Who is illiterate?
Learning to listen to our patients

Diane E. Meier, MD
Director, Center to Advance Palliative Care
diane.meier@mssm.edu
www.capc.org
www.getpalliativecare.org
@dianeemeier
Listen to me!

Listen to me!
No Disclosures
Objectives

➔ The case for integrated palliative care strategies as a counter to the current health “system” culture
➔ What works to improve quality for vulnerable people?
➔ How we can gain literacy in the needs of our patients and their families?
Concentration of Risk/$

Health Spending Is Very Highly Concentrated Among the Highest Spenders

Top 1% of spenders account for 23% of spending

Top 5% of spenders account for 50% of spending

NIHM Foundation analysis of data from the 2012 Medical Expenditure Panel Survey.
Value = Quality/Cost

Because of the Concentration of Risk and Spending, and the Impact of Palliative Care on Quality and Cost, its Principles and Practices are Central to Improving Value
Mr. B vs. The Culture of Medicine

- An 88 year old man with dementia admitted via the ED for management of back pain due to spinal stenosis and arthritis.

- Pain is 8/10 on admission, for which he is taking 5 gm of acetaminophen/day.

- Admitted 3 times in 2 months for pain (2x), falls, and altered mental status due to constipation.

- His family (83 year old wife) is overwhelmed.
Mr. B:

Mr. B: “Don’t take me to the hospital! Please!”

Mrs. B: “He hates being in the hospital, but what could I do? The pain was terrible and I couldn’t reach the doctor. I couldn’t even move him myself, so I called the ambulance. It was the only thing I could do.”

Modified from and with thanks to Dave Casarett
Who is illiterate in this situation?
Before and After

Usual Care Culture

➔ 4 calls to 911 in a 3 month period, leading to
➔ 4 ED visits and
➔ 3 hospitalizations, leading to
➔ Hospital acquired infection
➔ Functional decline
➔ Family distress

Counterculture

➔ Housecalls referral
➔ Pain/bowel management
➔ 24/7 phone coverage
➔ Support for caregiver
➔ Meals on Wheels
➔ Friendly visitor program
➔ No 911 calls, ED visits, or hospitalizations in last 18 months
The Modern Death Ritual: The Emergency Department

Half of older Americans visited ED in last month of life and 75% did so in their last 6 months of life.

Who are the costliest 5%?

- Functional Limitation
- Frailty
- Dementia
- Exhausted overwhelmed family caregivers
- Social + behavioral health challenges
- +/- Serious illness(es)
Functional Limitations as a Predictor of Risk

Figure 4
Among Medicare enrollees in the top spending quintile, nearly half have chronic conditions and functional limitations

Distribution of enrollees, by groups of enrollees

- All Enrollees: 15% Chronic conditions & functional limitations, 48% 3 or more chronic conditions only, 31% 1-2 chronic conditions only, 7% No chronic conditions
- Top 20% of Medicare Spenders: 46% Chronic conditions & functional limitations, 41% 3 or more chronic conditions only, 12% 1-2 chronic conditions only, 1% No chronic conditions
- Top 5% of Medicare Spenders: 61% Chronic conditions & functional limitations, 32% 3 or more chronic conditions only, 7% 1-2 chronic conditions only, 1% No chronic conditions

### Dementia As a Predictor of Risk

<table>
<thead>
<tr>
<th></th>
<th>Dementia</th>
<th>No Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare SNF use</td>
<td>44.7%</td>
<td>11.4%</td>
</tr>
<tr>
<td>Medicaid NH use</td>
<td>21%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Hospital use</td>
<td>76.2%</td>
<td>51.2%</td>
</tr>
<tr>
<td>Home health use</td>
<td>55.7%</td>
<td>27.3%</td>
</tr>
<tr>
<td>Transitions</td>
<td>11.2</td>
<td>3.8</td>
</tr>
</tbody>
</table>

Prospective Cohort of community dwelling older adults

Callahan et al. JAGS 2012;60:813-20.
Why? Health system illiteracy = Low Ratio of Social to Health Service Expenditures in U.S.

for Organization for Economic Co-operation and Development (OECD) countries, 2005.

Copyright © BMJ Publishing Group Ltd and the Health Foundation. All rights reserved.

Surprise! Home and Community Based Services are High Value

→ Improves quality: Staying home is concordant with people’s goals.

→ Reduces spending: Based on 25 State reports, costs of Home and Community Based LTC Services less than 1/3rd the cost of Nursing Home care.
A study published today in Health Affairs found if all 48 contiguous states increased by 1% the number of elderly who got meals delivered to their homes, it would prevent 1,722 people on Medicaid from needing nursing home care. The Brown University study found 26 states would save money because lower Medicaid costs would more than offset the cost of providing the meals.
What is Palliative Care?

➔ Specialized medical care for people with serious illness and their families

➔ Focused on improving quality of life based on what the patient and family prioritize. Addresses pain, symptoms, stress of serious illness.

➔ Provided by an interdisciplinary team that works with patients, families, and other healthcare professionals to provide an added layer of support.

➔ Appropriate at any age, for any diagnosis, at any stage in a serious illness, and provided together with disease treatments.
Conceptual Shift for Palliative Care

Disease-Directed Therapies

Palliative Care

Diagnosis

Time

Death and Bereavement

Life Prolonging Care

But

Life Prolonging Care

Not

This

Palliative Care

Hospice Care

Medicare Hospice

Conceptual Shift for Palliative Care
Palliative Care Improves the Quadruple Aim

Quality improves
- Symptoms
- Quality of life
- *Survival*
- Family satisfaction
- Family bereavement outcomes
- MD satisfaction

Costs reduced
- Hospital cost/day
- Use of hospital, ICU, ED
- 30 day readmissions
- Hospitality mortality
- Labs, imaging, pharmaceuticals
Palliative Care Improves Quality in Office Setting

Randomized trial simultaneous standard cancer care with palliative care co-management from diagnosis versus control group receiving standard cancer care only:

- Improved quality of life
- Reduced major depression
- Reduced 'aggressiveness' (less chemo < 14d before death, more likely to get hospice, less likely to be hospitalized in last month)
- Improved survival (11.6 mos. vs 8.9 mos., p<0.02)

Palliative Care in Nursing Homes

A REPORTER AT LARGE

THE SENSE OF AN ENDING

An Arizona nursing home offers new ways to care for people with dementia.

BY REBECCA MEAD

MAY 20, 2013

Comfort Matters

capc Center to Advance Palliative Care
Palliative Care at Home for the Chronically Ill
Improves Quality, Markedly Reduces Cost

RCT of Service Use Among Heart Failure, Chronic Obstructive Pulmonary Disease, or Cancer Patients While Enrolled in a Home Palliative Care Intervention or Receiving Usual Home Care, 1999–2000

KP Study Brumley, R.D. et al. JAGS 2007
The 5 Key Characteristics of Effective Palliative Care

➔ Target the highest risk people
➔ Ask people what matters most to them, design care plan to match
➔ Support family and other caregivers, address social determinants
➔ Expert pain/symptom management
➔ 24/7 access
Goal Setting

➔ Ask the person and family, “What is most important to you?”
4 Patient Stories: “What is most important to you?”

1. Mr. R: 67 year old Latino man with end stage liver disease, ventilator dependent x 4 months, no family.
2. Mr W: 44 year old AA man with AIDS encephalopathy, ventilator and TPN dependent x 2 months, mother and sister at bedside.
3. Mrs P: 60 year old Greek woman with witnessed cardiac arrest, anoxic encephalopathy, ventilator and feeding tube dependent x 6 months, 3 adult children.
cancer, I thought odd here. Jenny made sure her attention to what was urgent; she wanted to meet a couple hours later.

She came into the frail geriatric generally seen as slender, with a blonde hair, but what I had experienced too, was atypical.

She was diagnosis that time she had a tumor, the discovered outside the lung. Therapy and radiation York City cancer treatment and managing her treatment, she’d seen perhaps which she and her husband, world, while medical psychology of her daughter. With regression of disease, thought of a not each one worked by working to
“I don’t want Jenny to think I’m abandoning her.”

Response to my question asking an oncologist what he hoped to accomplish through intrathecal chemotherapy for a patient with brain metastases from lung cancer.

Meier DE. Health Affairs 2014;33:895-8
Jenny F., 65 year old with metastatic lung cancer seeking guidance

- Diagnosed age 59
- No smoking history
- Given prognosis of 6-12 months
- With expert oncologist, lived >6 years
- Sought palliative care as symptoms worsened for pain, insomnia, fatigue, questions about the future and what to expect
- Received simultaneous palliative and cancer care for over a year
- When cancer Rx no longer helpful, referred to hospice for 3 weeks, died peacefully at home surrounded by family
Oncologist Offers Intrathecal Chemo (aka most important lesson of my career so far)

→ Jenny asks what I think. I tell her I’ll call the oncologist.

→ I ask “I don’t have much experience with this procedure. What are you hoping we can accomplish with it?”

→ He says “It won’t help her.” Long pause.

→ I ask “Do you want me to encourage her to go ahead with it?”

→ He says, “I don’t want Jenny to think I am abandoning her.”
Conclusion

➔ Problem?
➔ Lack of Training
➔ Solution?
➔ Training
In Loving Memory
What is most important?

Survey of Senior Center and Assisted Living subjects, n=357, dementia excluded, no data on function.

Asked to rank order *what’s most important*:

1<sup>st</sup> Independence (76% rank it most important)
2<sup>nd</sup> Pain and symptom relief
3<sup>rd</sup> Staying alive.

Fried et al. Arch Int Med 2011;171:1854
What is most important? Families are Home Alone

→ 40 billion hours unpaid care/yr by 42 million caregivers worth $450 billion/yr
→ Providing “skilled” care
→ Increased risk disease, death, bankruptcy

aarp.org/ppi
http://www.nextstepincare.org/
Families Need Help

➔ Mobilizing long term services and supports in the community is key to helping people stay home and out of hospitals.

➔ Predictors of success: 24/7 meaningful phone access; high-touch consistent personalized care relationships; focus on social & behavioral health; integrate social supports with medical services.
Atul Gawande’s *Being Mortal: Medicine and What Matters in the End*

“I learned about a lot of things in medical school, but mortality wasn’t one of them.”

Page 1 Metropolitan Books, New York, 2014
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
Living with Serious Illness in America 2014 IOM Report

5 Recommendations

1. Palliative care everywhere as *standard of practice*

2. and 3. *Required universal* clinician training and certification in palliative care, clinician-patient communication and ACP

4. Policies and payment to *support both medical and social needs*

5. Public education and engagement
How do we work towards the IOM recommendations?

➔ All patients with serious illness should have access to quality palliative care.

➔ To get there we need to:
  – Expand palliative care to home and community care settings
  – *Train all clinicians* who treat seriously ill patients to provide basic palliative care
Palliative care as counterculture literacy in listening to patients
Listening to voices from the 1990’s: Ovarian Cancer and Neuropathic Pain

“I had the most excruciating pain I had ever experienced. The pain medication…did not even begin to penetrate the pain. I thought I was going to die…”

Listening to voices from the 1990’s: Chemo-Induced Neuropathy

“…It felt as if my feet were in too tight ski boots I could not remove. My balance was poor and my feet kept bumping into things. I could not stand for more than 3 or 4 minutes at a time-if I tried my feet ached unbearably. My hands were so numb that if I reached into my purse to get a lipstick, I might come up with a comb or keys instead- I could not tell the difference by feel. My handwriting was so uncontrolled I could not write a marketing list let alone a check or a note…”

Although the world is full of suffering, it is full also of the overcoming of it.

Helen Keller

Optimism, 1903
It is *our* job to be literate about our patients, who they are, what they want, and what they need

Training Resources on Communication skills

1. *Center to Advance Palliative Care*
   https://www.capc.org/membership/curriculum-catalogue/

2. *VitalTalk*
   http://www.vitaltalk.org/

3. *Serious Illness Care*
   https://www.ariadnelabs.org/areas-of-work/serious-illness-care/