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

My Decision to Die

A TERMINAL CANCER PATIENT'S CONTROVERSIAL CHOICE

Why Brittany Maynard, 29, plans to end her life in less than 3 weeks
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

Palliative care growth

Prevalence of US hospital palliative care teams 2000-2012

Series 1

Series 2

Series 3
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
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)
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
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](http://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
  • 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)
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
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

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<th>ICU LOS</th>
<th>Hospital LOS</th>
<th>Family satisfaction</th>
<th>Mortality</th>
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<td><strong>Studies</strong></td>
<td>Decreased 13/21 = 62%</td>
<td>Decreased 8/14 = 57%</td>
<td>Increased 1/14 = 7%</td>
<td>Increased 1/16 = 6%</td>
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<td>No change 14/16 = 88%</td>
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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
  - Measuring what matters

AHRQ 2012
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
"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

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