

End-of-Life Care in the US: Overview and Policy Challenges

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Michael K. Gusmano, PhD

**Research Scholar, The Hastings Center
Associate Professor of Health Policy and
Management, New York Medical College**

“It is hard to die in America”

Nancy Dubler

WHAT PERCENTAGE OF NURSING HOME PATIENTS IN THE U.S. ELECT THE MEDICARE HOSPICE BENEFIT?

- ✓ 1. A. 6%
- 2. B. 15%
- 3. C. 30%
- 4. D. 50%

Ethics goals for good end-of-life care

Relieve suffering

Respect both living and dying

Promote well-being

Respect persons

Respect dignity

Respect relationships

Respect difference

Promote equity

Preserve professional ethical integrity

Use organizational systems to support good care and ethical practice

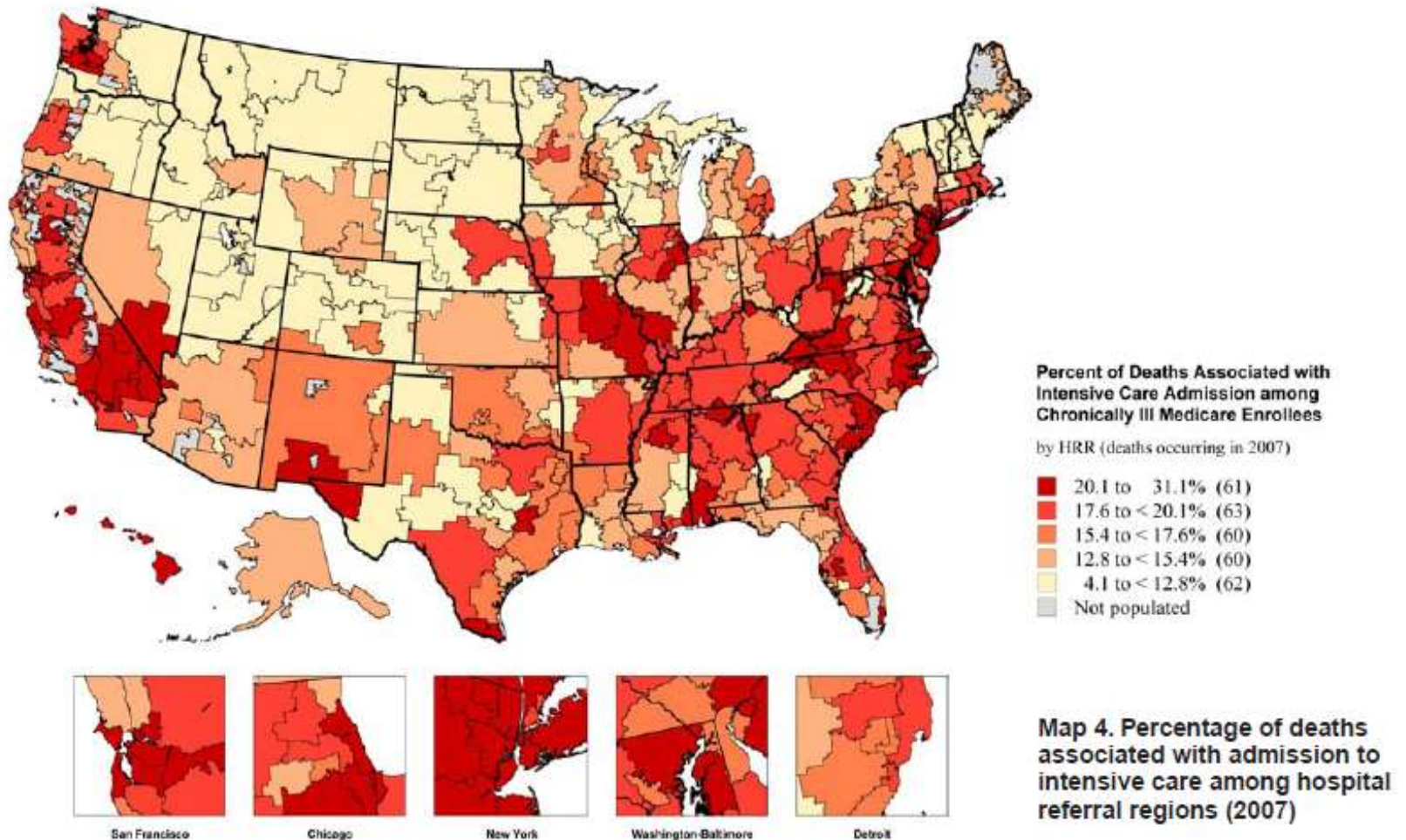
Gap between what people want and what they receive at the end of life

- A 1995 study found that physicians rarely talked to patients about their preferences for end-of-life care
 - Fewer than half of the physicians knew when patients preferred to avoid cardiopulmonary resuscitation.
- A 1998 study of a sample of 479 patients found that 391 expressed a preference to die at home rather than in a hospital – but nonetheless, 216 of those 391 patients ended up dying in the hospital!

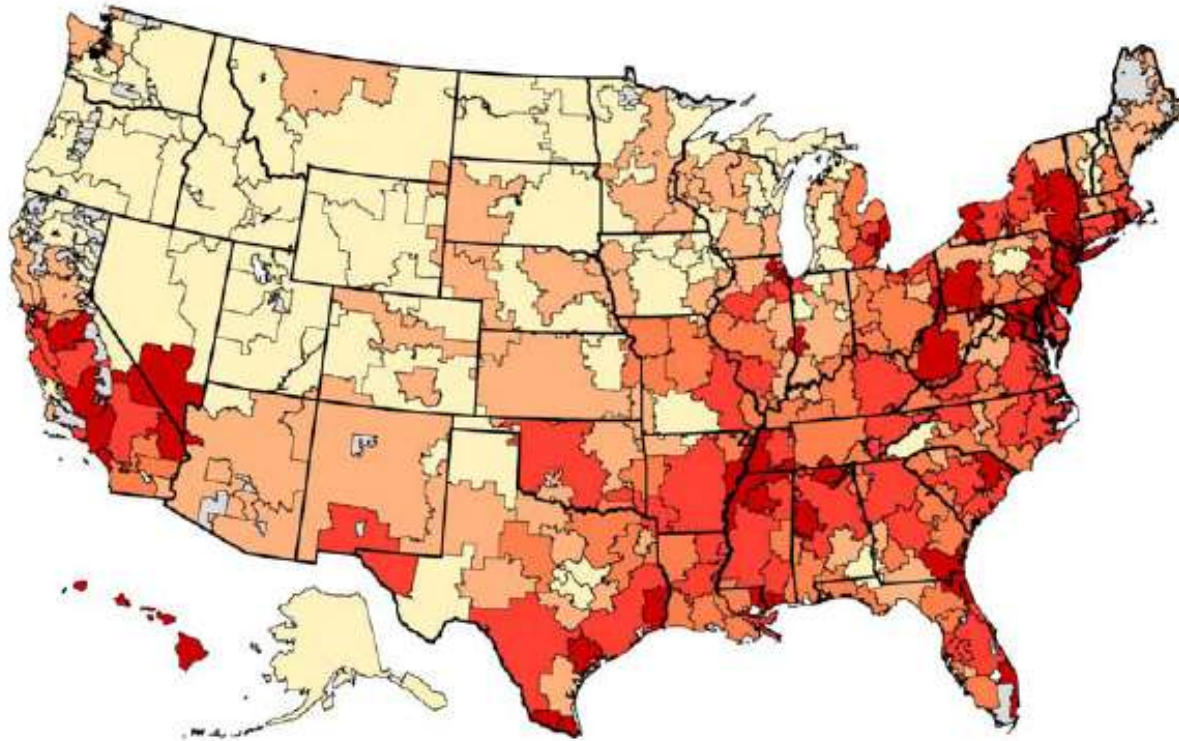
Some room for optimism?

- Medicare beneficiaries with severe chronic illness spent fewer days in the hospital at the end of life in 2007 than they did in 2003
- They were less likely to die in a hospital and more likely to receive hospice care in 2007 than in 2003

Percentage of Deaths Associated with Intensive Care Admission among Chronically Ill Medicare Enrollees

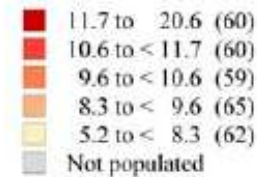


Average Number of Hospital Days per Chronically Ill Patient During the Last Six Months of Life



Average Number of Hospital Days per Chronically Ill Patient during the Last Six Months of Life

by HRR (deaths occurring in 2007)



San Francisco

Chicago

New York

Washington-Baltimore

Detroit

Map 6. Average number of days spent in hospital per chronically ill patient during the last six months of life among hospital referral regions (2007)

What should we do?

- The antidote was initially taken to be three reforms:
- Greater choice by patients at the end of life (by means of living wills and/or the appointment of a surrogate),
- Better physician training
- Hospice and palliative care.
- After 40 years, we have achieved modest success....
 - Why?

Do Advance Directives Work?

- Failure to provide sufficient instructions
 - Too too vague to be clear: ‘If I am close to death’
 - Too medically specific to be helpful in common clinical situations (for example, ‘If I am in a persistent vegetative state’)
- In 2005, a report by the President’s Council on Bioethics also expressed concern about the effectiveness of advance directives
 - “Trying to dictate the precise terms of one’s future care is often misguided or ineffective”
- *But* more recent studies suggest that they, when used, may provide real value
 - A study by Teno and colleagues, for example, found that “written advance directives, do not resuscitate orders, and orders to forgo artificial hydration and nutrition are associated with lower rates of feeding tube insertions”

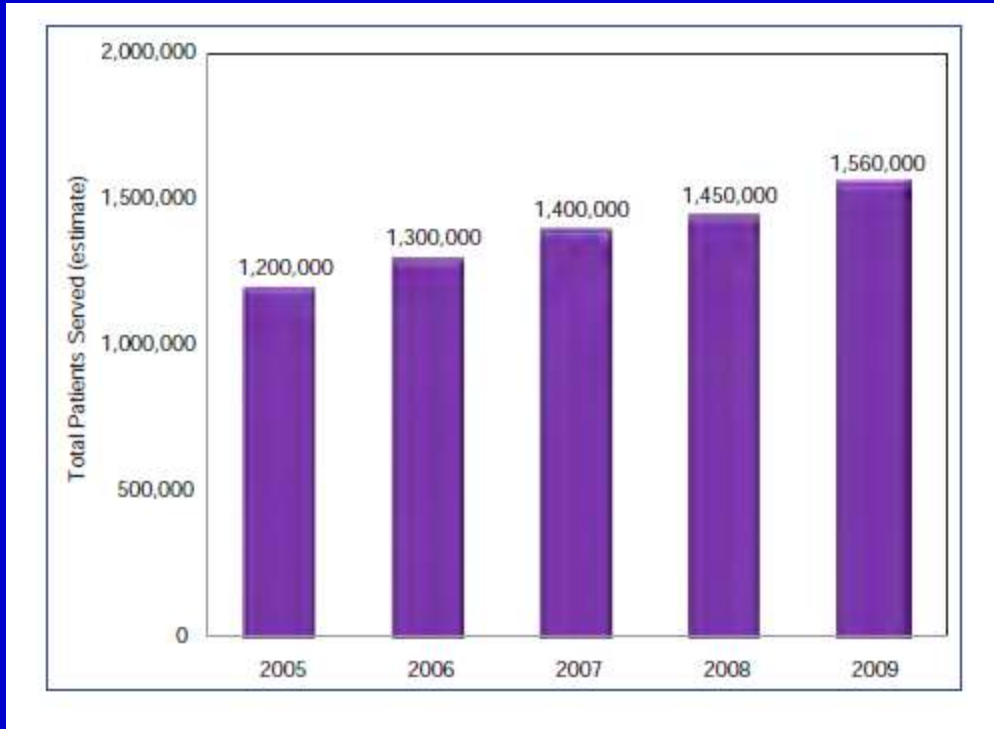
Durable Power of Attorney to the Rescue?

- The American Bar Association's Commission on Legal Problems of the Elderly *and* the President's Commission on Bioethics recommend the use of a "surrogate" through the use of "durable power of attorney"
- Only about 15 percent of Americans have arranged medical POAs—half the (modest) number with living wills.

The Evolution Hospice

- The term “hospice” was coined in 1967 by Dame Cicely Saunders, who founded a hospice (St. Christopher’s) in a London suburb.
- In the late 1960s, as Elizabeth Kubler-Ross’s book, *On Death and Dying*, drew popular attention to “death with dignity,” Florence Wald, dean of Yale’s School of Nursing, worked with Saunders and promoted hospices in the US.
- Important indicators steadily signaled that hospices were becoming “mainstream”
 - inclusion as a guaranteed benefit in President Bill Clinton’s failed reform plan of 1993
 - the issuance of a Hospice Care commemorative stamp in 1999
 - a national conference on access to hospice and palliative care in 2005
 - a World Day event in 70 countries in 2006 to “focus global attention” on hospices
 - a growing body of research purporting to show that hospice care reduces the costs of care at the end of life

Use of hospice growing, but still limited



National Hospice and Palliative Care Organization, 2010

Where is hospice delivered in the U.S.?

Location of Death	2009	2008
Patient's Place of Residence	68.6%	68.8%
Private Residence	40.1%	40.7%
Nursing Home	18.9%	22.0%
Residential Facility	9.6%	6.1%
Hospice Inpatient Facility	21.2%	21.0%
Acute Care Hospital	10.1%	10.1%

National Hospice and Palliative Care Organization, 2010

Too Little, Too Late

- The average length of stay in hospice care is 69 days, with a median length of 21.1 days
 - half received care for less than three weeks, and the other half more than that
- Since the majority of patients in hospice have cancer it is highly unlikely that it is not known they were dying until three weeks before they did or, for that matter, prior to the 69-day average.

Too Little, Too Late

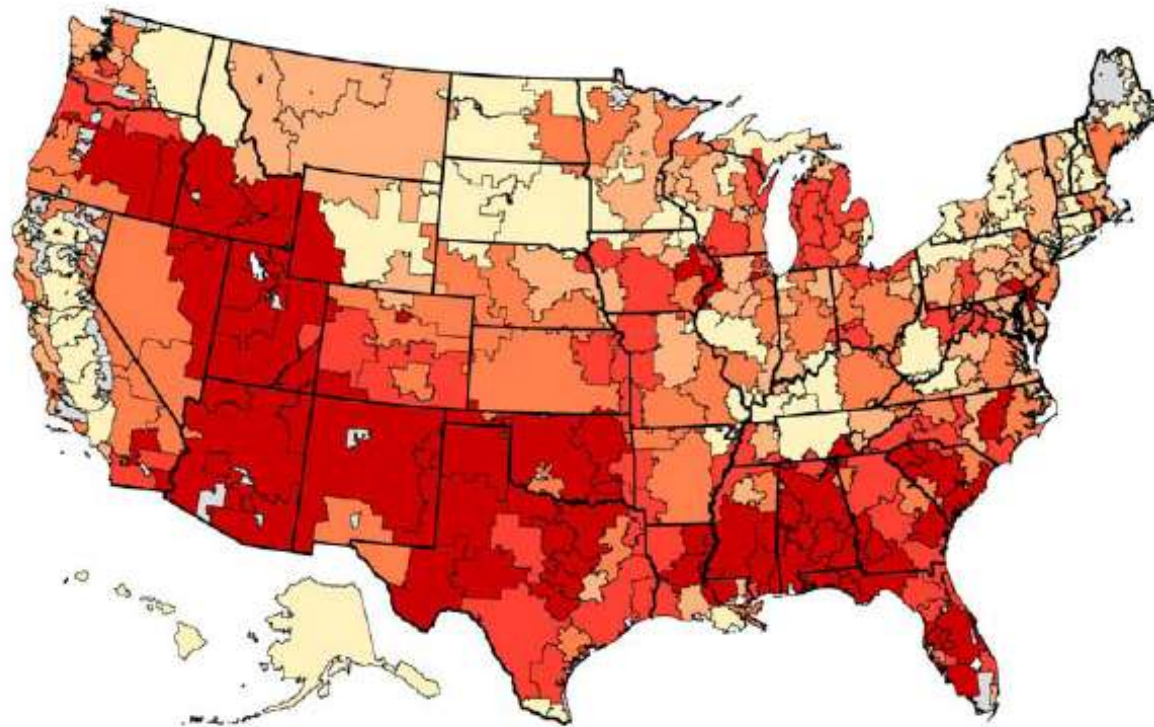
- A study of patients dying of heart disease found that over time a greater use of expensive intensive care occurred at the same time that hospice services were also rising
- While there is good evidence that hospice care can reduce costs, it is the costs incurred before hospice that have to be counted as well

Racial/Ethnic disparities in hospice use

Patient Race	2009	2008
White/Caucasian	80.5%	81.9%
Multiracial or Other Race	8.7%	9.5%
Black/African American	8.7%	7.2%
Asian, Hawaiian, Other Pacific Islander	1.9%	1.1%
American Indian or Alaskan Native	0.2%	0.3%

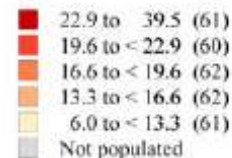
National Hospice and Palliative Care Organization, 2010

Average Number of Hospice Days per Chronically Ill Patient During the Last Six Months of Life



Average Number of Hospice Days per Chronically Ill Patient during the Last Six Months of Life

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Map 10. Average number of days spent in hospice care per chronically ill patient during the last six months of life among hospital referral regions (2007)

Palliative Care

- Palliative care is an umbrella term for services that aim to manage and reduce pain in patients who may concurrently get curative care and who may be, but need not be, terminally ill
- Hospice care invariably entails palliation, but this latter transpires in settings that include but extend beyond hospices, notably hospitals

Can Palliative Care Save Money?

- A recent study indicates that, for patients with metastatic non-small-cell lung cancer, palliative care led to cost savings
 - Why? These patients stopped receiving toxic treatments that provided little benefit.
- Palliative care teams provided support for care at home and avoided preventable emergency hospitalizations among these patients.

Financial Barriers to Extending Palliative Care

- Direct conflict of interest: Hospitals make money on intensive end of life care services
- Medicare (and most Medicaid programs) lack specific reimbursement categories for non-hospice based palliative care in hospitals

Financial Barriers to Palliative Care

- Palliative care is not the same as hospice, but they are often confused
- Rules governing the Medicare hospice program undermine the goal of providing early palliative care.
 - To qualify for the Medicare hospice benefit, a patient must receive a diagnosis that they have a life expectancy of six months or less.
 - Patients must agree to forgo all curative care and accept hospice benefits only.

Financial Barriers to Palliative Care

- Since most patients die in a hospital or nursing home, the hospice program must coordinate its efforts with the health professionals in the institution.
- Nursing homes are penalized financially for enrolling patients in palliative care
- Quality measures discourage nursing homes from enrolling patients in palliative care

Palliative Care and Chronic Cancer

- Nearly 12 million cancer survivors living with a previous diagnosis of cancer in the U.S.
 - Individuals whose early-stage cancer was treated and has not recurred
 - those living with chronic forms of cancer who are undergoing long-term treatment
 - people whose cancer is likely to recur
 - individuals with chronic cancer-related symptoms
- Palliative care outside of hospice tends to be organized as an in-patient consultation service
 - outpatients may lack consistent access to the full range of these services

Moralism and End of Life Care

- And no American tale could be complete without some examples of blatant meddling by religious "authorities"
 - Terri Schiavo
 - In 2010 a patient in Tulsa, Oklahoma
 - Section 1233 of H.R. 3200, 'Advance Care Planning Consultation'

Withholding vs. Withdrawing Care

- In the U.S., there is no legal or ethical distinction
 - Both are forms of foregoing care
 - withdrawing life-sustaining support is legally and morally distinct from physician-assisted suicide
 - Palliative sedation that may (in rare instances) hasten death is also distinct from physician-assisted suicide

Withholding vs. Withdrawing Care

- Medical professionals are less comfortable with the decision to withdraw because it “feels” different
 - It is important to acknowledge this – but if withdrawing treatment is consistent with what the patient wants, it isn’t ethical to go against this because it is hard to do

Removing Legal Obstructions

- Crucial court decisions that removed legal obstructions
 - Quinlan (1976)
 - Saikewicz (1976)
 - Bouvia (1986)
 - Schiavo (2005)

Legal Myths

- Few hospitals, nursing homes or physicians are sued for administering palliative sedation, failing to provide life sustaining treatment, or withdrawing life sustaining treatment
- But the *fear* that this might happen is often sufficient to prevent health care providers from acting in the best interests of their patients

The Unwinnable War Against Death

- Callahan and Nuland: Culture of American medicine and society (New Republic)
- Good end of life care requires a willingness to accept death as part of the human condition
 - By medical professionals
 - By patients and families
 - By the medical industry

The Unwinnable War Against Death

To accept death as part of the human condition means

- For medical professionals : accompanying patients on the way to death becomes as important as their earlier duty to lead them along the path to health
- For patients and families: medicine can not, in the end, save us from death
- For the medical industry: new and updated technologies that do no more than extend life for a few months (or maybe even for a year or so) at a high cost offer no real benefit
 - High health care costs
 - Encourage people to put off good end of life care: don't give up just yet, tight the good fight

Federal policy and the unwinnable war

- President Richard Nixon's 1970 declaration of a "war" on cancer and a rapid expansion of the research budget of the National Institutes of Health
- One of the casualties of the war against death was that medicine forgot its ancient history of care, its acceptance of death as an inevitable part of life, and the ethical duty of the physician to do everything possible to bring about a peaceful death
- The "technological imperative" was widely understood by doctors to mean an obligation to do everything possible to continue the life of the dying and to aggressively use the available technology to do so.
- A less well known "research imperative": a supposed duty to pursue unlimited medical progress