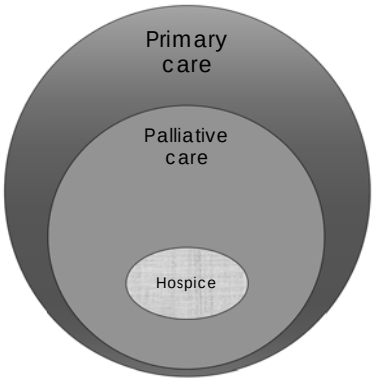
DEFINITIONS…




The NEW ENGLAND JOURNAL of MEDICINE

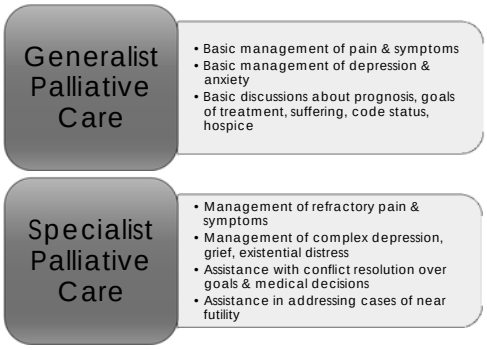
Perspective

Generalist plus Specialist Palliative Care — Creating a More Sustainable Model

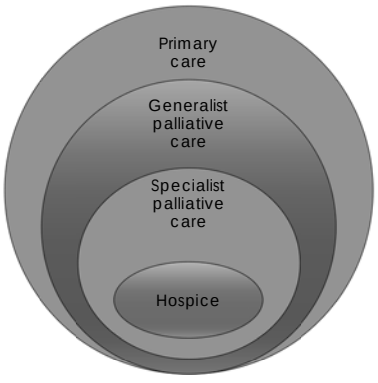
Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

Palliative care, a medical field that has been practiced informally for centuries, was recently granted formal specialty status by the American Board of Medical Specialties. The demand for palli- meeting, addressing veiled existential distress, and managing refractory symptoms. Now that the value of palliative care has been recognized, specialists are some-

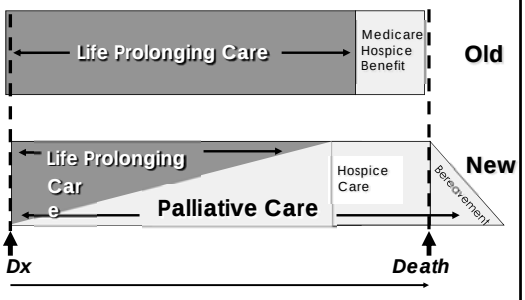
Quill TE, Abernathy AP. NEJM 2013



Quill TE, Abernathy AP. NEJM 2013



Conceptual Shift for Palliative Care



Source: Center to Advance Palliative Care, capc.org

WHAT IS "*PALLIATIVE CARE*"?

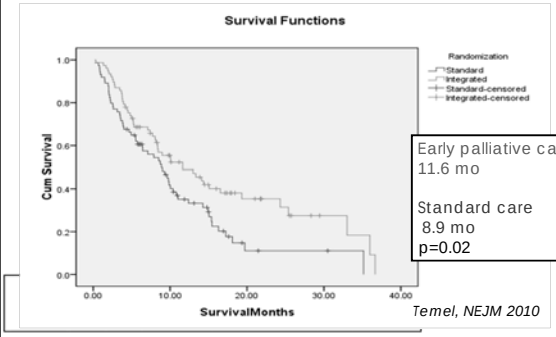
Old Thinking

- Death/Dying
- Failure
- "Giving up"
- End-of-life care

New Thinking

- Better quality of life, less stress
- "Extra layer of support"
- Creative problem-solvers
- Humanistic care
- Reduction of unwanted or harmful care
- Care across the continuum

Early palliative care improves survival in metastatic lung cancer



Early palliative care 11.6 mo

Standard care 8.9 mo p=0.02

Temel, NEJM 2010

RESOURCE UTILIZATION AT END OF LIFE

Measure	Standard Care N (%)	Early Palliative Care N (%)	*p*-value
Aggressive EOL Care	**30 (54)**	**16 (33)**	**0.05**
No hospice	22 (39)	15 (31)	
Hospice ≤ 3 days	5 (15)	1 (3)	
Chemo within 14 DOD	12 (24)	7 (18)	
Hospital/ER Admissions within 30 DOD	**31 (55)**	**19 (39)**	**0.12**
Days on hospice	**4 (0-269)**	**11 (0-117)**	**0.09**
Documented Resuscitation Preference	**11 (28)**	**18 (53)**	**0.05**

Zhang, Arch Int Med, 2009

MULTIPLE ISSUES CAUSING SUFFERING

Disease management	**Physical**	**Psychological**
Loss, grief		**Social**
End of life / death management	**Practical**	**Spiritual**

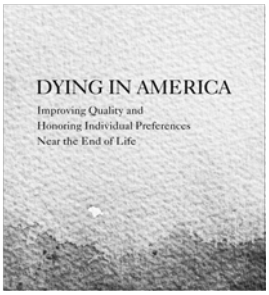
Cassel E. New Engl J Med 1982

ADVANCE CARE PLANNING

A LIFE-CYCLE APPROACH

"The advance care planning process can begin **at any age or state of health** and should center on frequent conversations with family members and care providers."

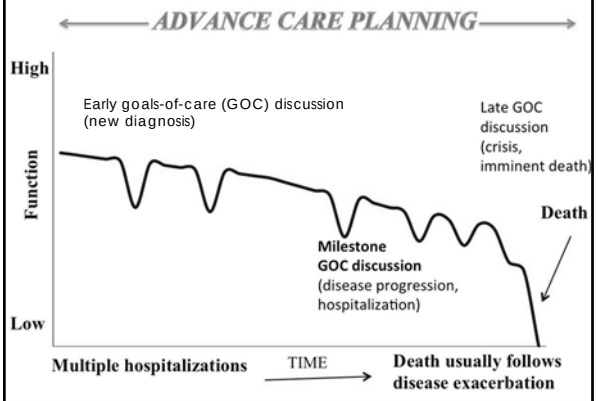
INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES



"I have an advance directive, not because I have a serious illness, but because I have a family."

Ira Byock, MD

The Best Care Possible, The Four Things That Matter Most, Dying Well



KEY DISCUSSIONS

Advance Care Planning

All adults

Health care agent

Big picture values

Specific desires

Serious Illness Conversation

Serious illness:

Current/future course

Goals in context to prognosis

Fears/concerns

CRITICAL CONVERSATION

The Family Meeting During Crisis

Life limiting/disease progress/dying:

Current/future course

Goals in context to prognosis

End-of-life planning:

✓ Goal-oriented treatments

✓ Code status/ICU/Hospice

"I'M AFRAID OF TAKING AWAY HOPE"

- Coping with Cancer Study:
  - Multi-site, prospective cohort study of advanced cancer patients and their informal caregivers (n=332 dyads) over 6 years.
  - No evidence EOL discussions were associated with increased emotional distress or psychiatric disorders.
  - EOL discussions a/w less aggressive medical care and earlier hospice referrals.
  - Surviving caregivers experienced less regret and better mental health during bereavement period if EOL discussion occurred.

Wright AA, et al. JAMA 2008

EOL DISCUSSIONS: NON-CANCER DIAGNOSES

Chronic Obstructive Pulmonary Disease

- After EOL discussions:
  - Twice as likely to rate 'best care possible' (p=0.04)
  - Twice as likely to be satisfied with the quality of their care (p = 0.02)
- 2/3 of patients wanted EOL discussions with their physician, but only 14.6% reported having these conversations.

End-Stage Renal Disease

- <10% of patients reported discussing prognosis or having EOL discussions in the previous 12 months.
- Almost 50% of patients wanted to have EOL discussion with their nephrologist.

Leung, Chest 2012 ; Davison, Clin J Am Soc Nephrol 2010

Ariadnelabs.org

ELEMENTS OF DIFFICULT CONVERSATIONS

- Invest in pre-work (clarifying medical facts, talking with consultants)
- Recognize goals of care as an evolving process – not a one-time event
- Make time in private setting
- Involve loved ones

Bernacki R, Block S. JAMA Intern Med 2014

DISCUSSIONS…

- Ask what they understand about their health
- Clarify and share information
  - "hope for the best, prepare for everything else"
- Listen and respond to emotion
- Explore priorities/goals, fears and worries
- Offer hope and options
- Make recommendations based on shared decision-making

DIFFICULT, BUT IMPORTANT, QUESTIONS

- "Given the severity of your illness, what is most important to you right now?"
- "How are you coping? How is your family coping?"
- "What gives you strength when you've gone through hard times?
- "What is your quality of life like now?"
- "How do you think about balancing quality of life with length of life in terms of your treatment?"
- "If you were to die sooner rather than later, what would be left undone?"

DISCUSSIONS…

- Reassure ongoing, excellent care and non-abandonment
- Make a plan for next steps
- **Document** and communicate across care settings

- Recognize our own need for self-care when being with suffering

DOCUMENTATION & STORAGE

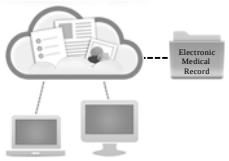
TODAY

Plans stored inconsistently in paper medical records or at the patient's home

Providers, family and friends not aware of person's end-of-life wishes

TOMORROW

Plans synchronized with the EMR



Patient shares plan electronically with family, friends and providers

PROCESS IMPROVEMENT

CASE STUDY: UMASS MEMORIAL

Opportunities

Patients
- Prepare patients
- Prompt them to discuss with family, PCP

Clinicians
- Train clinicians to have EOL conversation
- Trigger primary clinician to have the conversation

System
- Document in Electronic Medical Record
- Track quality metrics

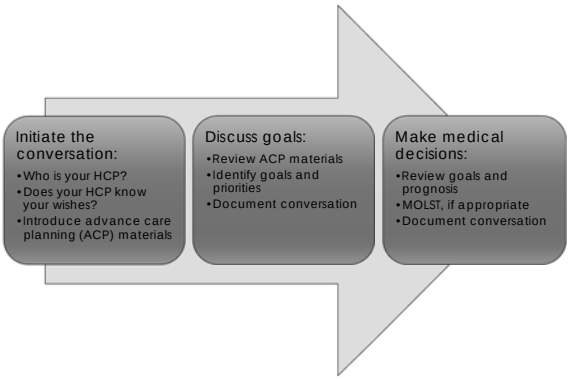
Strategies

Patients
- Online advance care planning (ACP) tool (umass.luminat.com)
- ACO care managers introduce concept of ACP

Clinicians
- Simulation training in goals-of-care conversations for hospitalists, residents, NPs
- ACO care managers trigger PCP re: conversation

System
- Epic transition: maximizing functionality and data tracking

OUTPATIENT WORKFLOW?



TOOLBOX

END-OF-LIFE CARE: HOSPICE

PCP'S ROLE IN HOSPICE

- Assess eligibility/needs, and recommend hospice
  - "the surprise question": would you be surprised if your patient died in the next six months?
  - Introduce by matching patient/family's needs to services hospice can provide
- Consult with hospice team if uncertain about eligibility and/or services provided
- Acknowledge the stigma and myths

PCP'S ROLE…

- Become part of the interdisciplinary team
- Collaborate primarily with hospice RN case manager to implement an agreed-upon plan of care
- After patient's death, care for bereaved loved ones who are also patients

THE HOSPICE BENEFIT

- Eligibility
  - ✓Patient elects to focus on symptom management over curative goals
  - ✓Patient's personal physician and hospice medical director certify that in their judgment, ***given the usual course of the disease,*** the patient has a life expectancy of six months or less

THE HOSPICE BENEFIT

- Reimburses at no cost to the patient if *related to the terminal diagnosis*
  - ✓Professional services of the inter-disciplinary team
  - ✓All tests and treatments
  - ✓All medications
  - ✓Durable medical equipment & supplies
  - ✓24/7 hotline for questions, emergencies

THE HOSPICE BENEFIT

- Settings of hospice care
  - Home
  - Skilled Nursing Facilities
  - Hospice Facility
  - Hospital
- PCP can remain the physician of record
- Patient can have access to other consulting physicians

HOSPICE MEDICAL DIRECTOR

- Works with the PCP and hospice team to understand the patient/family's priorities and goals
- Serves as consultant to treat refractory pain and symptoms
- Performs hospice eligibility consultations
- Becomes physician of record if requested by PCP.

THE HOSPICE BENEFIT

- Levels of Care
  - ✓Access to inpatient level of care for acute problems or imminent death
  - ✓Access to period of continuous home care
  - ✓Access to inpatient stay for family respite
- Bereavement services for 13 months after the death at no cost

THE HOSPICE BENEFIT

- Patient eligibility must be recertified every 2 – 3 months by the primary physician and the hospice medical director
- Program can be continued as long as diagnosis and 6 month prognosis exist
- Patient can revoke the benefit at any time and return to prior system of care

MEDICARE COVERAGE OF OTHER CONDITIONS

- Medicare continues to cover care and treatment for conditions other than the terminal illness

  Ex: 68 year-old woman with metastatic breast cancer and CHF goes to the emergency room in pulmonary edema
- Medicare Hospice Benefit covers hospice services for breast cancer
- Medicare A covers hospital care for CHF
- PCP and consulting physicians bill under Medicare B

HOSPICE VERSUS HOME CARE

- Hospice does not require patients to be homebound
- Hospice does not require a skilled need
- Interdisciplinary model of care
- Bereavement services
- Hospice covers pharmacy and DME costs related to the diagnosis

HOSPICE: TRUTH VS. MYTH

TRUTH	MYTH
Most insurances pay for IDT, meds, equipment, 24/7 hotline.	Hospice provides 24/7 live-in caregivers.
Hospice supports dying people & families at their emotional pace.	Patients must "accept" they are dying, & have a DNR order.
Hospice sees patients wherever they live.	Patients must be homebound.
Hospice collaborates with the PCP.	Patients must give up relationships with PCPs and other MDs.
Patients have "comfort packs" of sublingual meds for symptoms as needed.	Hospice hastens death with indiscriminate use of morphine.

Curing: making the problem go away.

Healing: giving people the resources to enjoy life when they cannot make the problem go away.

Rabbi Harold Kushner

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