

A sunset over a body of water with mountains in the background. The sky is a mix of purple, orange, and yellow, with the sun low on the horizon. The water in the foreground is dark with some reflections of the sunset colors. The mountains in the background are silhouetted against the bright sky.

# STATE OF THE SCIENCE IN PALLIATIVE CARE

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PC Grand Rounds

March 10, 2011

# Learner Objectives

- Summarize 4 important peer-reviewed articles from 2010 PC Literature
- Critique their methodologies and understand their conclusions
- Determine if the findings are relevant to the care of your patients

# Key Issues To Be Considered

- Is the question important?
- What are the results?
- Are the results valid?
- Can I apply the results to my patients?

A sunset over a body of water with mountains in the background. The sky is a mix of purple, orange, and yellow, reflecting on the dark water below. The mountains are silhouetted against the bright horizon.

# Early Palliative Care for Patients with Metastatic NSC Lung Cancer

Temel JS, Greer JA, Muzikansky A, Gallagher ER,  
Admane S, Jackson VA, Dahlin CM,  
Blinderman CD, Jacobsen J, Pirl WF, Billings JA,  
Lynch TJ

N Engl J Med 2010 363:733-42

# Methods

- Design: Non-blinded RCT of early outpatient palliative care integrated with standard oncologic care compared with standard oncologic care alone. All participants received standard oncologic care.
- Setting: Massachusetts General Hospital
- Inclusion Criteria: Pathologically confirmed metastatic NSCLC diagnosis within last 8 wks, ECOG 0-2, able to read and respond in English
- Exclusion Criteria: Already receiving PC, but could receive PC after enrollment
- Funding: ASCO Career Development Award, Joanne Monahan Cancer Fund, Golf Fights Cancer

# Palliative Care Intervention

- Patients met with a PC Team member (MD or NP) in OP setting within 3 weeks after enrollment and at least monthly until death.
- Additional visits were scheduled at the discretion of the patient, oncologist, or PC Team
- Guidelines for visit were adapted from National Consensus Project for Quality PC
- Attention paid to physical/psychological symptoms, goals of care, decision making regarding treatment, and coordinating care



# Outcomes

- Patient Reported Measures
  - Quality of Life
    - Well-being, function, symptoms
  - Mood
    - Depression (HADS and PHQ-9)
- Health Care Use
  - Chemotherapy, hospice, hospital, ED
  - Aggressive care=chemo within last 14 days of life, no hospice, <3 days in hospice
  - Resuscitation preferences in EMR
- Survival

# Analysis

- Baseline questionnaire before randomization
- Follow-up assessments at 12 weeks – either completed during OP visit or mailed
- Evaluated change in QOL and mood over 12 weeks, Kaplan Meier for survival



# Key Findings: Enrollment

- 283 patients eligible, 210 approached and offered, 151 randomized (72%)

	<u>Standard Care</u> (n=74)	<u>Early PC</u> (n=77)
Age	65	65
Female	49%	55%
White	95%	100%

- All but one patient randomized to PC received at least one PC visit, mean of 4, (0-8)
- 10 patients randomized to standard care received PC

# Key Findings: QOL and Mood

- PC patients had 2.3 point increase in mean QOL score compared to 2.3 decrease in QOL for standard care pt (p=.04)
- PC group had lower rates of depression

	Standard Care	Early PC	p
HADS-D	38%	16%	0.01
PHQ-9	17%	4%	0.04

# Key Findings: EOL Care and Survival

- 105 (70%) of patients died
- Standard care patients more likely to receive aggressive care (54% vs. 33%,  $p=0.05$ ) and less likely to have resuscitation preferences documented in EMR (28% vs. 53%,  $p=0.05$ )
- PC patients had longer median survival
  - **11.6 vs 8.9 months,  $p=0.02$**

# Key Issues

- Is the question important?
- The RCT for which we in Palliative Care have been waiting!!
- The benefit of PC has always been known to PC Champions, but we have needed to prove the added benefit (and lack of harm) to other clinicians and community.

# Key Issues

- What are the results?
- Early Palliative Care provided at the same time as life-sustaining treatments for patients with metastatic NSCLC has multiple benefits.
- Palliative Care is associated with improved mood, QOL, less use of aggressive therapies, and improved survival.
- Results don't fully explain why



# Key Issues

- Are the results valid?
- High quality trial of a Palliative Care intervention in patients with advanced disease
- Issue of power to detect difference in some outcomes
- Intervention could have been described in greater detail



# Key Issues

- Can I apply the results to my patients?
- Be careful to not over-generalize
  - Specific group of lung ca patients
  - Proves benefit of Palliative Care, helps dispel concerns about shortening life and depressing patients
  - Predominantly white population
- Trial in a single academic med center with very mature PC Program

# Clinical Bottom Line

Early Palliative Care integrated with standard oncologic care for patients with metastatic NSCLC is associated with improved QOL, mood, less use of aggressive therapies at the end-of-life and longer survival.

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# One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation: A cohort study

- Unroe M, Kahn JM, Carson SS, Govert JA, Martinu T, Sathy SJ, Clay AS, Chia J, Gray A, Tulskey JA, Cox CE
- Ann Internal Med 2010 153: 167-75

# Methods

- Design: Prospective cohort study
- Setting: 5 ICU's at Duke Univ Med Center
  - Surgical, trauma, neurologic, cardiothoracic, cardiac, medical
- Participants: Adult, English-speaking ICU pts, surrogates, physicians
- Prolonged mech ventilation:
  - $\geq 21$  days with  $< 48$  hrs unassisted breathing
  - $\geq 4$  days of ventilation + s/p trach for expected prolonged vent support
- Funding: None

# Data Sources and Outcomes

- Data Sources:
  - Patient/surrogate interviews at 0,3,12 months
  - Medical records
  - Administrative data
- Outcomes:
  - Mortality
  - QOL, functional status
  - Resource utilization
  - Costs

# Key Findings: Enrollment

- 135 (80% eligible) patients enrolled, complete data on 126

<u>Characteristic</u>	<u>n=126</u>
Age	55 yrs
Male	60%
White	53%
Af/Am	38%
Living at home PTA	98%
Functional dependencies	0 ADL's



# Key Findings: Hospital Course

- 18% died in hospital
- Survivors – significant care requirements at hospital discharge
  - 63% discharged to facility
  - LTAC, rehab, SNF
  - 16% discharged to home with intensive home care services
  - 2% hospice

# Outcomes at 1 Year

- 126 patients had - - -
  - 457 care location transitions
  - 150 Hospital readmissions
  - \$38.5 million in health care costs
- 44% died
  - 43% on vent
  - 39% after withdrawal
  - Location of death - - - 82% in a facility, 13% in hospice and 5% at home

# Outcomes at 1 Year

- 56% were alive
- 83% at home
- 17% at a facility
  
- Quality of life - - -
- Good: 27%
- Fair: 24%
- Poor: 49%

# Patient Trajectories

- Functional independence was rare
  - 7 to 8.5%
- Improvement between 3 and 12 months was rare
  - 13%

# Key Issues

- Is the question important?
- Increasing numbers of patients receive prolonged mechanical ventilation
- Patients, surrogates and clinicians have high expectations for survival and good functional outcomes
- Long term QOL and functional status not well described to date

# Key Issues

- What are the results?
- Patients who received prolonged mechanical ventilation had high rates of mortality and functional dependence at hospital discharge
- Between hospital discharge, 3 months and 12 months, improvement in functional status was rare, high mortality persisted, and QOL was poor



# Key Issues

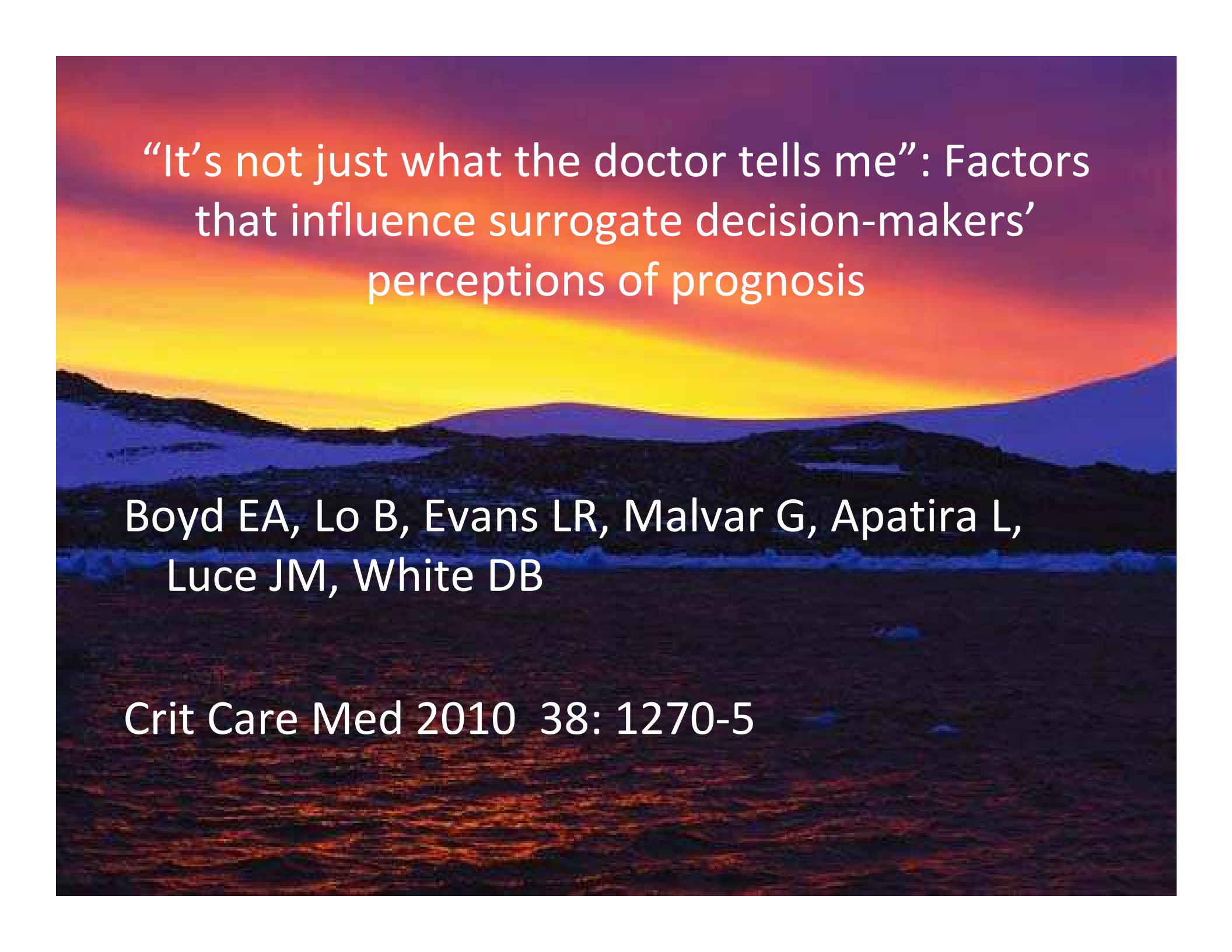
- Are the results valid?
- High enrollment and data completion rates
- Multiple data sources to assess outcomes
- Resource utilization tracked by patient or surrogate interviews and records review in one health system
- Financial costs to families not assessed

# Key Issues

- Can I apply the results to my patients?
- These data contrast with patient, surrogate and clinician's high expectations for recovery
- May help patients and families to make more informed decisions
- Single center in area with high long-term acute care facility penetration
- Chronically critically ill are a population in need of palliative care

# Clinical Bottom Line

- Patients who receive prolonged mechanical ventilation have high mortality and functional dependence and poor quality of life a year after hospital discharge

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“It’s not just what the doctor tells me”: Factors  
that influence surrogate decision-makers’  
perceptions of prognosis

Boyd EA, Lo B, Evans LR, Malvar G, Apatira L,  
Luce JM, White DB

Crit Care Med 2010 38: 1270-5

# Methods

- Design: Mixed quantitative and qualitative analysis of semi-structured interviews
- Setting: 4 ICU's at UCSF Medical Center  
Medical, surgical, neurologic, and cardiac
- Participants: Adult, English-speaking, surrogates of ICU patients
  - Mechanically ventilated, lacked decision-making capacity
  - APACHE II in hospital mortality > 40%
- Funding: NIH/NCRR

# Interview Protocol

- One-on-one in private room near ICU
- Surrogate provided numeric estimate of patient's survival (0-100%)
- “Can you tell me a little bit about what has made you think this is his/her prognosis?”
- Audio-taped, transcribed for analysis



# Qualitative Analysis

- Multidisciplinary Team
  - Critical care, ethics, sociology, communication and end-of-life care
- Line-by-line coding - - emerging themes, preliminary coding scheme modified in application to remaining transcripts
  - Inter-rater reliability excellent (20% sample)
- Results checked with study participants

# Key Findings: Enrollment

- 179 surrogates (78% eligible) enrolled

<u>Surrogate Characteristic</u>	<u>n=179</u>
Age	47 yrs
Male	53%
White	61%
Asian/PI	16%
Hispanic	15%
Af/Am	11%
Child of pt	37%
Spouse of pt	22%

# Surrogates' Prognostic Estimate

- Surrogates estimated survival at 69% on average
- 55% of patients survived the hospitalization

# Information from Physicians

- Received prognostic information from physicians --- **79%**
- Based estimate *partially* on information from physicians - - - **47%**
- Based estimate *solely* on information from physician - - - **2%**

# Other Sources of Prognostic Information (N=5)

- Interpretation of the patient's physical appearance or status
- Optimism, faith, and intuition
- Patient's intrinsic qualities, will to live
- Power of support

# Patient's Physical Appearance or Status

- Physical appearance: facial expression, skin hue, comfort or discomfort, synchrony with ventilator
- Pre-morbid status; physical fitness, age
- Changes over time
- “He just looks really, really sick.. You get discouraged when you do not see any improvement.”

“I think he has 90% . . . Because today he opened his eyes when we were talking to him.”



# Optimism, faith or intuition

- Optimism: “We want to be positive.. That’s why we’re saying he’s going to have a 90% chance to survive. We do not want to be negative.”
- Intuition: “In my heart, I think there’s more than a 50% chance that the doctors are giving us.”
- Faith: “My daughter is very, very sick, but I believe her faith in God and her faith in being cured will give her the strength to survive.”

# Pt's History of Illness or Survival

- “He beat cancer so I feel very strongly that he can beat this pneumonia.”
- “She’s been in this situation, very similar, many times and she’s somehow defied the odds.”

# Pt's Intrinsic Qualities, Will to Live

- Stubborn or determined disposition: “I chose the high number because, basically, I know that my wife is a fighter beyond the normal person.”
- Fading strength: “I do not know if my aunt has the fight left in her anymore.”

# Power of Support

- Family, friends, support groups, and religious groups could improve prognosis
- “Well, I think a lot of his surviving has been with her help of myself and my daughter... The fact that we’ve been by his side, whenever we possibly can, and we have been talking in his ear, yelling in his ear, telling him to think positive... And I think that really helped him a lot.”

# Key Issues

- Is the question important?
- Provider-surrogate concordance about prognosis is often poor
- Providers may not understand why families make decisions that are incongruous with clinical prognostic estimates
- The sources families use to assess prognosis are poorly understood



# Key Issues

- What are the results?
- Information from providers/clinicians are only **one** of many sources families use to estimate a patients' prognosis
- Key sources of information are:
  - Families' knowledge and observations of the pt
  - Intuition and faith
  - Support of loved ones



# Key Issues

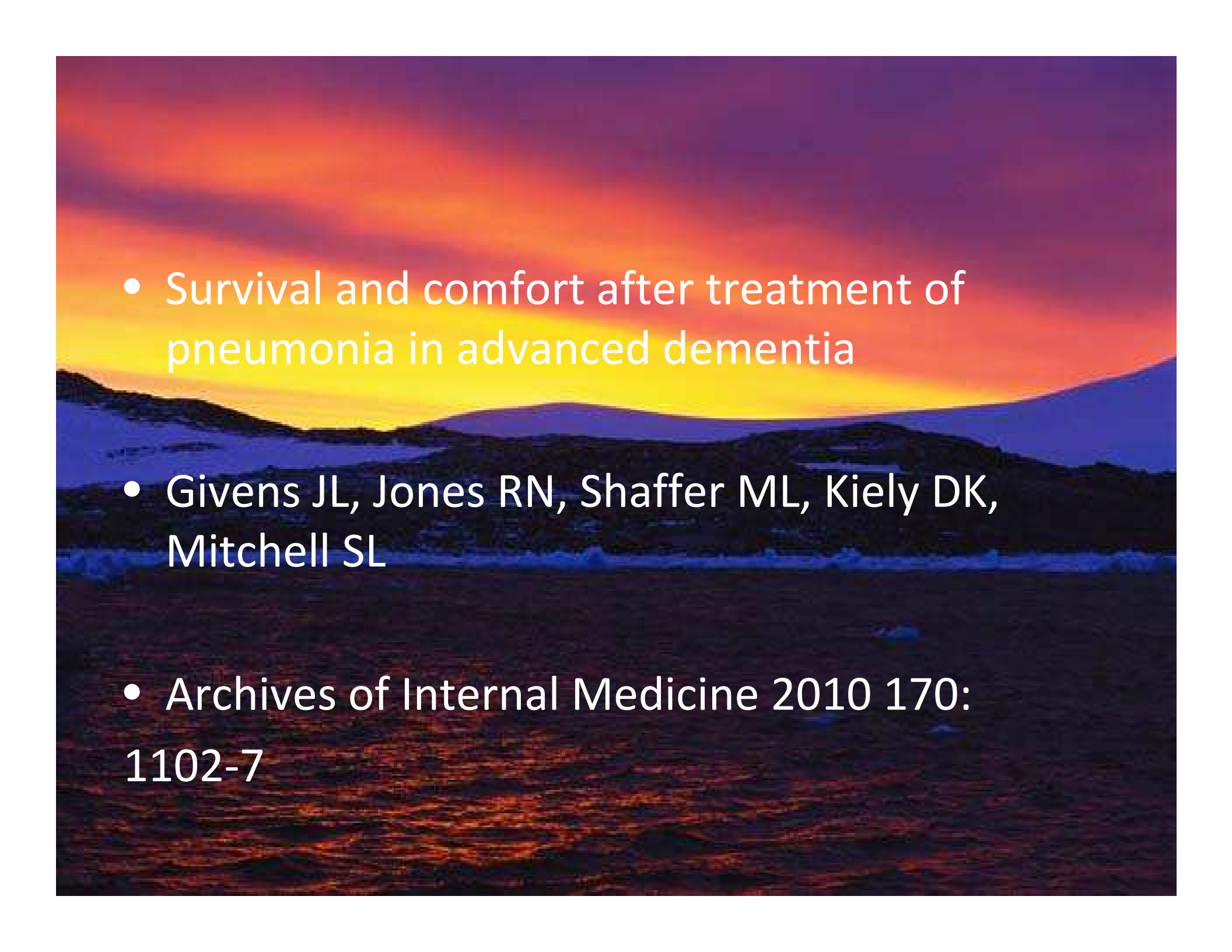
- Are the results valid?
- High enrollment rate
- Multidisciplinary team coded transcripts
- High inter-rater reliability
- Results checked with participants
- Describes sources, but not relative importance of each source compared to others

# Key Issues

- Can I apply the results to my patients?
- Conceptual model of prognostic communication: process of sharing understanding vs. unidirectional transmission of knowledge from clinician to family.
- English-speaking surrogated, ICUs in single academic center
- This model may apply to other settings

# Clinical Bottom Line

- Surrogates integrate information from a number of sources when estimating a patient's prognosis, including providers knowledge, their knowledge of patient, intuition, observations, faith, and support of loved ones.

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- A sunset over a body of water with mountains in the background. The sky is a mix of purple, orange, and yellow, reflecting on the water. The mountains are dark and silhouetted against the bright sky.
- Survival and comfort after treatment of pneumonia in advanced dementia
  - Givens JL, Jones RN, Shaffer ML, Kiely DK, Mitchell SL
  - Archives of Internal Medicine 2010 170: 1102-7

# Methods

- Design: Prospective cohort study of nursing home residents with advanced dementia and their health care POA's
- Sites: 22 NH with more than 60 beds, located within 60 miles of Boston
- Subjects: Age>60, advanced dementia per cognitive performance scale and global deterioration scale), proxy who could provide consent
- Funding: NIA, Hartford Foundation

# Data Collection

- Chart Review, nurse interviews, and physical exam
  - Baseline and then quarterly for 18 months
- Data collected about deceased subjects within 2 wks of death
- Charts reviewed for pneumonia documented by primary care provider
- Recorded unstable V.S., if aspiration was the cause, and use of X-ray



# Treatments

- None
- Oral antibiotics
- IM antibiotics
- IV antibiotics or hospitalization

# Outcomes

- Survival: days from episode until death or end of f/u period
- Nurse reported resident comfort every 90 days
  - Symptom management at EOL in Dementia
  - Measures pain, dyspnea, depression, fear, anxiety, agitation, resistance to care
  - Record frequency and scores converted to 0-45 scale; higher= greater comfort
- Related scale used for residents who died, completed within 2 wks of death

# Key Findings: Enrollment

- 572 eligible NH residents, 323 (57%) enrolled
- 41% had at least 1 pneumonia episode (total of 225 episodes of pneumonia)

<u>Characteristic</u>	<u>n=225</u>
Age	86
Female	81%
White	92%
Live on dementia unit	44%

# Treatments

- Of 225 episodes
  - 9% not treated
  - 55% oral antibiotics
  - 16% IM antibiotics
  - 20% IV antibiotics
- Aspiration suspected in 56% of episodes
- Of 77% with CXR, 84% confirmed pneumonia

# Key Findings: Survival

- Antimicrobial treatment by any route was associated with lower mortality after suspected pneumonia compared with no treatment
  - Mean increase in survival was 273 days
- No statistical difference in survival based on route of antibiotics

# Key Findings: Comfort

- Among those who lived at least 90 days from episode (n=159) comfort scores were highest among those who were not treated with antibiotics and were progressively worse for increasingly aggressive treatments of pneumonia
- For patients who died, no association between receiving antibiotics and comfort



# Key Issues

- Is the question important?
- Pneumonia is common in NH residents with adv dementia
- Palliative care and hospice clinicians are often asked to assist with treatment decisions
- Distinction between survival and comfort is often of great importance to families

# Key Issues

- What are the results?
- Treatment with antimicrobial agents associated with longer survival
- No differences between survival based on route of antibiotics
- Patients who lived and received antibiotics had more discomfort
- For patients who died, no difference in comfort for those who did or did not receive antibiotics

# Key Issues

- Are the results valid?
- Well designed and large prospective study
- Pneumonia episodes were identified using chart review, although most confirmed with CXR
- Did not examine choice of antibiotic agent only route
- Symptom assessment in pts who survived not necessarily collected at time of pneumonia episode

# Key Issues

- Can I apply the results to my patients?
- Regardless of the practice setting, many of us care for NH patients with dementia
- Only facilities in Boston area, well known regional variations in care
- Provides concrete data about survival vs. comfort which can be useful when advising families
- Oral route as effective as other routes

# Clinical Bottom Line

- For nursing home residents with advanced dementia who develop pneumonia, antimicrobial treatment prolongs life, but is associated with more discomfort
- For those who die, withholding of antimicrobial agents doesn't appear to be associated with increased suffering