Palliative Medicine
A Retrospective

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Spectrum of Palliative Care

SPECTRUM OF PALLIATIVE CARE

PALLIATIVE CARE

HOSPICE

COMFORT CARE

CURATIVE AND LIFE-PROLONGING TREATMENTS

INFUSIONS

PAIN MANAGEMENT
Contributing Factors to Evolution of Palliative Medicine In Last 30 Years

- Bioethical thought leaders and organizations
- Professional societies
- Court decisions
- Legislative action
- Philanthropy
- Research
- Literature
- Health care policy and financing
- Technological developments and IT
Contrasting Paradigms

**CURATIVE**
- analytic and rational
- clinical puzzle-solving
- mind-body dualism
- disvalues subjectivity
- biomedical model (disease)
- discounts idiosyncrasy
- death = failure

**PALLIATIVE**
- humanistic & personal
- patient-as-person
- mind-body unity
- privileges subjectivity
- biocultural model (illness)
- respects idiosyncrasy
- unnecessary suffering = failure
History of PC and Hospice

- Prehistoric
- Late middle ages
  - *Hospices as havens for weary or ill travelers &/or hospitals for the poor*
  - *Rene Descartes and mind-body dualism*
- Modern day Hospice
- Palliative Care
Early days of Palliative Care
Early IDT providing comforting emotional and spiritual support
Breakthrough Medication
Hospices de Beaune—Hotel-Dieu de Beaune
Beaune, France  Founded 1443
Hospices de Beaune
Beaune, France   Inside Chapel
1960-70’s

- Early Hospice pioneers
- Development of field of Bioethics; Ethics Committees/forums
- Landmark Court Decision
  - Karen Ann Quinlan
- Operational
  - National Hospice Project—1979-1982
- Philanthropic
Early Pioneers

◆ Florence Wald RN
  - *Dean of Yale School of Nursing invited Cicely Saunders to lecture in 1963*

◆ Dame Cicely Saunders RN, SW, MD
  - *Began work with terminally ill in 1948 at age 30*
  - *St Christopher’s, Sydenham, London; Fund-raised; opened in 1967*
  - *Crowned Dame 1980*

◆ Elizabeth Kubler-Ross MD, Univ Chicago
  - *On Death and Dying--1969*
  - *Care in the home; participate in decision-making*
  - *Senate hearings on death with dignity—1972*

◆ Balfour Mount MD
  - *Royal Victoria Hospital in Montreal; McGill University—1973*
  - *International Congress launched 1976*
  - *“Father of PC in N. America”—officer in Order of Canada—2003*
Early Pioneers (con’t)

- Kathleen Foley MD
  - Memorial Sloan-Kettering; First Pain Management Service in a Cancer center—1981
- Florence Wald and Sylvia Lack MD
  - Connecticut Hospice, Branford CT—First in USA, 1974
- William Twycross MD
- Sandal Stoddard
  - The Hospice Movement—1st edition 1977
- Eduardo Bruera MD
  - Edmonton; now Chair of Palliative and Rehab Medicine at MD Anderson
  - 1000 articles and over 900 major addresses
  - Champion for developing countries in Latin America, Europe, India
Early Pioneers (con't)

- Andrew Billings MD and Susan Block MD
  - *Harvard School of Medicine*

- Irene Higginson MD
  - *Palliative care outcome scale* ([www.pal-pos.org](http://www.pal-pos.org))
  - *Dir Cicely Saunders Institute at Kings College. World’s first purpose-built institute of PC, integrating research, education, clinical services, and information and support services*

- Early Local Hospices
  - *Hospice of Marin—William Lamers MD 1974*
  - *Hospice of Petaluma—1977; Memorial Hospice 1998; North Co Hospice 2009*
  - *Home Hospice Sonoma County—1979*
  - *Napa Valley Hospice (Collabria Care) began as part of St Helena Home Health—1979*
Dame Cicely Saunders (1918-2005)

“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders
Nurse, Doctor, Social Worker and Writer
Founder of the Hospice Movement (1918-2005)
St. Christopher’s Hospice
Sydenham, London 1967
St. Christopher’s’s Hospice
Sydenham, London  1967
Balfour Mount MD
The Father of Palliative Care in N. America
Richard Lamerton MD
St Joseph Hospice and New Age Hospice
The Doctrine of Informed Consent and Prognostication

- The duty of the physician is to disclose to the patient all information relevant to a meaningful decisional process for a reasonable person.

- The disclosure must include the available choices with respect to proposed therapy and of the dangers potentially involved (in both treatment and non-treatment).

- The weighing of these risks against the individual subjective fears and hopes of the patient is not an expert skill [but rather a] non-medical judgment reserved to the patient alone.

--Cobbs v. Grant, CA Supreme Ct. (1972)
Right to Withdraw Life Support

Karen Ann Quinlan—1976

- PVS 2ry LOC
- Hospital refused parents’ request to withdraw vent
- Local judge said was doctor’s purview
- New Jersey Supreme Court ruled favoring parents
  - Cited Pope Pius XII in this decision
- Patient surprisingly survived 9 more years on TF

Triggered hospital ethics committees and nation’s 1st “living will” statute: California Natural Death Act—1976
Living Will: Major limits

- Patient had to be imminently dying
- 14 day waiting period
- Limited to extraordinary means
- No proxy designation option
- No penalty to disavow
Scientific, technological, & social developments in mid 1900’s produced rapid changes in health care which challenged prevalent conceptions of what the moral obligations of health professionals and society are in meeting needs of sick and injured.

Ethical theory ➔ principles and rules ➔ case judgments ➔ inadequacies of health care ➔ justification for reform

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice—access to care
- Professional-patient relationships
Further highlights

- US Senate: Church and Moss: Federal funding rejected 1974
- HEW task force: more humane care, possibly \(\downarrow\) costs; worthy of federal support—1978
- National Hospice Organization.
- HCFA commissions National Hospice Study to define what programs should look like and assess costs--1979
- Kellogg Foundation grant to JCAHO to develop standards--1980
Principles of Biomedical Ethics
1980’s

◆ Thought Leaders
  - Eric Cassel—Nature of Suffering—Cornell University
  - Kathleen Foley—Memorial Sloan Kettering—Pain Management and PC
  - Declan Walsh—1st US academic hospital PC program; Cleveland Clinic--1987
  - Eduardo Bruera—Edmonton, Canada—ESAS.

◆ Legislative and regulatory
  - Medicare Hospice Benefit—1983
  - JCAHO initiates accreditation of hospices --1983

◆ Bioethical
  - Wanzer et al.—NEJM ethics article
  - Appleton Consensus
1980’s

Organizations

- International Hospice Institute - Josefina Magno
- Academy of Hospice Physicians, Gerald Holman 1988 ➔ AAHPM
- National Hospice Organization
  - NHPCO
- Hospice and Palliative Nurses Association

Philanthropy

- W.K. Kellog Foundation
- Arthur Vining Davis Foundation
- Funded standards and research leading to Medicare hospice benefit
- Robert Wood Johnson Foundation
  - Starting in late 1980’s and ongoing, donations in excess of $180M into palliative care and EOL care

International—1980’s
The Nature of Suffering

“Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering, but becomes a source of suffering itself.”

The Nature of Suffering and the Goals of Medicine
Cassel E. NEJM 1982
The Nature of Suffering

- Basic obligation of medical profession is relief of suffering
- Mind-Body Dualism: Body—science Church—Mind/spirit
- Suffering lies within medicine’s domain only insofar as it relates to the body
- Three main points
  - Suffering is experienced by persons
  - Occurs when an impending destruction of the person is perceived
  - Can occur in relation to any aspect of the person
- Personhood consists of 12 domains:
  - Body, personality, character, past, future, secret life, roles, cultural background, political being, behaviors, transcendent dimension
Medicare Hospice Benefit—1983

- Quality of Life is the primary focus
- Interdisciplinary team
- Tailored to patient/family needs and wishes
- Vigorous pain and symptom management
- Integrated emotional and spiritual support
- Bereavement support
- Daily per diem rate—4 levels
- Care may be at any site
“The Physician’s Responsibility Toward the Hopelessly Ill Patient”

- To initiate timely discussions with patients about dying
- To solicit Advance Directives
- To aggressively utilize pain-relieving substances, even when such use may result in shortened life

The Appleton Consensus: suggested international guidelines for decisions to forego medical treatment

John M Stanley, Lawrence University, and 34 others

Author’s abstract

Thirty-three physicians*, bioethicists, and medical economists from ten different countries met at Lawrence University, Appleton, Wisconsin, to create The Appleton Consensus: International Guidelines for Decisions to Forego Medical Treatment. The guidelines deal with four specific decision-making circumstances:

1. Five guidelines were created for decisions involving competent patients or patients who have executed an advance directive before becoming incompetent, and those guidelines fell into three categories.

2. Thirteen guidelines were created for decisions involving patients who were once competent, but are now incompetent, and have not executed an advance directive.

Twenty-five of the thirty-three delegates were physicians, representing eleven different medical specialisations. Of the eight non-physicians, six had extensive clinical experience in ethics consultations. One of the eight was a medical economist. Seven were bioethicists: two with backgrounds in philosophy, two in theology, two in law, and one in comparative religion and ethics. Several of the delegates had had experience in the creation of important medical ethics guidelines in the past.

Twenty-six of the thirty-three delegates had met together in a preparatory conference one year earlier. Seven of the delegates were new (3).

Two particular sets of concerns had emerged in the first Appleton working conference: 1) concerns regarding decisions to forego medical treatment,
Appleton Consensus

- 33 Physicians, bioethicists, & medical economists
- Guidelines for 4 distinct decision-making circumstances
  - With current capacity or Advance Directive
  - Past capacity; no AD
  - Never had capacity
  - Scarcity of medical resources
- 4 *Prima facie* moral values or principles govern norms of care
  - Respect each other’s autonomy
  - Non-maleficence: not to harm
  - Beneficence: to benefit others
  - Justice: to act fairly in context of scarce resources
1990-1995

- **Landmark Court Decisions**
  - *Nancy Cruzan--1990*

- **Literature**
  - *How We Die. 1994. Sherwin Nuland MD*

- **Research**
  - *SUPPORT study JAMA 1995*

- **Bioethical**
  - *Catholic Ethical and Religious Directives-1995*
  - *AMA Council on Ethical and Judicial Affairs*

- **Philanthropy**
  - *Open Society Institute, founded by George Soros*
  - *Robert Wood Johnson*
Bernardo 54 y.o. Latin-American ♂
Head & Neck CA
Interior Argentina
No running water or electricity
Midazolam by subcutaneous infuser device
Edmonton Infuser
E. Bruera developer
Inexpensive device to deliver calibrated medication dose by subcutaneous route
Roberto Wenk MD
Latin America pioneer
Right to Withdraw Ordinary Measures

- Nancy Cruzan
  - Ejected from vehicle at age 25; resuscitated
  - PVS on TF for 4 years
  - Hospital refused to allow W/D of TF per parents wishes
“The liberty guaranteed by the Due Process clause must protect, if it protects anything, an individual’s deeply personal decision to reject medical treatment, including the artificial delivery of food and water.”

Cruzan v. Director Missouri Dept. Health, 1990

O’Connor: “does not preclude future determination……requires the States to implement decisions…..surrogate”
“Clear and Convincing” Evidence

- Supreme Court established need for “clear and convincing” evidence of wishes in case of person lacking capacity
- Ultimately a lower court heard new evidence and allowed FT withdrawal in 1990
- Laws allowing surrogate decision-making
- Patient Self-determination Act requiring hospitals to provide information 1991
Hope lies not only in expectation of cure or even remission of present distress.

For dying patients, the hope of cure will always ultimately be false, and even the hope of relief too often turns to ashes.

When my time comes, I will seek hope in the knowledge that insofar as possible, I will not be allowed to suffer or be subjected to needless attempts to maintain my life;
I will seek it in the certainty that I will not be abandoned to die alone.

I am seeking it now, in the way I try to live my life, so that those who value what I am will have profited by my time on earth and be left with comforting recollections of what we have meant to each other.
Catholic Religious Perspectives

- ...presumption in favor of providing nutrition and hydration to all patients... as long as this is of sufficient benefit to outweigh the burdens involved to the patient.

- Ethical and Religious Directives for Catholic Health Care Services; 1995
SUPPORT Study: JAMA, 1995

◆ GOAL: to understand what was good and bad about dying in US hospitals and to design interventions for improvement

- Timely DNR ordered
- Patient preferences known & honored
- Time in ICU
- Pain controlled
- Resources consumed
SUPPORT Study: JAMA, 1995

OUTCOME:

- No appreciable difference in any of the five parameters
- No difference in level of patient satisfaction
- Less than expected change in physician practice patterns
## Prognostication in Practice (SUPPORT)

*JAMA* 1995; 274: 1591-98

<table>
<thead>
<tr>
<th></th>
<th>Physician Received Information</th>
<th>Physician Acknowledged Reception</th>
<th>Physician Discussed With Patient</th>
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<tr>
<td>Prognostic Information</td>
<td>94%</td>
<td>59%</td>
<td>15%</td>
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<tr>
<td>Patient Preference</td>
<td>78%</td>
<td>34%</td>
<td>15%</td>
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</tbody>
</table>
Hastings Center Supplement: 1995

- SUPPORT Conclusions
  - Inadequate physician input; lack of nurse authority
  - Interventions were too late
  - Patients and physicians: different viewpoints
  - Patient/MD communication remained poor
  - No change in cultural norms in the way hospitals functioned in US or in attitudes toward death
Philanthropy
a catalyst for change

- Open Society Institute--Project on Death in America
  - 9 year, $45M investment in understanding and transforming the culture and experience of dying and bereavement” in the US

- Robert Wood Johnson

- Areas of investment
  - Career paths
  - Development of various curriculae
  - Technical assistance to build capacity
  - Development of new models
  - Regulatory and policy changes
  - National Consensus project
  - Media outreach, e.g. Bill Moyers “On Our Own Terms”
1996-2000

- **Literature**
  - *The Goals of Medicine: Hastings Center*
  - *Dying Well: Ira Byock*
  - *Responding to Intractable Terminal Suffering: Quill, Byock*

- **Landmark Court Decisions**
  - 9th Circuit Court in SF overrules WA state law against PAD and 2nd Circuit Ct of Appeals in NY does same
  - *Vacco v. Quill. US Supreme Court*

- **Legislative**
  - *Oregon DWDA*

- **Operational**
  - *Institute of Medicine report*
  - *Center to Advance Palliative Care*
The Goals of Medicine--1996

- International project of The Hastings Center, an institute devoted to research and analysis of bioethical issues
- Recommendations regarding ethics and justice in health care priorities and delivery
The Goals of Medicine

Key question:
- Where ought medicine be going for society it serves

Task force make-up:
- Representatives from medicine, biology, philosophy, law, politics, public health, theology, health policy from 14 countries on 5 continents over 4 years
- In the end, skeptics converted to an understanding that this “theoretic” work was critical to practical planning
The Goals of Medicine

- Prevention of disease and injury and maintenance of health
- Relief of pain/suffering caused by maladies
- Care and cure of those with a malady and care of those who cannot be cured
- Avoidance of premature death and the pursuit of a peaceful death
Caveats

- Advances in medicine are a 2-edged sword:
  - Enable mankind to live longer and often better lives through interventions and restorative procedures
  - At the same time create the reality of:
    - At times greater suffering
    - Illnesses of aging
    - Dramatic escalation of costs
    - Inequitable access to care
Caveats

- Criticisms of previous efforts at health care reform:
  - *Too much focus on technical & mechanistic means of health care delivery*
  - *Discussion usually involves markets, lives, cost control, cost shifting, & privatization*
  - *However there is a poverty of discussion on the purpose & direction of medicine*
Caveats

- Relief of pain & suffering is an ancient and traditional goal, but there are many barriers to access

  - *Palliative Medicine should be well supported and vigorously advanced*

  - Point of departure should be whole person

- Humane management of death is final and perhaps most humanly demanding responsibility of the physician
Reflection

◆ Death is not the “enemy” itself. Instead it is:

- *Death at the wrong time*
- *Death for the wrong reason*
- *Death in the wrong way*
“Medical ethics do not allow me to assist in your death. I am, however, permitted to keep you miserable as long as possible.”
“Just as a state may prohibit assisting suicide, while permitting patients to refuse unwanted treatment, it may permit palliative care related to that refusal which may have the foreseen but unintended double effect of hastening the patients death.”

- Vacco vs. Quill, 1997
“A patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death.”

*O’Connor and Souter in Washington v. Glucksberg; Quill v. Vacco, 1997*

*Bottom line: PAS not a constitutional guarantee but a State’s right issue*
- However intensive symptom relief is guaranteed
Death With Dignity Act
Oregon and Washington

- Oregon first state to legalize physician assisted death
- Great controversy in public as well as medical circles
- Hospice programs and professional organizations grappled with how to best support the patients they served and the health professionals they represented
- Importance of quality End of Life care became even more visible as a result
Responding to Intractable Terminal Suffering

- Role of Terminal Sedation and Voluntary Refusal of Food and Fluids
- American College of Physician—ASIM consensus panel
- Outlined a standard for extraordinary response to extraordinary suffering, with careful
- Generated further controversy regarding what is and is not acceptable as the medical field response to severe suffering
  
  - *What is the clarity of the intention*
Further Highlights

- Institute of Medicine issues its report--1997
  *Approaching Death: Improving Care at the EOL*
  - Marilyn Field and Christine Cassel
  - Called for fundamental changes in
    - Education, research priorities, health care policy
  - Trusted roadmap for philanthropy
  - Palliative Care specifically endorsed as a discipline

- Center to Advance Palliative Care (CAPC)—1999
- International—1990’s
CAPC
“Palliative Care Everywhere”

- Began with grants RWJ Foundation; now 900 members
- Diane Meier MD Med Dir. Icahn School of Medicine at Mount Sinai, NYC
- #1 resource for development and growth of PC programs
- Goals
  - Improve clinician knowledge and skills
    - National Quality Forum—Guidelines and standards
    - Centers of Excellence
  - Enable organizations to support and deliver PC
    - National Palliative Care Registry—essential metrics
    - Operational materials
  - Raise public awareness: getpalliativecare.org
2001-2005

Landmark Court Cases

- Terri Schiavo

◆ National Consensus Project for Quality PC—2001-4
  - Guidelines and standards for the field
    - AAHPM, HPNA, CAPC, NHPCO, Last Acts Partnership

◆ Organizations
  - AHP ➔ AAHPM: 1400 members: J. Palliative Medicine 2004
  - Grant from Open Society; partners with HPNA annual assembly

◆ Literature
  - Access to Hospice Care: Expanding Boundaries, Overcoming Barriers
Withdrawal of Treatment (Tube Feeding)
--the saga of Terri Schiavo

- In 1990, 26 yo Florida woman suffered cardiac arrest but was resuscitated to PVS; no AD
- Husband petitioned to have FT removed 8 yrs later, but parents and right-to-life movement resisted
- 8 yrs of court and media battle before ultimately being allowed to die as an expression of what her wishes would have been
- Further renewed interest in Advance Directives
Cultural Differences

◆ TIME Magazine
  - “The End of Life: Who Decides?”
  - The Battle over Terri Schiavo
  - --April 4, 2005

◆ Table of Contents Title Page:
  US edition          European edition
  The War Over Life    To Live or Let Die?
National Consensus Project

- Clinical Practice Guidelines for Quality PC—2013
  - 8 Domains: Processes, Physical, Psychological, Social, Spiritual, Imminently dying, Ethical and Legal
- National Quality Forum 38 Preferred Practices
Negotiating Cross-Cultural Issues at the EOL: “You Got To Go Where He Lives”

-- Kagawa-Singer M, Blackhall L. JAMA. 2001;286(23): 2993-3001

- Case studies: African-American and Chinese American
- Practical approaches to exploring the experience of illness, tolerance for full truth, and acceptable decision-making methods for patients of different cultures
- Issues of communication, spirituality, trust, family involvement
- Strategies to address issues important to EOL care
Access to Hospice Care: Expanding Boundaries, Overcoming Barriers

Hastings Center Report March-April 2003 based on a 3 yr study of the Hasting Center and the National Hospice Work Group outlining a new vision

- Addressing gaps in delivery, arguing for equal access in particular for most vulnerable populations
- Addressing need to provide hospice type care upstream from the narrower 6 month prognosis, with hospice serving as a coordinating center for a wider range of services
Improving End of Life Care: Why Has It Been So Difficult?

- Hastings Center Special Report 2005
- Dan Callahan wrote about “Death: the Distinguished Thing”
- Psychological clash of accepting inevitable death against rejecting death for a research–ambitious medicine
2006-1010

- ABMS approves of the new subspecialty of Hospice and Palliative Medicine—2006; AMA delegate
  - Board exam and Fellowship training programs 2008

- Research
  - Effect of Proactive PC in ICU: Norton, 2007
  - Benchmarks of PC: Twaddle, 2007
  - Cost Savings: PC Hospital Consult Programs: Morrison, 2008
  - Early PC for NSC Lung Cancer: Temel, 2010
Clinical/Operational

- National Quality Forum utilizes Consensus Project guidelines to establish the National Framework and Preferred Practices for Palliative and Hospice Care.

- NHPCO Standards of Practice for Pediatric Hospice and PC-2009

- AB1745 Partners for Children– Pediatric Waiver 2008

- Institute for Healthcare Improvement-2009

International

- World Hospice and Palliative Care Alliance--2007
Effect of Proactive PC on ICU patients
-Norton SA. Crit Care Med 2007;35:1530-1535

126 patients consulted with matched controls

- Hi risk for death
  - ICU transfer after >10 days in hosp;
  - >80 yo with 2 or more life-threatening co-morbidities
  - Active stage IV malignancy
  - Post cardiac arrest
  - ICH on vent

- Reduced ICU LOS from 16.28 to 8.96 d [p=.0001]
- No change overall hosp LOS or death rate; trend to hospice
Palliative Care Benchmarks from Academic Medical Centers:

- Identified 11 key performance measures at 35 centers
  - Pain assessment and quantification and reassessment by 48h
  - Dyspnea assessment and reassessment by 48h
  - Documentation of physical status
  - Patient-family meeting by day 7
  - Discharge plan by day 4

- Greater compliance with KPM $\Rightarrow$ better outcomes
  - Improved quality indicators
  - Shorter LOS
  - Lower Cost
The Nature of Suffering and the Goals of Nursing

- View of nursing’s essential and unique role in addressing the suffering of those who are ill
  - Associated with loss, a sense of brokenness, intense emotions, loneliness, detachment from world
  - Intensely personal; linked to recognition of own mortality
  - Often spiritual distress

- Nurse’s Role
  - Confidants, competent symptom relief and hands-on care
  - Listen; offer presence; accompany on jouirney
  - Relieve distress and restore wholeness via human connection
  - Help patients to regain control, to cope with vulnerability
Cost Savings Associated with US Hospital Palliative Care Consultation Programs


Cost Savings Associated With US Hospital Palliative Care Consultation Programs

R. Sean Morrison, MD; Joan D. Penrod, PhD; J. Brian Cassel, PhD; Melissa Caust-Ellenbogen, MS; Ann Litke, MFA; Lynn Spragens, MBA; Diane E. Meier, MD; for the Palliative Care Leadership Centers’ Outcomes Group

Background: Hospital palliative care consultation teams have been shown to improve care for adults with serious illness. This study examined the effect of palliative care teams on hospital costs.

Methods: We analyzed administrative data from 8 hospitals with established palliative care programs for the years 2002 through 2004. Patients receiving palliative care were matched by propensity score to patients receiving usual care. Generalized linear models were estimated for costs per admission and per hospital day.

Results: Of the 2966 palliative care patients who were discharged alive, 2630 palliative care patients (99%) were matched to 18427 usual care patients, and of the 2388 palliative care patients who died, 2278 (95%) were matched to 2124 usual care patients. The palliative care patients who were discharged alive had an adjusted net savings of $1696 in direct costs per admission ($P = .004) and $279 in direct costs per day ($P < .001) including significant reductions in laboratory and intensive care unit costs compared with usual care patients. The palliative care patients who died had an adjusted net savings of $4908 in direct costs per admission ($P < .001) and $374 in direct costs per day ($P < .001) including significant reductions in pharmacy, laboratory, and intensive care unit costs compared with usual care patients. Two confirmatory analyses were performed. Including mean costs per day before palliative care and before a comparable reference day for usual care patients in the propensity score models resulted in similar results. Estimating costs for palliative care patients assuming that they did not receive palliative care resulted in projected costs that were not significantly different from usual care costs.

Conclusion: Hospital palliative care consultation teams are associated with significant hospital cost savings.

Arch Intern Med. 2008;168(16):1783-1790
Cost Savings Associated with US Hospital Palliative Care Consultation Programs  
--Morrison RS et al. *Arch Intern Med* 2008;168(16):1783-1790

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<thead>
<tr>
<th></th>
<th>Net Cost Savings/Admit</th>
<th>Net Cost Savings/Day</th>
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<tr>
<td>PC patients discharged alive</td>
<td>$1696 (p=0.004)</td>
<td>$279 (p&lt;0.001)</td>
</tr>
<tr>
<td>PC patients died in hospital</td>
<td>$4908 (p=0.003)</td>
<td>$374 (p&lt;0.001)</td>
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Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


ABSTRACT

BACKGROUND
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS
We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung and Hospital Morbidity Questionnaires.
Early Palliative Care for Metastatic NSCLC

- RCT of early and ongoing PC plus standard oncologic care with oncologic care alone @ Mass General Hospital
- NSC Lung Cancer within 8 weeks of diagnosis
- Methodology
  - Patient/family met with member of PC team within 3 weeks and then at least monthly
  - National Guidelines for Quality Palliative Care
  - Symptom review, goals of care, difficult decision making, coordination care
  - Measured QOL outcomes
# Early Palliative Care for Metastatic NSCLC

<table>
<thead>
<tr>
<th>PARAMETER</th>
<th>Standard Care</th>
<th>Early Palliative</th>
<th>P value</th>
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<tr>
<td>FACT-L</td>
<td>91.5</td>
<td>98</td>
<td>.03</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>38%</td>
<td>16%</td>
<td>.01</td>
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<tr>
<td>PHQ-9</td>
<td>17%</td>
<td>4%</td>
<td>.04</td>
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**Early Palliative Care for Metastatic NSCLC**

<table>
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<tr>
<th>VARIABLE</th>
<th>STANDARD CARE [%]</th>
<th>EARLY PALLIATIVE [%]</th>
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<tbody>
<tr>
<td>Chemo &lt; 14 days before death</td>
<td>24</td>
<td>17.5</td>
</tr>
<tr>
<td>Admission within 30 days of death</td>
<td>53.6</td>
<td>36.7</td>
</tr>
<tr>
<td>ED visit &lt; 30 days before death</td>
<td>30.4</td>
<td>22.4</td>
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<tr>
<td>Admit hospice &lt;4 days before death</td>
<td>14.7</td>
<td>3</td>
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<tr>
<td>Median days on hospice</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Home or Hospice residence</td>
<td>69.8</td>
<td>83.7</td>
</tr>
</tbody>
</table>
Early Palliative Care for Metastatic NSCLC

<table>
<thead>
<tr>
<th>PARAMETER</th>
<th>Standard Care</th>
<th>Early Palliative</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival (in mos)</td>
<td>8.9</td>
<td>11.6</td>
<td>.02</td>
</tr>
</tbody>
</table>
A framework for early access to seamless care for patients with advanced illness

- Patient and family at center
- Continuous communication
- Case management
- Core services available 24/7
2011-2016....

- **Legislative and Policy**
  - Berkeley Forum
  - California State Health Care Innovation Plan
    - Health and Human Service Agency
  - End of Life Option Act—California
  - PCHETA: PC and Hospice Education & Training Act

- **Literature**
  - Choosing Wisely
  - Valuing What Matters

- **Advance Care Planning**
2011-2016....

- Operational
  - Joint Commission Certification for PC
  - Palliative Care Quality Network
  - National Palliative Palliative Care Research Center

- ASCO, AHA, ASA all promote palliative now in position statements
Collaboration of public and private sector leaders—vision for transformation of California health care and payment systems

Focus Areas

- Global payment systems—integrated models of care
- Patient-centered medical homes
- Palliative care
- Promotion of Physical activity
- Increase in mid-level practitioners
- Access to Pre-natal care
California State HealthCare Innovation Plan

Goal

- *Bring healthcare expenditure growth rate in line GSP*
- *Establish targets for 38 health care indicators*
- *Reform payments to better reward value*

Focus on 4 main initiatives

- Health homes for complex patients
- Palliative Care
- Accountable care communities
- Maternity Care

Six Building blocks
Worldwide Hospice Palliative Care Alliance
Worldwide Hospice Palliative Care Alliance

- What is the current worldwide need
- What are the key barriers
- What is the current response
- Describe models
- What are resources at global/regional levels
- What is the way forward
World Health Assembly Resolution

- In 2014, the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19, called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on primary care
WHO Collaborating Centers for Palliative Care

- Sir Michel Sobel House; Oxford, England
- Catalan Institute of Oncology; Barcelona, Spain
- Institute of Palliative Medicine; Kerala, India
- King’s College; London, England
- University of Wisconsin School of Medicine and Public Health; Madison, Wisconsin
- Trivandrum Institute of Palliative Sciences; Trivandrum, India
Choosing Wisely
Initiative of the American Board of IM; 2012

- Mission to advance Medical Professionalism to improve health care
- Advance a national dialogue on avoiding wasteful or unnecessary medical tests, treatments and procedures.
  - *Conversations. Evidence-based recommendations*
- Am College Emergency Phys; Soc Gyn Onc list early palliative amongst 5 key recommendations
Advance Care Planning

- Books and Articles—refining the art
- National POLST paradigm
  - All but 4 states at some stage of development
  - California/Oregon/W. Virginia most mature
    - CCCC in California
Being Mortal—Medicine and What Matters in the End
The Conversation
Volandes A. 2015. New York: Bloomsbury
Further Advance Directive Literature

- Structured visit with surrogate

- Video effect on preferences—GBM pts
  - El-jawahri. *J Clin Oncol* 2010

- Elderly SNF patients, use of video, & concordance of AD

- Refining the “Planning” in ACP: Preparing for EOL Decision Making
Frailty Screening ➔ Palliative Care ➔ Reduced mortality in Surgical Candidates

-- Ernst KF et al. JAMA Surg. 2014; Sept 2010

- Surgical post op patients
- Underwent frailty screening and provided PC consultation at a certain threshold
- Control for age, frailty level, and procedure
- Those receiving PC consultation experienced 33% reduction in 6-month mortality
## CAPC Registry data:

<table>
<thead>
<tr>
<th>PC TEAM STAFFING LEVEL</th>
<th>PENETRATION (%)</th>
<th>LOS PRE-CONSULT</th>
<th>LOS POST-CONSULT</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOW</td>
<td>1.4 %</td>
<td>8.3</td>
<td>8.2</td>
</tr>
<tr>
<td>MEDIUM</td>
<td>3 %</td>
<td>6</td>
<td>5.9</td>
</tr>
<tr>
<td>HIGH</td>
<td>6.8 %</td>
<td>3.9</td>
<td>4.7</td>
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</tbody>
</table>
Recent growth.....

- Certified nurses: 2010-2014: 11,300-13,500
- Certified MD: 2008-2013: 1100-6500
- Hospital PC teams: 2000-2013: 22%-77%
- Medicare hospices:
  - 1984: 31  2010: 3407
- Hospice patients served:
  - 1982  25,000  -2005  1,200,000
  - 1990  200,000  -2010  1,400,000
  - 1995  400,000  -2014  1,650,000
  - 2000  700,000
Valuing What Matters to Patients….

- **Value-Based Payments**
  - *JAMA 2015; 314(14):1445-46*

- **Measuring Value**
  - *Current metrics: Professional standards for disease management—generally congruent with patient needs/wants*
  - *Serious illness: professional standards may not address*
    - Hopes/fears; comfort; QOL; connectedness; honoring family and social role; spiritual well-being

- **Process of careful conversation and engagement can lead to identification of meaningful and achievable goals that informs medical and non-medical interventions**
Valuing What Matters to Patients

- Delivery system must proactively help people to articulate their priorities
- Must be informed by honest and accurate predictions
- Measure and incentivize
- Caregiver and family support; ready access to care
- EHR consolidate in one place easily visible and retrievable ACP materials
- Failure in this endeavor: people will get treatments mostly correct if they were healthier, but their priorities will neither be noticed nor met
California End of Life Option Act

- Aid in Dying now legally available to 1/6 US citizens
- Demonstrates cultural shift
- Accessed by more privileged
- Heightened awareness of need for excellent EOL care
- Resources:
  - California Coalition for Compassionate Care
  - CMA
  - Compassion & Choices
Institute for Human Caring
www.providence.org/institute-for-human-caring

  - Ira Byock MD, CEO

- Promote a transformation of health care services to an emphasis on whole person care
  - Resources, training and support to help clinicians have more open and meaningful conversations with patients and their families
  - Provide individualized communication & planning tailored to each patient’s personal needs, values, preferences and priorities for care through the end of life
In Retrospect….

- Transformations in bioethical thought and application to clinical setting
- Exploration into what the *Goals of Medicine* ought to be
- Development of the concept of modern day hospice with a focus on quality of life based on individualized patient values & autonomous choice
- Development of a specialty field of Palliative Medicine
  - 1980’s: transformation in bioethics and development of hospices
  - 1990’s: Spread of concept upstream via palliative care
  - 2000’s: spread of concept across settings; specialty field; high prevalence hospital teams
  - 2010’s: Proof of concept through measurement, research; highly respected—strong public and professional awareness; effective advocacy; strong position in health care reform models, innovative models of care delivery
Where do we think we are heading?

Within health care reform
- How do we justly provide access to care?
- What kind of care for whom and at what time?
- How do we keep care affordable; in balance with other demands?
- Triple Aim: Improve outcome and experience of care for less cost
- Amidst change and pressures, how do we preserve the profession as a sustainable and healthy career?

What about palliative care?
- What is its right place in the continuum of care?
- How do we measure and hold accountable to a standard?
- How do we invigorate a culture shift to one of whole person care?
- How do we assure quality PC for all….not just PC consults or hospice?
- How will we meet the capacity needs of the specialty?