SAFE PASSAGE:
OPPORTUNITIES TO REDUCE HARM WHILE PROVIDING CARE AT THE END OF LIFE

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Goals

- Highlight the challenges and opportunities in ensuring that end-of-life care is as safe as possible.

- Illuminate some of the more surprising aspects of end-of-life care in the United States in 2012 and most of all…
Goals

…broaden and refine a working definition of “Patient Safety” to incorporate and build on fundamental principles of Hospice and Palliative Care.
First, some definitions

Hospice: a system that provides care to patients with a prognosis of 6 months or less.

Nationally, 84.3% of Hospice care is paid for by Medicare.
Included benefits are:

- Nursing care
- Social work care
- Home health aide care

PLUS…
Hospice Benefits, continued

• Spiritual care
• Volunteer care (5% of all care)
• Physical therapy and/or occupational therapy
• Medications related to the terminal diagnosis
• Medical equipment related to the terminal diagnosis
• Oversight by a pharmacist
• Oversight by a medical director
• Bereavement counseling/support for survivors for up to 13 months following the patient’s death
Palliative Care

Palliative Care is an internationally-recognized approach to the care of patients with progressive, life-limiting illnesses that emphasizes patient goals and quality of life, but does not exclude curative treatments.

Exists in many different forms, including:
- Inpatient service
- Outpatient office-based service
- Home/residential facility-based service
Palliative Care
Palliative Care
Hospice and Palliative Care

- Comprehensive Patient Care
  - Palliative Care
    - Hospice Care
Safety
Tom

- 62 year old male with AML
- Responding to chemotherapy with cytarabine and daunorubicin
- Receiving transfusions of red blood cells and platelets every six to eight weeks
- Working part-time
- Goal: as much time with family as possible
Allan

- 62 year old male with AML
- Initially responded to post –remission chemotherapy with cytarabine and daunorubicin
- Received transfusions of red blood cells and platelets every week for six weeks; now requiring twice-weekly transfusions
- Increasingly weak and fatigued, cannot ride comfortably in car
- Goal: comfort, as much time with family as possible, no more time in hospitals
Safety of Blood Transfusions

When considering the safety of blood transfusions, it is not just the intervention that must be considered.

What’s “safe” for Tom may not be “safe” for Allan
Built on the same foundation

Hospice and Palliative Care

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Patient Safety

Primum non nocere
Doris

- 81 years old
- 3 hospitalizations in the past 5 months, all for CHF exacerbations; intermittent medication compliance
- 2 ED visits in the last 2 months
- Day #3 of her fourth hospitalization
- Doris’ floor is part of pilot program involving automatic trigger for Palliative Care consultation:
  
  3\textsuperscript{rd} hospitalization in < 6 months

  \downarrow

  Palliative Care consult
Doris

Past Medical History:
- s/p MI in 2007
- Atrial fibrillation
- CHF with EF of 30% in 2009
- DMII
- Osteoporosis
- Compression fractures in L2, L3
- s/p fall 2 months ago
Doris

**Medications:**
Glipizide 5 mg qd
Carvedilol 12.5 mg bid
Furosemide 40 mg bid
Spironolactone 25 mg bid
Digoxin 0.125 mg qd
Aspirin 81 mg qd
Coumadin 5 mg M, W, F
                   2.5 mg T, Th, Sa, Su
Acetaminophen 325 mg  1-2 tabs po q 4-6 hours
Calcium citrate 500 mg bid
Vitamin D 500 IU bid
Paroxetine 20 mg qd
Alendronate 70 mg q week
O2 @2 L/min
Doris

Social History:
Widowed; lives alone
Former 7\textsuperscript{th} grade teacher
Two daughters; one local (Anne); one on East coast (Nancy)
Has hired caregiver 4 hours/day
Doris

Physical exam:
Sitting up in bed, dyspneic at rest, wearing O2
BP 132/86…HR 98…RR 20…T 98.4…BMI 20.2
Chest: Bibasilar crackles
CV: irreg irreg, no m/r/g
Abd: soft NT
Ext: 3+ edema to midcalf
What happened in the Palliative Care consult?

- What’s your understanding of what’s going on?
- What are you hoping for?
- What do you fear?
- Does anyone else know how you feel?
- How might we help?
Doris’ answers

- What’s your understanding of what’s going on? “I keep getting sicker and sicker”
- What are you hoping for? “I wish I could stop coming to the hospital”
- What do you fear? “I worry how short of breath I am. I also worry about Anne and Nancy— they have lives and I don’t want them to have to worry about me.”
- Does anyone else know how you feel? “I don’t know... Anne understands but Nancy says I’m going to get better... I just have to keep fighting”
- How might we help? “I don’t know... you’re the doctor!”
Meeting with Doris and Anne

Focus on Doris’ goal: to stay out of the hospital

Hospice system and approach are introduced

Advance Directives/POLST form reviewed
Eligibility for Medicare Hospice Benefit

An individual must be:

1. Entitled to Medicare Part A
2. Certified as being terminally ill: it is more likely than not that a patient’s prognosis is 6 months or less should the terminal illness follow its usual course.

That’s it.
A Word on Prognostication

343 doctors provided survival estimates for 468 terminally ill patients at the time of hospice referral

% of predictions that were accurate (within 33% of actual survival): 20%

Overoptimistic: 63%

Overpessimistic: 17%

Overall overestimation survival factor: 5.3

Medicare/NHPCO Guidelines for Medical Eligibility for Patients with Heart Failure

- Functional NYHA Class IV (i.e. symptomatic at rest)
- Symptomatic despite maximum medical management tolerable to the patient
- Treatment resistant arrhythmia
- Ejection fraction <20%
- History of cardiac arrest
- Cerebral embolism of cardiac origin
- Persistent resting tachycardia
Physician Orders for Life Sustaining Treatment
Doris and the POLST

“Hospice sounds good – I don’t want to come back to the hospital, but I can’t give up until I’ve talked with Nancy. She made me promise not to sign anything like this without talking to her.”
It is illegal for any Hospice to make DNR status a requirement for a patient to receive Hospice services.
Palliative Care – Can it actually do harm?

**CONTEXT:** “Without evidence that end-of-life discussions improve patient outcomes, physicians must balance their desire to honor patient autonomy against a concern of inflicting psychological harm.”

**STUDY:** US multisite, prospective, longitudinal cohort study of patients with advanced cancer and their informal caregivers (n = 332 dyads) September 2002-February 2008.

**RESULTS:** “End of life discussions are associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with worse patient quality of life and worse bereavement adjustment.”

What’s happening in a Palliative Care consult?

151 patients with newly-diagnosed metastatic NSCLC randomized to receive standard oncologic care or standard oncologic care integrated with Palliative Care.

<table>
<thead>
<tr>
<th></th>
<th>Standard Care</th>
<th>Early Palliative Care</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggressive Care</td>
<td>54%</td>
<td>33%</td>
<td>p=0.05</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>91.5</td>
<td>98</td>
<td>p=0.03</td>
</tr>
<tr>
<td>(scores on FACT-L, 0-136, higher score correlates with higher QOL)</td>
<td></td>
<td></td>
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<tr>
<td>Depressive Symptoms</td>
<td>38%</td>
<td>16%</td>
<td>p=0.01</td>
</tr>
<tr>
<td>Median Survival</td>
<td>8.9 months</td>
<td>11.6 months</td>
<td>p=0.05</td>
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</table>

In Conclusion: Doris’ Palliative Care Consult

1. Arrangement for discharge to home with Hospice.
2. Doris remains Full Code – discussion to be continued when Nancy arrives.
3. Medications **added**: Morphine 5 mg po q 4 hours prn pain or dyspnea.
4. Medications **deleted/reduced**:
   - Coumadin: increasing risk for falls
   - Acetaminophen: dose not to exceed 3 g/day
Doris goes home

Over the next two weeks:

- Medications reviewed and entered in Hospice medical record
- Home environment reviewed
- Recommendation made for increased caregiving
- Doris’ case is discussed in detail in Interdisciplinary Team meeting (RN, MSW, CNA, MD, pharmacist, spiritual care, volunteer)
- Nancy comes home; code status is discussed and changed to **DNR/AND** (Allow Natural Death) when incompatibility of “Full Code” and “No Hospitalization” is explored
Over the next six months

• Ongoing RN, MSW, CNA, volunteer, spiritual care

• Has another fall – prompts review and transfer to an Adult Family Home

• Recertified at 3 months – prognosis still remains 6 months or less

• After 5 ½ months on Hospice, hospice physician visits Doris at AFH; she has less edema, is now dyspneic only with exertion; takes morphine occasionally

• Overall condition is improved; Doris is decertified
Hospice Graduation: Why are we surprised?

Survival of Patients with Terminal Disease in days

<table>
<thead>
<tr>
<th>Disease</th>
<th>Non-hospice</th>
<th>Hospice</th>
<th>p-value</th>
</tr>
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<tbody>
<tr>
<td>CHF</td>
<td>321</td>
<td>402</td>
<td>p=0.05</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>240</td>
<td>279</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>189</td>
<td>210</td>
<td>p=0.01</td>
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<tr>
<td>Colon cancer</td>
<td>381</td>
<td>414</td>
<td>p=0.07</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>410</td>
<td>422</td>
<td>p=0.61</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>510</td>
<td>514</td>
<td>p=0.83</td>
</tr>
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Hospice “Graduation”: Implications

- In 2010, 1.58 million patients received Hospice care in US

- 259,000 (16%) “live discharges” – due to change in prognosis, desire to pursue curative treatment, or other reasons (combination of decertification and revocation)

2011 NHPCO Facts and Figures: Hospice Care in America

Implications for continuity of care, recognition of DNR status, and rapid response to change in prognosis
Instructions to Doris, family, AFH, and Doris’ PCP

• When decline is evident, call Hospice

• Advance Directive Conflict: WAC 388-76-10250 vs. POLST form
Two months later

- Anne calls Hospice: Doris is more short of breath, having more generalized pain, and has worsening edema

- Re-admission to Hospice that day

- Doris dies 6 days later
A few observations: Morphine

**Questions:** Do high doses of morphine (>120 mg/day) or rapid dose escalation (increasing initial dose by a factor of > 2 in last 7 days of life) at the end of life actually hasten death?

**Study:** Retrospective cohort study of 223 patients with cancer who died at home on a home hospice program.

**Results:**
- Median survival in Lower Dose Group: 2 days
- Median survival in High Dose Group: 6 days
- p=0.01, but difference not statistically significant after adjustments for age, gender, performance status, and prior opioid exposure

- Median Survival in Patients Not Receiving >Twofold Increase in Morphine: 9 days
- Median Survival in Patients Receiving >Twofold Increase in Morphine: 22 days
  - p<0.0001

_Opioid use at the end of life and survival in a hospital at home unit. Bengochea et al; J Pall Med 2010; 13:1079-83._
Safety of Opioids at the End of Life

At the end of life, is it safe NOT to aggressively treat pain?
A few observations: Patient and family satisfaction

Family Evaluation of Hospice Care (FEHC) Overall Rating
Percent of individuals rating the quality of hospice care “excellent”

- 75.6%

Global measure of hospice quality based on 17 core measures

- 86.6%

Comfortable Dying Measure
Patient’s pain brought to a comfortable level within 48 hours of initial assessment

- 72.5%

A few observations: Cost savings

On average, Hospice saves Medicare $2309 per patient.

Medicare costs would be reduced for 7 out of 10 hospice recipients if hospice was used for a longer period of time.

In conclusion

- End of life marks a time of multiple transitions in location, provider, and goals of care.

- With every transition there is an opportunity to minimize harm, beginning with establishing patients’ goals of care, which generally change over time.

- Many misconceptions persist regarding end-of-life care that may jeopardize safety for dying patients…

…and now you are equipped to clarify them!
Getting in touch

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