The California End of Life Option Act: Reflections on Preparing for and Responding to Legalization

Barbara A. Koenig
Professor & Director, UCSF Bioethics
University of California, San Francisco
History

• Governor Jerry Brown signed the End of Life Option Act on October 5th, 2015

• It went into effect on June 9th, 2016
“A Bioethics Emergency” (?)
Background of Convening Efforts

- December 2015
- September 2017

OFFICE OF THE GOVERNOR

To the Members of the California State Assembly:

AB 215 is not an ordinary bill because it deals with life and death. 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 or suffering.

I have carefully read the thoughtful opposition materials presented by a number of doctors, religious leaders and those who champion disability rights. I have considered the theological and religious perspectives that any deliberate shortening of one’s life is sinful.

I have also read the letters of those who support the bill, including heartfelt pleas from Brittany Maynard’s family and Archbishop Dennis J. Vunic. In addition, I have discussed this matter with a Catholic Bishop, two of my own doctors and former classmates and friends who take varied, contradictory and nuanced positions.

In the end, I was left to reflect 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.

Sincerely,

[Signature]

Edmund G. Brown Jr.
EOLOA Project Website

END OF LIFE OPTION ACT TASK FORCE

To promote thoughtful deliberation on topics that will be relevant to healthcare systems as they create patient-centered policies to respond to the End of Life Option Act in California.

Thank you to the California HealthCare Foundation and Stupski Foundation for making this possible.

End of Life Option Act - One Year Later Convening

Hosted by UCSF Bioethics, UCLA Health, and the Coalition for the Compassionate Care of California
Marriott Courtyard-Midtown, Sacramento
Monday, September 25, 2017 & Tuesday, September 26, 2017

Welcome & Opening Keynote

Framing the EoLOA within the Larger End of Life Context

www.eoloplctionacttaskforce.org
How California Prepared for Implementation of Physician-Assisted Death: A Primer

Physician-assisted death is now legal in California, and similar laws are being considered in

Laura A. Petrillo, MD, Elizabeth Dzeng, MD, PhD, MPH, Krista L. Harrison, PhD, Lindsay Forbes, Benjamin Scribner, RN, and Barbara A. Koenig, PhD
Activities

• Convening and follow up resource sharing (Barbara Koenig and Judy Thomas)

• Survey of California Health Care Systems (Cindy Cain and Neil Wenger)

• Collection of In-depth Patient Narratives (Helene Starks)
Moral Ambivalence

• Simple implementation?
  – Some had difficulty being present for discussions

• Moral concerns will not simply disappear

• Concern about being the “go to” physician or institution
Responses to the EOLOA

• Choices and Variability in Practice
  – On premises?
  – Mental health evaluation?
  – Palliative care involvement?
  – Ethics referral?
  – Who will participate?
  – How to honor conscientious objections by providers while respecting patient choice?
Responses to the EOLOA

• Implementation has been tough, uneven
• Requires significant resources, including clearly identified patient navigators
• Only easily practicable when built on a good hospice/palliative care program
• Physician willingness to prescribe is not a simple yes/no
Implementation Issue: Sunset Clause

• Sunsets January 1, 2026

This bill, until January 1, 2026, 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.

• Creates a duty to evaluate “implementation”
Implementation Issue:
Final Attestation Form

• Not routinely collected, reported
Implementation Issue: Role of Interpreters

• Concern about being asked to assure compliance with the law
Role of California Department of Public Health

• Did not release all data

• Need for additional data elements

• How to capture race/ethnicity data and other “categories of difference” including social and economic status
“Best Practices”

• Data Collection
  – Impact on diverse populations

  – Research thus far suggests that a significant degree of social/cultural capital is needed to initiate and carry through a request
Barriers?

• Waiting periods
  – What constitutes a request?

• Is lack of access a justice concern?

• Development of specialty referral practices offering PAD?

• Funding for research? (Too controversial?)
Next Steps in Research

• Symbolic impact of the EOLOA
  – On EOL & palliative care generally
• Consequences for the role of healer
• Impact of “routinization”
  – Mandated disclosure of EOL options
  – Advance care planning
• Consumer-driven health care (trust)
• How can we implement genuine democratic public engagement about PAD?
Our Team

• Barbara Koenig, PhD
• Lindsay Forbes
• Cristina Nigro, MS
• Judy Thomas, JD
• Neil Wenger, MD
• Cindy Cain, PhD
• Helene Starks, PhD, MPH
Funders

California Health Care Foundation

STUPSKI FOUNDATION