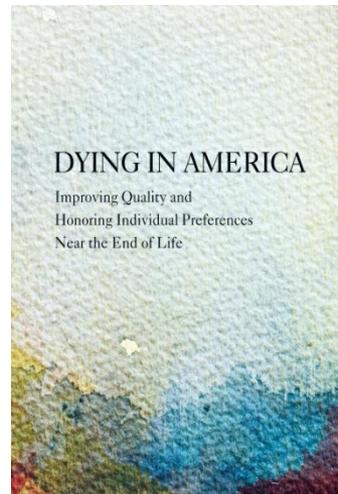


Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life



*“Making your wishes known”
Consumer Voice: Washington DC
November 16, 2014*

Judith R. Peres, LCSW-C

Overview

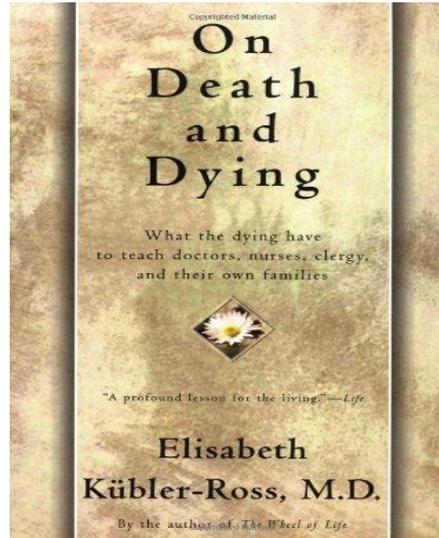
- Brief History on Lead up IOM 2013 EOL Committee
- Role of IOM – Public Policy
- “Dying in America” – Recommendations
- How Advocates can use Recommendations to help “*Make wishes known*”

How Americans Die: A Century of Change

	<u>1900</u>	<u>2000</u>
Age at death:	46 years	78 years
Top Causes:	Infection Accident Childbirth	Cancer Organ system failure Stroke/Dementia
Disability: death	Not much	2-4 yrs avg. before
Financing:	Private, modest	Public, substantial- in US - 83% in ~1/2 of women
Medicare die on Medicaid		

Hospice & Palliative Care

- **Origins of Palliative Care**
 - Hospice Movement, Dame Cicely Saunders
 - Elizabeth Kubler-Ross



Right to Die

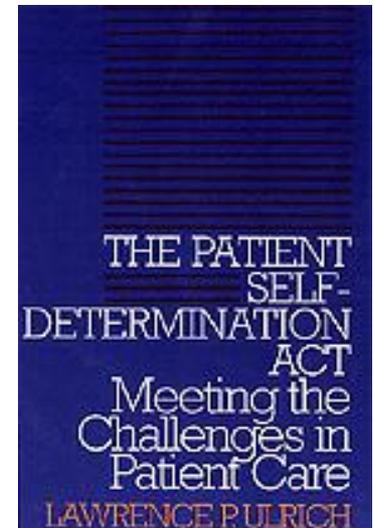
- Karen Ann Quinlin - 1985
- Nancy Cruzan - 1990
- Terri Schiavo - 2005



Advance Directives

Patient Self-Determination Act (PSDA) 1990

- Requires all health care facilities receiving Medicare or Medicaid funding to inform patients of their right to refuse medical treatment and to sign advance directives.



Approaching Death in America: Improving Care at the End of Life IOM, 1997



JAMA[®]

The Journal of the American Medical Association

Original Contributions

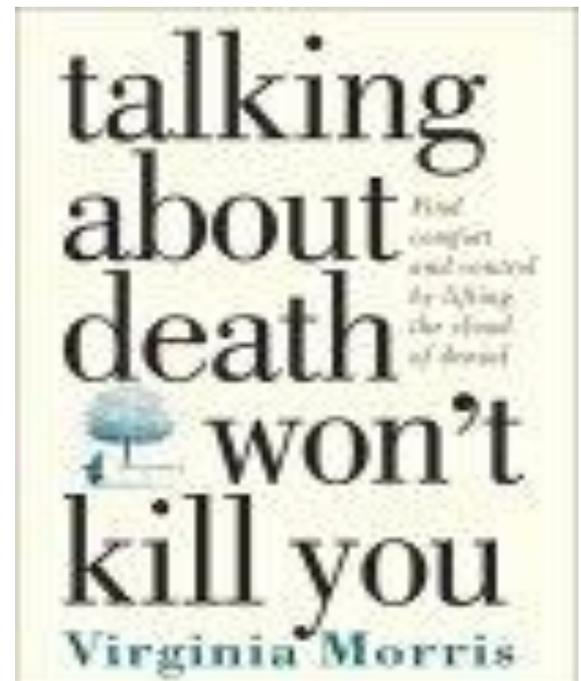
A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

The Study to Understand Prognoses and Preferences
for Outcomes and Risks of Treatments (SUPPORT)

The SUPPORT Principal Investigators

Public Policy Attempts to “have the conversation”

- Welcome to Medicare – 2003
- Affordable Care Act - 2010
- Wellness Visit - 2011



NOV 21, 2006

TIME

HOW TO DIE

What I Learned from the Last Days of My Mom and Dad

By Jay Byars

www.time.com

NOVEMBER 12, 2006

Newsweek

THE CASE FOR KILLING GRANNY

CURBING EXCESSIVE END-OF-LIFE CARE
IS GOOD FOR AMERICA

BY EVAN THOMAS

I WAS A TEENAGE DEATH PANELIST

BY JOHN MEECHAM

PLUS:

THE WAY OUT OF AFRICANISM
BY FARIED ZAKARIA

THE ADULTS OF THE '60S OF CRASH
BY MALL FERGUSON

OSAMA'S CRIMINALITY CAP
BY GEORGE F. WILL





INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

**IOM Committee on Approaching
Death: Addressing Key End of Life
Issues**

STUDY CHARGE



Why does the IOM matter?

The IOM exists to secure the services of eminent professionals in examination of policy matters pertaining to the health of the public. The IOM acts under the National Academy of Sciences through its congressional charter as *advisor to the federal government*.

Committee Statement of Task*

- Current state of end of life care with respect to:
 - Delivery of medical care and social supports
 - Patient-family-provider communication of values and preferences
 - Advance care planning
 - Health care costs, financing, and reimbursement
 - Education of health professionals, patients and loved ones, and the public at large
- *Abbreviated version. Full statement of task in committee report.



“Dying in America” Five Recommendations

1. Person-centered, family-oriented (palliative) care
2. Clinician-patient communication and advance care planning
3. Professional education and development
4. Policies and payment systems
5. Public education and engagement



I. Delivery of Care

All payers should cover palliative care and all health organizations should provide it.



2. Communication and ACP

- Professional and quality organizations should develop **standards for clinician-patient communication** and advance care planning that are measurable, actionable, and evidence based.
- **Adherence to these standards should be tied to credentialing, licensing, and reimbursement.**



"There's no easy way I can tell you this, so I'm sending you to someone who can."



3. Professional Education and Development

Establish training, certification, and licensure requirements that **strengthen the palliative care knowledge and skills of *all* clinicians** who care for individuals with advanced serious illness...



VITAL talk



CSU The California State University

Institute for Palliative Care

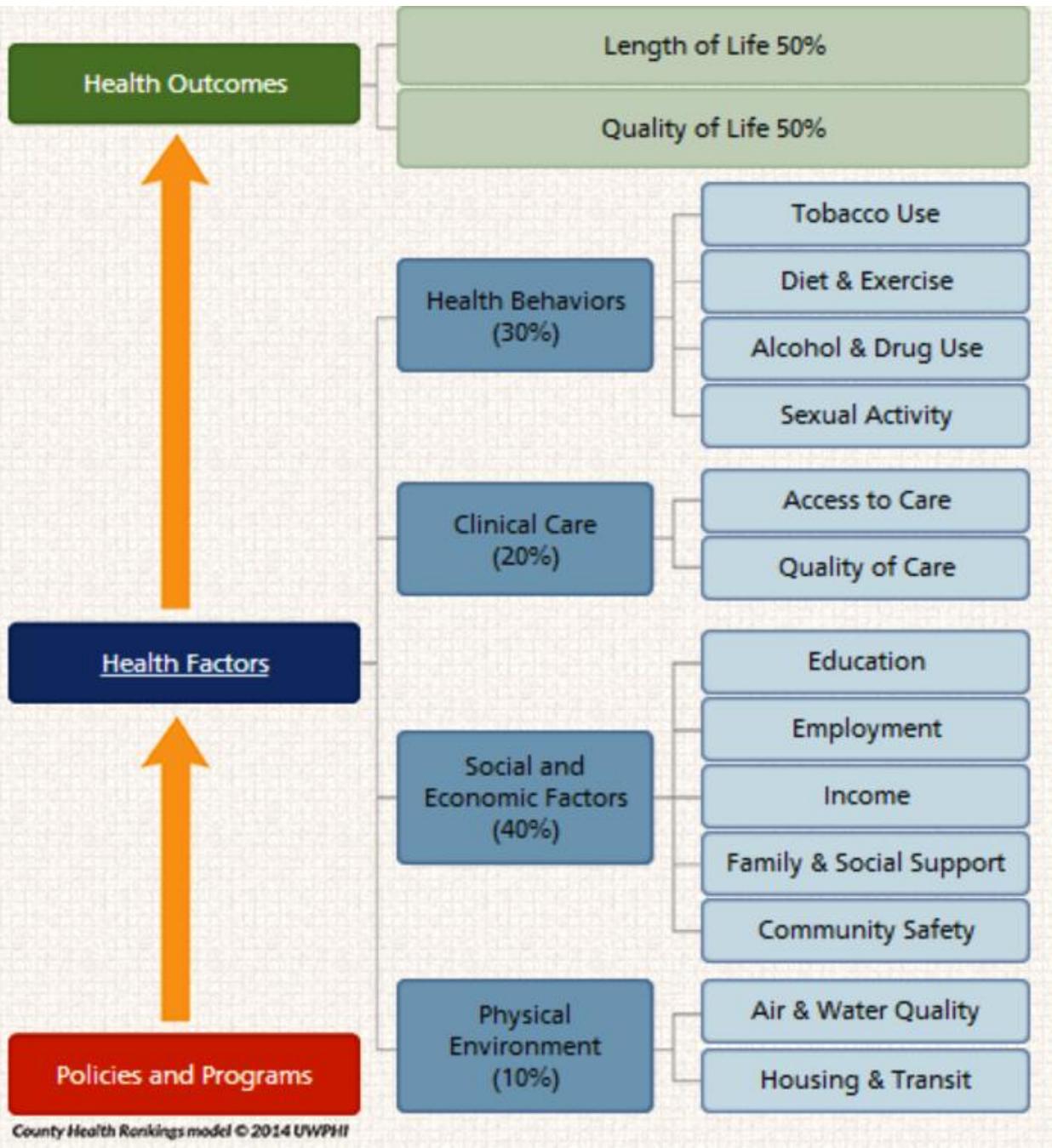
Lets Talk About... **Culturally Competent Palliative Care for Latinos**



4. Policies and Payment Systems

Federal, state, and private insurance and health care delivery programs should **integrate the financing and delivery of medical and social services;**

And require public reporting of quality and costs for care near the end of life.





5. Public Education and Engagement

Every element of society should engage their constituents and provide factual information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.



A Third Say ACA Includes Death Panels, Another One In Five Unsure

I'm going to read you a list of specific elements or parts of the law. For each, please tell me whether you think it is included in the health reform law, or not.

ELEMENTS THAT ARE NOT INCLUDED IN THE HEALTH REFORM LAW

	Yes	No (correct answer)	Don't know
Allow a government panel to make decisions about end-of-life care for people on Medicare			
Total	36%	45%	20%
Democrats	35	54	10
Independents	36	44	20
Republicans	41	39	21
Create a new government run insurance plan to be offered along with private plans			
Total	52%	30%	18%
Democrats	43	38	19
Independents	50	34	16
Republicans	68	20	13

Note: Items asked of separate half samples.

Source: Kaiser Family Foundation *Health Tracking Poll Omnibus Supplement* (conducted March 1-4, 2012)



How can consumers
leverage the report's
recommendations to:
“Make Your Wishes known”



The IOM's Assessment for Leveraging Reports

Commonalities among reports with major impact, from Harvey Fineberg MD, immediate past president of the IOM:

- **Excellence of the product:** objective, evidence-based, grounded in science, well-reasoned, understandable, thorough, and persuasive
- ***Importance, Timeliness, and Relevance***
- **Contending Values and Interests**
- **Communication and Promotion**
- ***Repetition and Consistency***

Opinions of Policy Makers

Predictors of impact according to folks on the Hill and in the legislative branch

- Sponsor
- Charge
- Repetition of a *consistent message by all stakeholders*
- Stakeholder effectiveness/credibility as advocates



3 Key Elements of Stakeholder Effectiveness

- Stories
- BIG coalition, aligned “asks”
- Legislative champions

Fighting to Honor a Father's Last Wish: To Die at Home

By NINA BERNSTEIN SEPT. 25, 2014



Maureen Stefanides at NewYork-Presbyterian Hospital with her father, Joseph Andrey, waiting to move to a nursing home despite their efforts to arrange for 24-hour care at his apartment.

Victor J. Blue for The New York Times

Consumer Role in Advocating ACP

- Consumer advocates must continue to help create an environment in which people can live and die well... we must:
 - Engage in ACP ourselves
 - Teach providers
 - Work to create the right institutions
 - Ensure that treatment preferences will be followed
 - Assist in developing policies that make quality palliative care available



What more can you do?

Ask for a palliative care program applying IOM recommendations in support of your or your “family” member’s care; or, in the absence of a program, use recommendations to request core elements of care.



What more can you do?

- Champion adoption and use of guidelines in your organization and field and share with colleagues.
- Work in Coalition

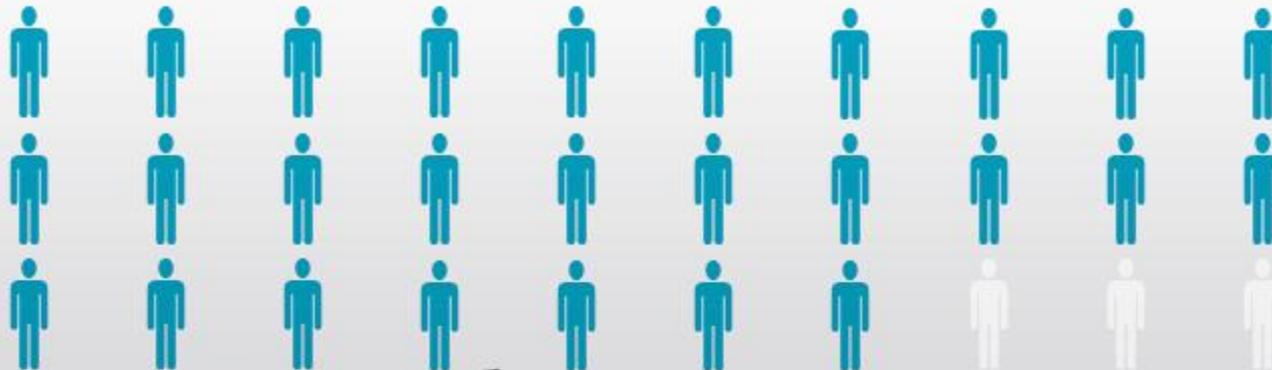
What we know:

Population is aging & more diverse;

We are living longer with greater frailty;

Consumers need to express values & preferences for care;

Critical to name surrogate decision maker



More than a quarter
of all adults have given little
or no thought to their
end-of-life wishes.

Have you?

Learn more: iom.edu/endoflife

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