November 2, 2014
THERE ARE ONLY TWO THINGS THAT MATTER IN END OF LIFE CARE:

1) RESPECT (of the patient’s wishes)

2) COMFORT (for the patient’s suffering: physical and spiritual)
One does not ask of one who suffers: What is your country and what is your religion?

One merely says: You suffer, this is enough for me: you belong to me and I shall help you.

LOUIS PASTEUR MD 1886
Resources:

*Being Mortal* by Atul Gawande MD

*Can’t We Talk About Something More Pleasant* by Roz Chast

*The Conversation* by Angelo Volandes MD

*Knocking on Heaven’s Door* by Katy Butler

*Aid in Dying: The Ultimate Argument* by Byron Chell

Compassion & Choices - [www.compassionandchoices.org](http://www.compassionandchoices.org)

“*How to Die in Oregon*” a movie by Peter Richardson
Life is short
and we have
not too much time
to gladden the hearts of those
who travel the way with us.
Oh! Be swift to love!
Make haste to be kind!
HENRI AMIEL
We’re all just walking each other home.

– Ram Dass –
Translating Patients Wishes at the Federal Level
Federal Programs

Federal Policy Agenda / 2016 & Beyond

Dying in America
Improving Quality and Honoring Individual Preferences Nearing the End of Life
Broad Policy Areas

• Delivery of family-oriented person centered care
• Clinician Patient Communication and Advanced Care Planning
• Professional Education and Development
• Policies and Payment Systems
• Public Education and Engagement