Palliative care and critical care: A new decade

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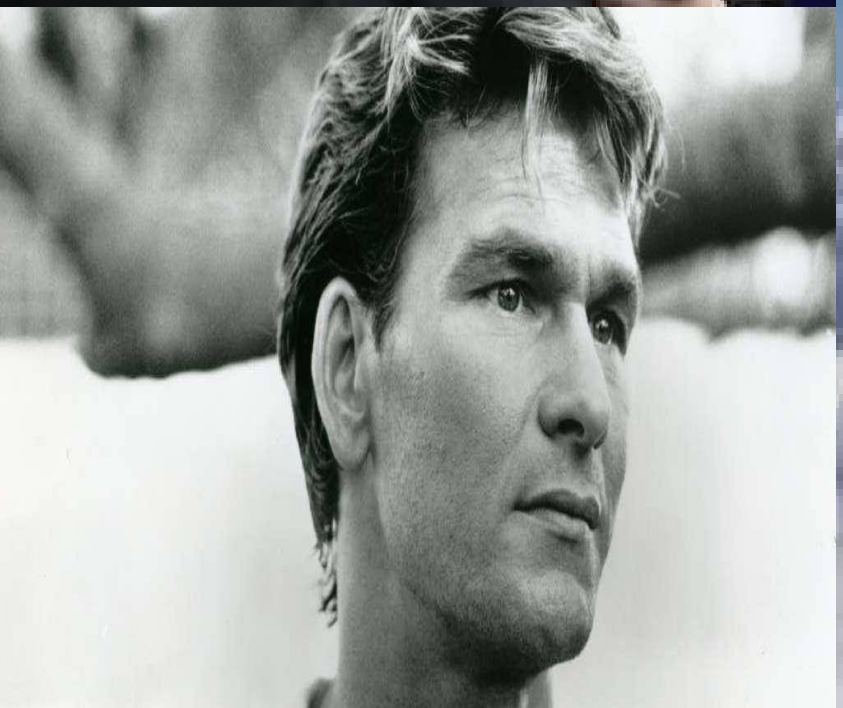
Breathe out, look in, let go
John Welwood

Objectives

- Describe milestones behind the convergence of palliative care and critical care
- Discuss the current state and evidence supporting palliative care in the critical care setting
- Examine how the interdisciplinary team can incorporate primary and specialist palliative care in the practice setting

- How did we get here and what can you do…

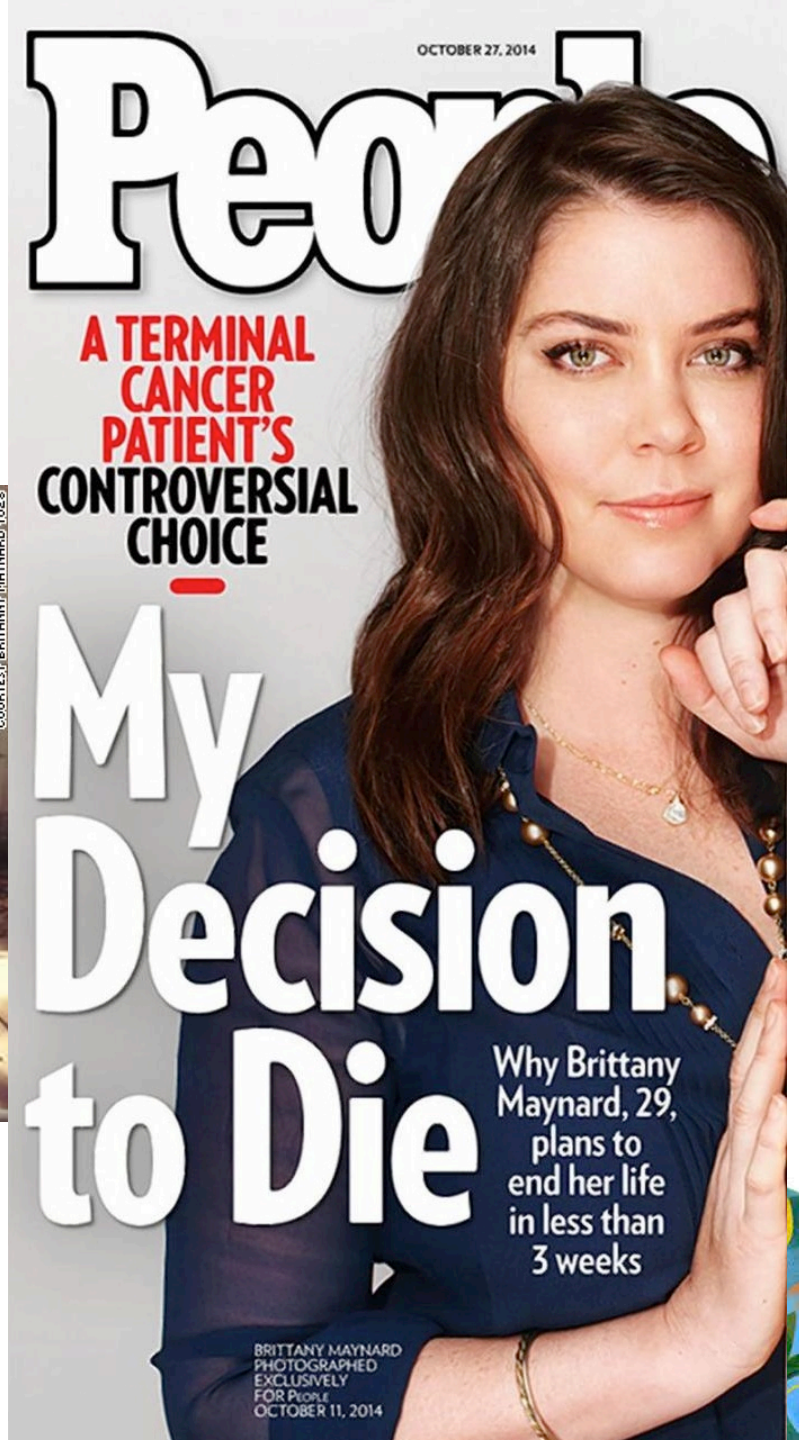


How did we get here…

- Early 20th century
  Hospitals : locus of scientific medicine and cure
- Shift to hospital deaths 1950-1980s
  49% deaths in hospital; 15% home
- Modern ICUs: mysterious, locked doors, limited visitation
- Death and dying-twice removed, invisible
- Public reaction late 1980s

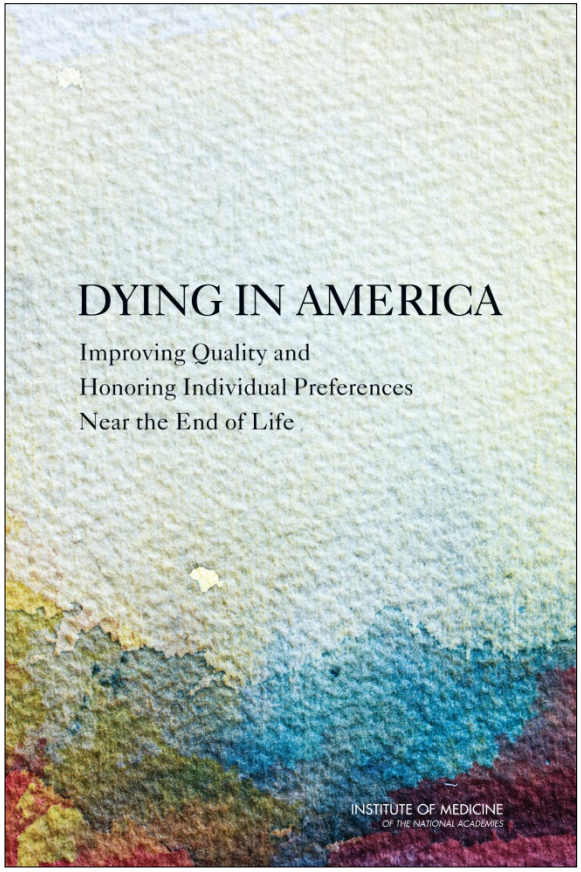
Rothman Where we die NEJM 2014;370:2457

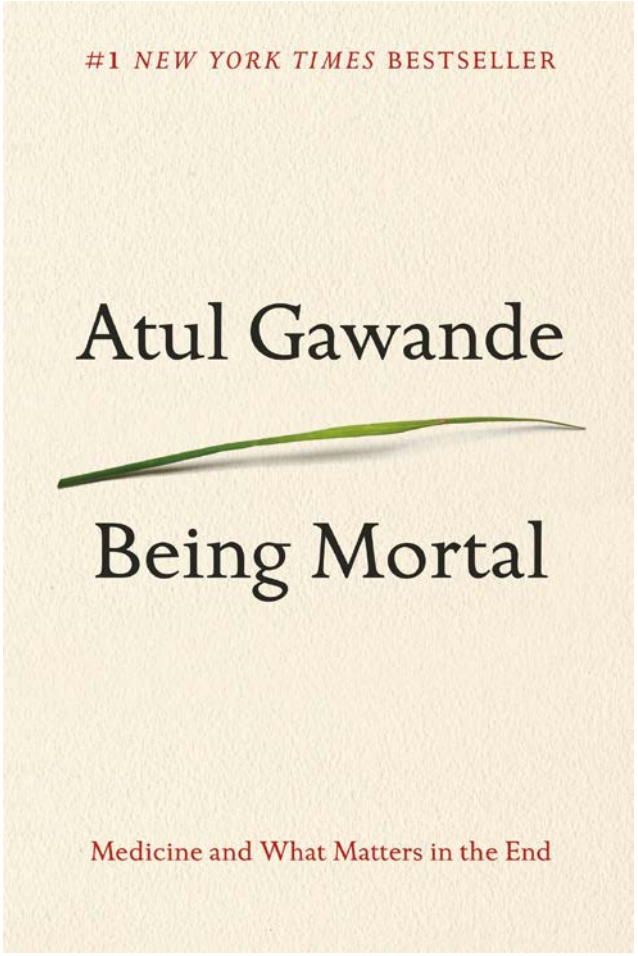
Brittany Maynard



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

www/iom.edu/endoflife





Suggested citation: IOM (Institute of Medicine). 2014. *Dying in America: Improving quality and honoring individual preferences near the end of life.* Washington, DC: The National Academies Press.

Popular media: We listen

- "We are not even sure what the word dying means anymore. In past decades, medical science has rendered obsolete centuries of experience, tradition and language about our mortality and created a new difficulty for mankind: **How to die**.
- "Escalate to critical care- a modern tragedy repeated millions of times. Rarely is there nothing more that doctors can do. "

  Atul Gawande: Being Mortal
- "Hospitals are no place to live or die."

  What really matters at the end of life BJ Miller TED talk 9/15

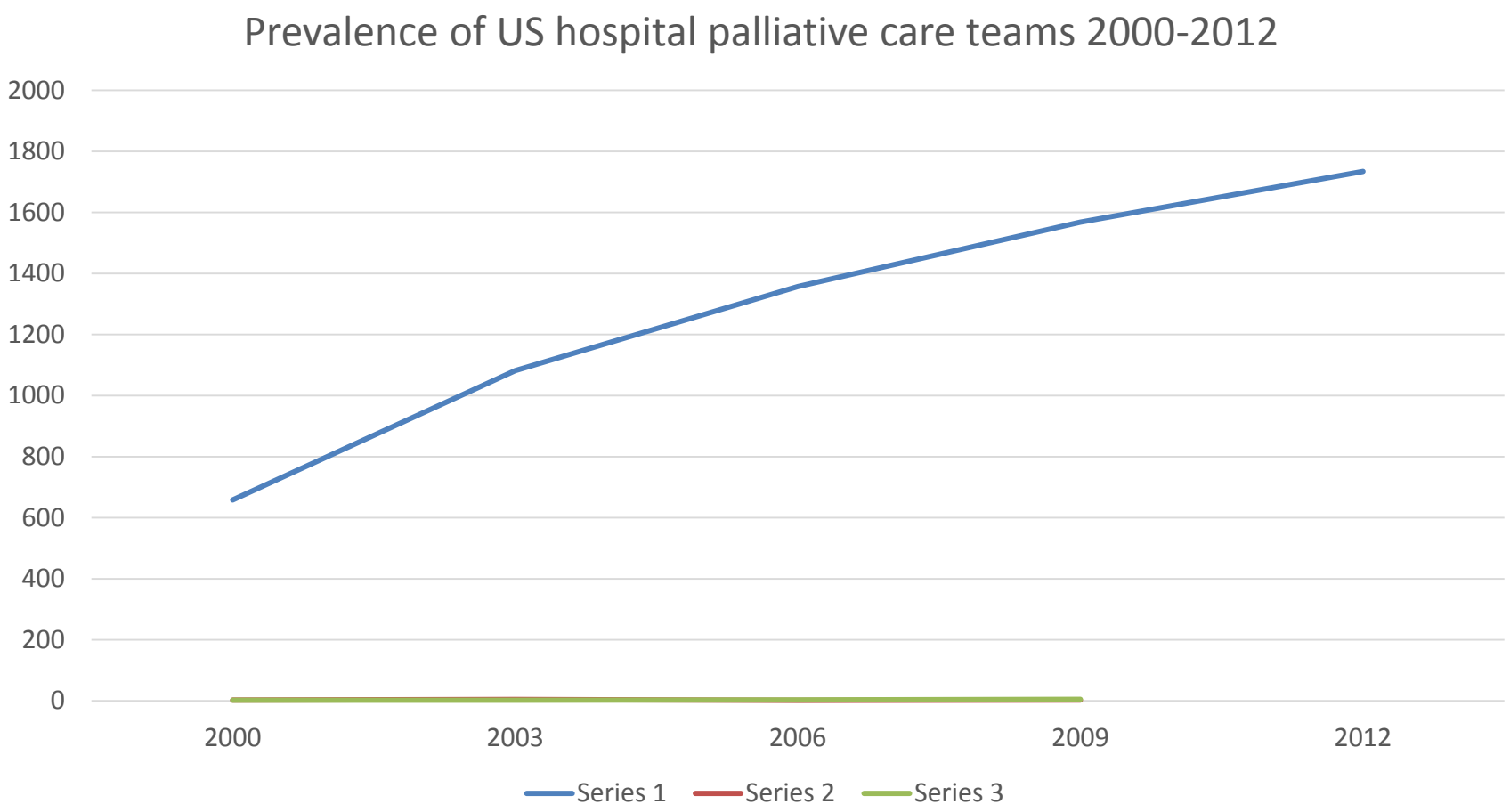
IOM talks…we listen

- 17 years of progress 1997-2015
  - Aggressive public and private sector efforts
- Funds to support education and research
  - RWJF Last Acts Campaign – 800 partner organizations
  - Soros Foundation – Project on Death in America
- Scientific studies tripled – 3,000 publications

SUPPORT Study

- Multi center, RCT
- N=9,500 seriously ill patients
- 2 phases
- Findings
  - >50% patients die in moderate-severe pain
  - > 50% do not die in preferred place
  - Providers had difficulty in determining when critically ill approaching EOL
  - System barriers to the conversation
    - SUPPORT JAMA 1995:274(20):1591-1598.

Palliative care growth

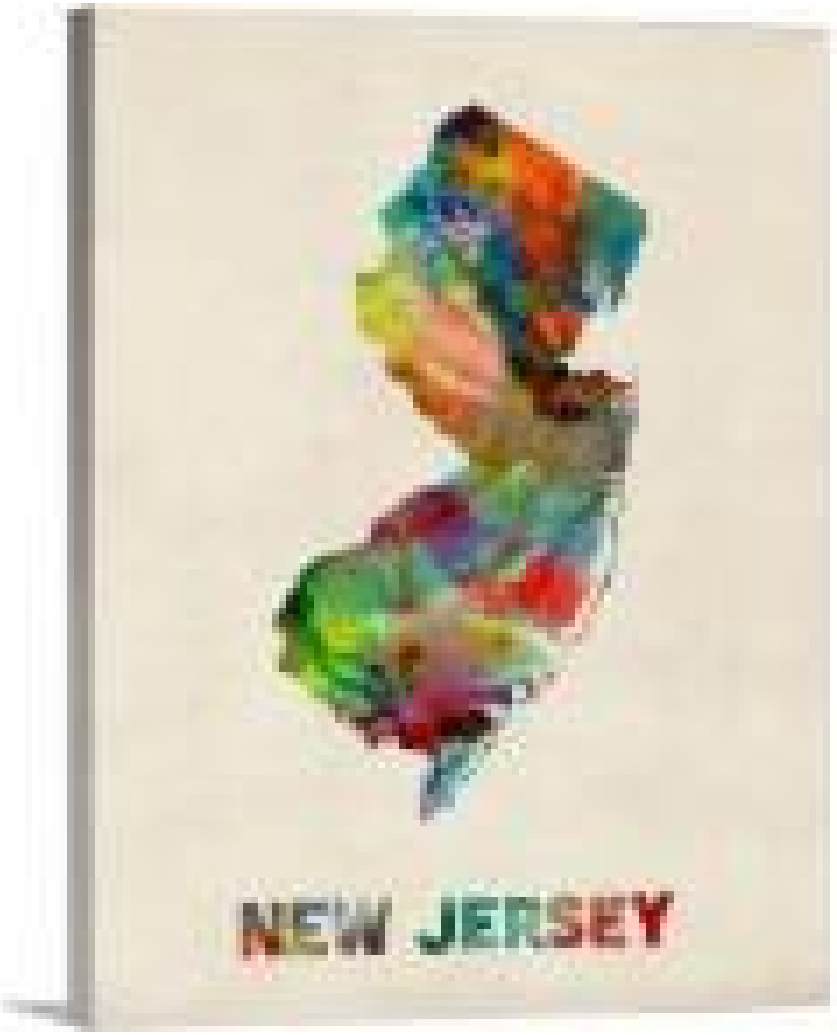


CAPC
Center to Advance Palliative Care

- Resources, registry, stats
- 2015 State by State report card
- 67% US hospitals > 50 beds
- States with A grade
  - more than 80% of state's hospitals
  - increased from 3% to 17% between 2011-2015

- www.capc.org

Grade: A



Death panels controversy

- 7 years 2009-2016
- Politicalization of the conversation
- 2013 poll: 60% of Americans either believed or were unsure “death panels” were law
- 2011 poll:
  - 97% agreed or strongly agreed important that patients be educated about PC and EOL along with curative treatment
  - Conversations should be fully covered by insurance(86%)or by Medicare (81%)
    - Wolf, Berlinger, Jennings NEJM 2015 372;7:678-682

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Numbers, polls and words

- January 2016
  - CMS CPT codes: 99497 and 99498
- CAPC poll (2011)
  - ❖ 90% had either no or limited knowledge of palliative care
  - ❖ When described, 90% said they would want it for self or loved one
- *The conversation matters more than the checkbox*

Advanced Care Planning (ACP)

- **Convergence: Consumer rights movement with public awareness of darker side of heroic measures**
- **Patient Self Determination Act (PSDA 1990)**
  - ❑ **Form obsession – check the box**

- **ACP a process - Not event or product**
- **Professional societies should develop standards for clinician-patient communication and ACP**
  - ❑ **measurable, actionable, and evidence based**

IOM 2014 : In Summary

- Palliative care merits rapid expansion
- Healthcare system ill designed to meet needs of persons at EOL
- Americans talking about death and dying
  - Consumers less willing to accept care that violates goals
  - Shared stories of bad deaths transcends all racial, ethnic, social, and religious groups

  - Misconception: EOL care major driver of high costs
  - In 2009, 31% of total health care costs due to :
    unnecessary services, inefficiency, excess admin costs, high prices, lack of preventions, fraud

40 year view

1976-1994

- Secured rights to refuse, withhold, withdraw life sustaining therapies
- Karen Ann Quinlan, Nancy Cruzan
- PSDA 1990 drove efforts to promote advance directives

1995-2009

- Faced the clinical reality that not enough to validate a person's right to choose or refuse care
- Barriers revealed in major research studies and reports: SUPPORT Study, IOM report 1997, professional association issue statements, Death with Dignity laws, Hasting's Center report
- Controversy and politicalization Terri Schiavo (2005), Death panels, ACA

Wolf, Berlinger, Jennings NEJM 2015; 372(7): 678-682.

2010 to present…

- Reform needed in health care systems
- Integration incomplete despite ample evidence of benefit
- Progress depends on: communication training, generalist and primary pall care training, remove financial disincentives (late ICU admissions, dialysis, PEG tubes, late hospice referral for end stage cancer, etc)

jama.com

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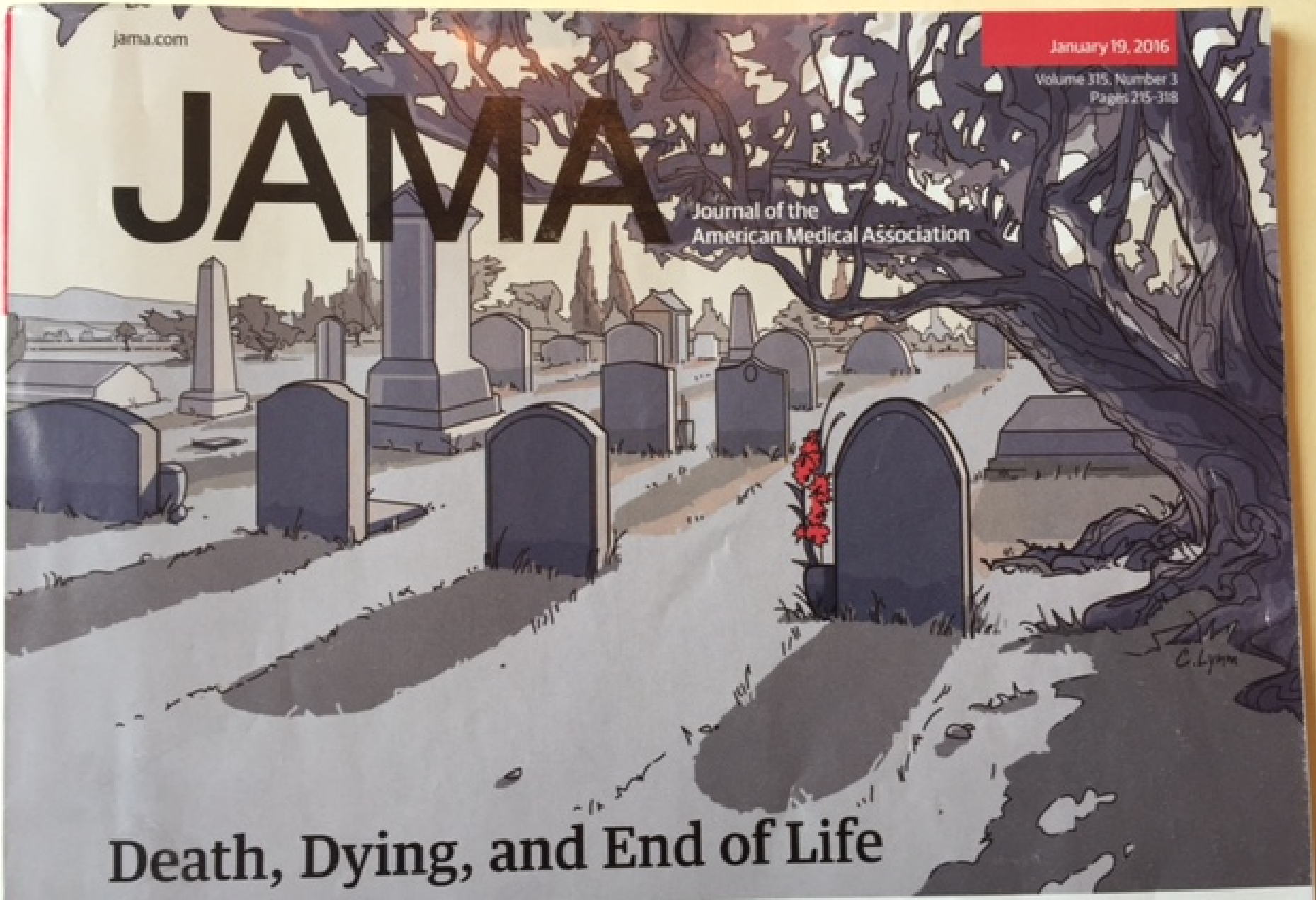


Death, Dying, and End of Life

ICU's evolved…

- ICUs have evolved since 1950's
  - Highly specialized and technological; better survival
  - Provide palliative care and end of life care

- Americans more likely to be in ICU at EOL because more ICU beds than other countries 30 beds/100,000

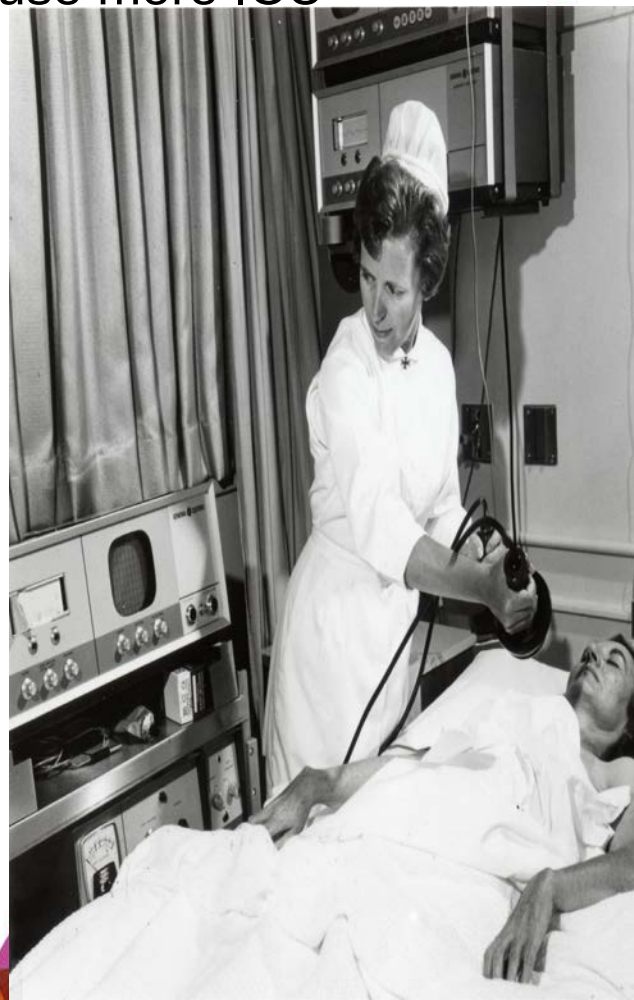
- Cultural norm: technological imperative

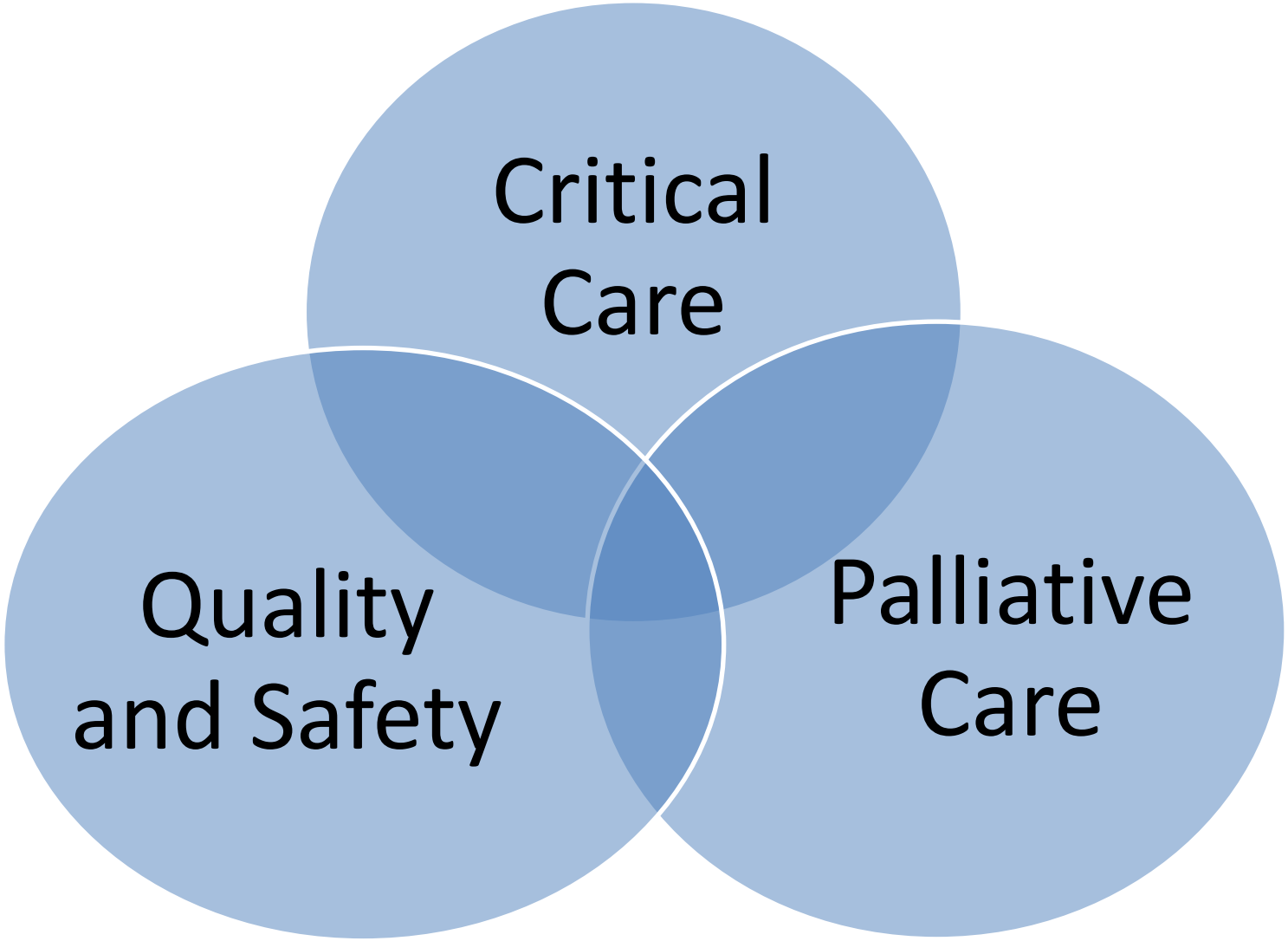
Angus, Troug JAMA 2016

- 2000-2009
  - Hospice use increased
  - Site of death has changed : hospital deaths
    Decreased from 33 to 25 %
  - ICU use increased
  - 40% of late enrollments in hospice preceded by ICU stay

Teno et al JAMA 2013:309

CARE




Critical Care
Quality and Safety
Palliative Care

Current state of the relationship

- The standard
  - ➢ essential component of high quality acute and critical care
  - ➢ Professional societies: standard setting
- The expectation
  - ➢ palliative care incorporated in the routine practice of ICU nurses, physicians and team
- Primary and specialist palliative care

Standards for Palliative Care

- National Consensus Project for Quality Palliative Care
  - structure and processes of care
  - physical aspects of care
  - psychological aspects of care
  - Social aspects of care
  - spiritual, religious aspects of care
  - Cultural aspects of care
  - care of imminently dying patient
  - ethical and legal aspects of care

  - 3rd edition 2013

Standards for ICU Palliative Care

- Critical Care Peer Workgroup 2003

  Patient/family centered decision making
  Communication
  Continuity of care
  Emotional support of patients/families
  Symptom management and comfort care
  Spiritual support
  Clinician support and self care

  Clarke, Curtis et al Crit Care Med 2003

- IPAL-ICU Integrating palliative care in the ICU

Structured approach: 4 steps
1. Convene multidisciplinary group
2. Assess needs and resources
3. Develop action plan
4. Engage the team to create a **culture** that supports integration of palliative care processes

Nelson et al Crit Care Med 2010
www.capc.org/ipal/ipal-icu

AACN's Bold Voice

- Participated in Last Acts: A national coalition 1997
- Agenda for the nursing profession on EOL care 1999
- AACN Acute and Critical Care Choices Guide to Advanced Directives 2005
- Online self assessment 2008
- Promoting excellence in palliative and end of life E-learning course 2008
- Major voice initiative since 2005
  - 2016 National Academy of Medicine Summit
  - ELNEC-critical care New Orleans NTI 2016
  - Coalition to Transform Advanced Illness Care
  - IHI Institute for Healthcare Improvement

Critical Care Societies

- American College of Critical Care Medicine (2001,2008)
  - Withdrawal of life-sustaining treatments
  - Communication
- College of Surgeons 1998
  - Surgical Palliative Care Task Force formed
- American Thoracic Society 2008
  - All patients receiving curative or restorative care
- ACCP 2005
  - Support for patient and family
  - Care of the patient
  - Responsibility of the professional caregiver

The IPAL-ICU Project, www.CAPC.org
Aslakson et al CCM 2014;42:2418-2428

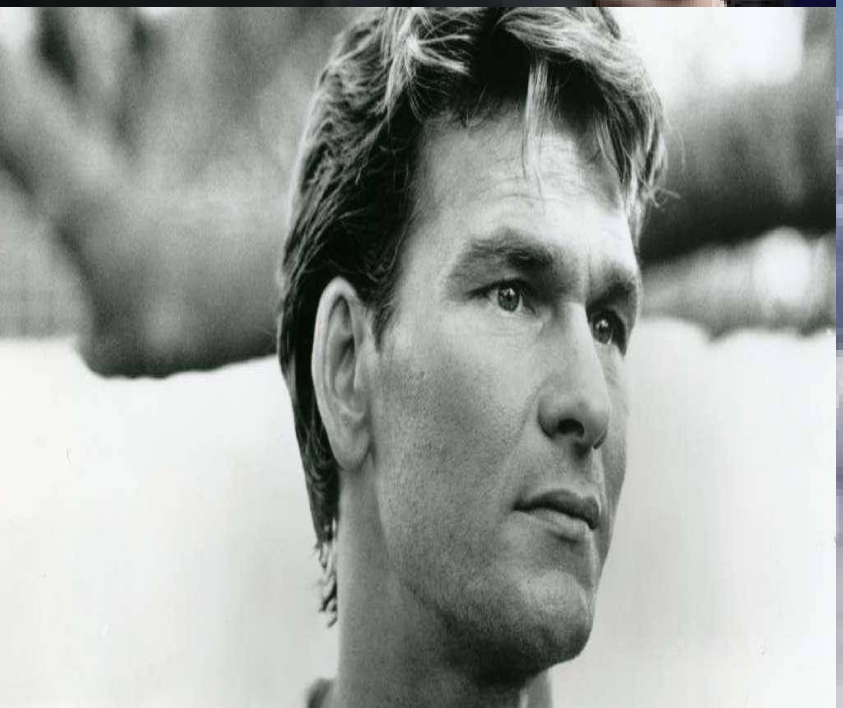
Choosing Wisely

- ❑Don’t order tests at regular intervals
- ❑Don’t transfuse RBCs in stable, non-bleeding patients with hemoglobin > 7g/dl
- ❑Don’t use parenteral nutrition …within first seven days of ICU stay
- ❑Avoid deep sedation of ventilated patients
- ❑**Don’t continue life support for patients at high risk of death or severely impaired functional recovery without offering care…focused on comfort**

Barriers

- Unrealistic expectations: patients, families, clinicians
- Misperception of PC and CC as mutually exclusive or sequential
- Palliative care = hospice
- Palliative care will hasten death
- Lack of communication training
- Competing demands without reward for palliative care experience/delivery

Aslakson et al CCM 2014; 42:2418-2428



The new decade

Old: Dichotomous: Patient must wait, must choose

New : Simultaneous

- Mixed model just like other consults
- Consultative - specialist
- Integrative – primary

Primary palliative care

- Skills that all clinicians should have
  - Routine practice by all ICU clinicians

Aslakson, Curtis, Nelson The changing role of palliative care in the ICU. CCM 2014;42:2418-2428

- Experts set the challenge
  - Quill, Abernathy NEJM 2013 368:1173-1175
  - Kelley, Morrison NEJM 2015
  - Halpern, S NEJM 2015 373:2001-2003
  - The Hastings Center
  - Health Care Organizational Ethics Sabin 2016
  - ANA Professional Issues Panel : Nurses lead and transform palliative care

Primary palliative nursing

- **Management of pain and symptoms, combined with discussion of treatments, disease progression, and imminent death**
- Understands the natural trajectory of illnesses and conditions
- Recognizes and treats common conditions, including care of the dying patient, by using basic principles and evidence based pain and symptom management
- Discusses advance care planning, goals of care, issues of advanced disease, and provides culturally appropriate psychosocial support
- Understands palliative and hospice care services, eligibility, and how to access these services
- Attends to population-specific concerns across the continuum of care and life
- Understands community resources. (HPNA; Dahlin 2015)

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What is the evidence?

- Effect of palliative interventions in the ICU

  Decrease ICU and hospital LOS

  Improve quality and quantity of communication

  Decrease distress in family members

  Decrease use of procedures

  Decrease time between admission and DNR
- Do not increase mortality
- No evidence of harm
  - Aslakson, Cheng et al J Palliat Med 2014;17:219-235

Systematic Reviews

- Communication interventions
- 1995-2010 180 studies 21
- Integrative and consultative models
  - Scheunemann et al Chest 2011; 139:543
  - Nelson et al CCM 2010 38:1765

Evidence in the ICU

- Concise definitive review

  Medline data base Aslakson et al CCM 2014

- Systematic review of interventions

  Journal of Palliative Medicine 2014

  Search : 3328 references 1949-2011

  37 studies met criteria

- Economic implications

  Current Opinions in Critical Care 2014

Economic Implications

- ROL to examine impact of consults and advanced care planning (ACP) on ICU length of stay
- 11/16 studies consults and ACP decreased ICU LOS
  - Khandelwal, Curtis Curr Opin Crit Care 2014;20:1-6

What works? Outcomes

	ICU LOS	Hospital LOS	Family satisfaction	Mortality
Studies	Decreased 13/21 = 62%	Decreased 8/14 = 57%	Increased 1/14 = 7%	Increased 1/16 = 6%
			Decreased 0/14 = 0%	Decreased 1/16 = 6%
				No change 14/16 = 88%

State of the Science: AHRQ

- Most consistent evidence for effective interventions that target
  - Patient satisfaction
  - Pain management
  - Communication interventions on ICU utilization
- Gaps
  - Methods: sample size, standardization of outcome measures AHRQ 2012
- Measuring what matters

Measuring what matters

- AAHPM/HPNA quality metrics for palliative care
  - Comprehensive assessment of every patient
  - Physical symptom screening
  - Pain treatment
  - Dyspnea screening and management
  - Discuss emotional and psychological needs
  - Discuss spiritual/religious concerns
  - Care consistent with documented preferences
  - Documentation of surrogate decision maker
- A divergent view
  - “We report survival rates for specific conditions but do not have measures that ask how effectively care supports well-being”
  - Metrics too focused on safety and health to promote effective palliative care
    - Atul Gawande Senate Special Committee on Aging June 2016

Words create worlds

Withdraw technology

Death with dignity

Allow a natural death

Withdraw care

Nothing more we can do

We will do everything

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

What should ICU care be?

- ICU's should not be destination therapy

  Angus D, Truog Toward better ICU use at the end of life

  JAMA 2016;315(3):255-256.

- ICU admissions should be time-limited trails
  - Hasting's Center Report 1987 ethics of EOL care
  - Quill, Holloway JAMA 2011; 306:1483-4

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Change four things

- Change “What is the matter with you?” to “what matters to you?”
- Delete: Withdrawal of care
- Provide evidence based primary palliative care with your teams as a simultaneous model
- Use systematic QI methods to drive change that matters

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