The Evidence and Data Around Medical Aid in Dying

Kim Callinan, Chief Executive Officer
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Experience

- Full disclosure: Supporter
- Consumer Perspective
- Hands on experience helping patients access the law
- Goal is availability not usage
- Full range of options
- Science & Evidence: Health Affairs Blog

Compassion & Choices
What Do Patients Want?
"You’ve got six months, but with aggressive treatment we can help make that seem much longer."
Yes on 106: Colorado End of Life Option Act

- Passed by 30 point vote margin (65% vs. 35%)
- Received more “Yes” votes than any other issue, including minimum wage, cigarette tax and universal health care.
- Drew support across virtually every demographic group
Public Opinion Support Is Strong

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?
Two-thirds of Americans said it was “morally acceptable for terminally ill patients to ask their doctors for help in ending their lives.” (Lifeway)

Majority support spanned a variety of demographic groups, including:

- Christians (59 percent)
- Catholics (70 percent)
- Protestants (53 percent)
- Other religions (70 percent)
- Non Religious (84 percent)
- White Americans (71 percent)
- Hispanic Americans (69 percent)
- Black, non-Hispanics (53 percent)
Strong Support Among Hispanic Leadership & Organizations

Dolores Huerta  Edward James Olmos  Mauricio Ochmann  Jorge Ramos
How Is Medicine Responding?
Doctor Public Perception

State Medical Society Surveys

- Colorado - 56% support
- Maryland - 65% support
- Massachusetts - 62%

Should Physician Assisted Suicide or Physician Assisted Dying Be Allowed?

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<th>2010</th>
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<td>Yes</td>
<td>41</td>
<td>57</td>
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<td>No</td>
<td>46</td>
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Ten state medical societies have dropped their opposition to Medical Aid in Dying

- Oregon Medical Association (1994)
- California Medical Association (2015)
- New York State Academy of Family Physicians (2016)
- Colorado Medical Society (2016)
- Maryland State Medical Society (2016)
- Medical Society of the District of Columbia (2016)
- Nevada Medical Society (2017)
- Maine Medical Association (2017)
- Minnesota Medical Association (2017)
- Massachusetts Medical Society (2017)
The Move Toward Engaged Neutrality

John Frye, MA and Stuart J. Youngner, MD,

Compassion & Choices
What happens with implementation?
Patient Experience Accessing the Law

- 6 month prognosis often late
- Takes a long time and energy to get through process
- Thoughtful balance between protections and access
Research & Reporting

Research on medical aid in dying vs. other end-of-life care options (e.g. VSED, Palliative Sedation, Withdrawal of medication palliative care, hospice, etc.)

Caution on over collection
- Intrusive
- Stigmatizing
- Deterrent for doctors
Key Issues

- Differences by state
  - Washington experience
  - California experience
- Specialized doctor versus greater adoption across system
- Long term care/facilities
- The role of the law versus the role of medicine
- Choice & Care
- Distinction between disparity in wanting the law; wanting the option; accessing option
Research

- Why has patient demand for this option increased in recent years? What does it tell us about patient directed care?
- Which regulatory requirements are really necessary? And which ones create unnecessary delays and stigma?
- What impact will additional data collection have on the patient’s ability to access the law? and doctor’s willingness to practice?
Research

- Should we be researching all end of life options (VSED, Palliative sedation, withdrawal of treatment, etc) rather than just Medical Aid in Dying?
- What is the impact of not passing these laws (e.g. people committing suicide, underground practice without regulations, conversations about end of life remain taboo, etc.)?
- Given the small number of people who choose to access the law and 40 combined years of implementation with no evidence of abuse or coercion, where are research dollars best spent to advance end of life care?
It’s About Balance: Reporting & Research Versus Patient Care
What is the Opportunity?
Leverage Patient Interest to Improve End of Life Care

- Bring the practice in the open and regulate it
- More open conversations between doctors and patients
- Opens patients eyes to other end of life care options
- People enter hospice earlier (help move historically disadvantaged population into care sooner)
- A move toward patient-directed care similar to the child birth movement
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  1886
French Biologist/Father of Germ Theory
Questions?

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Thank You!