Serious Illness Care in Primary Care

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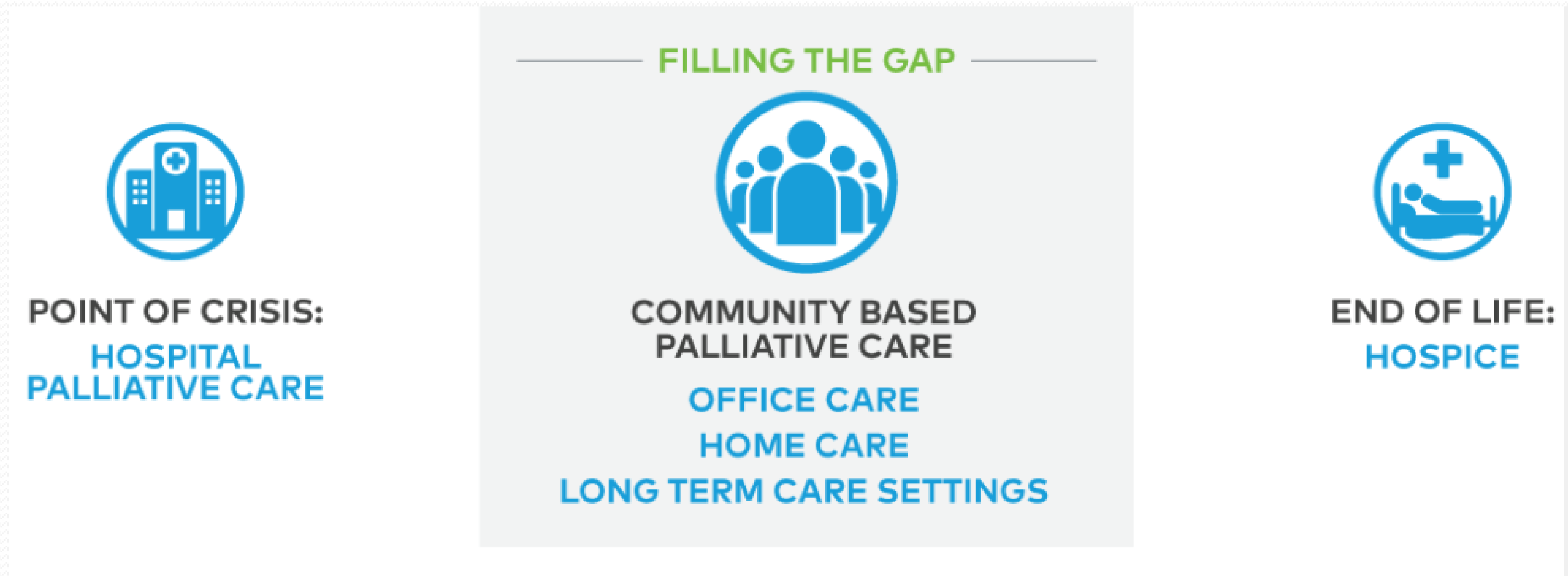
Touch on

- Intersection of Palliative and Primary Care
- What are some gaps in pc at primary care level?
- Suggestions - Policies, payment, people

Palliative care has historically been provided in the inpatient hospital setting or in hospice under the Medicare hospice benefit.



Palliative care historically has not been provided in other community settings, where the majority of patients living with serious illness would benefit from its availability.

But, its likely a good idea!

- Available data indicate that palliative care integrated into Primary Care can be both of high quality and cost effective even in a low-income country.
- This integration also may save money for health care systems and provide financial risk protection for patients' families by reducing dependency on hospital outpatient and inpatient services.

Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete X et al. On behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief: an imperative of universal health coverage. Lancet. Published online 12 October 2017; pii: S0140-6736(17)32513-8 (http://dx.doi.org/10.1016/S0140-6736(17)32513-8, accessed 17 March 2018).

Why should primary care clinicians play a role in palliative medicine?

- “I don't have that many patients who die.”
    - home hospice, nursing homes, intensive care unit
    - PCP does not feel herself to be on the front line of care of the dying is understandable.
- Yet – have <u>many</u> patients with chronic and life limiting illness
- Elderly and the bereaved (5%-9% of the population sustain loss of close relationship each year)

Overlap of Palliative Care with Primary Care

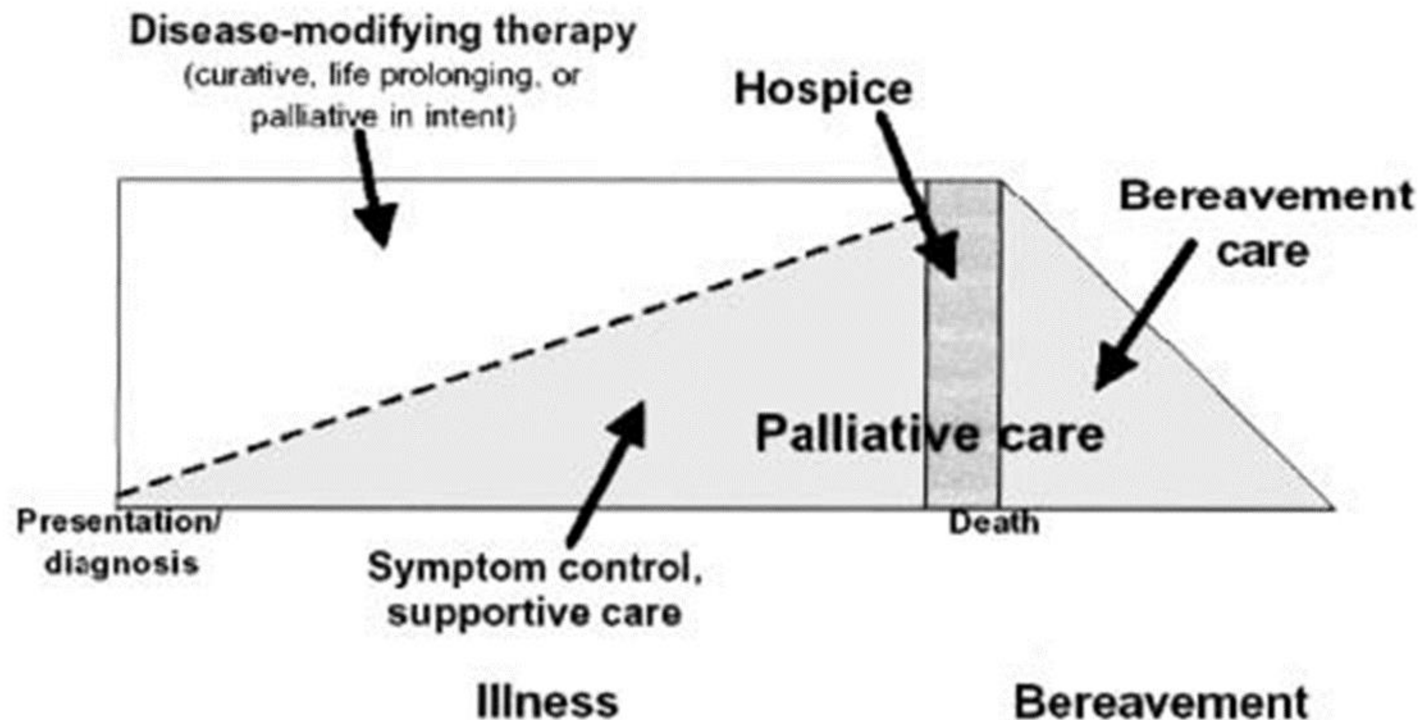
- Attitudes and competencies
- RELATIONSHIP-CENTERED Care
- Communication Skills
- Understanding the patient’s “life world”
- Comprehensive integrated care of patient and family
- Attention to psychosocial and spiritual concerns
- Emphasis on QOL and maximizing function
- Respect for patients' values, goals and priorities in managing illness
- Provision of care in the community
- Responding to cultural diversity
- Coordination and collaboration with other professionals

Primary Palliative Care

- ❖Critical role in guiding patients through the early phases of an illness that will eventually become terminal
- ❖Patient-physician communication and medical decision making that occur—or should occur—early in the illness.
- ❖Symptom assessment and management
- ❖Treating depression in seriously ill patients.

When? What?

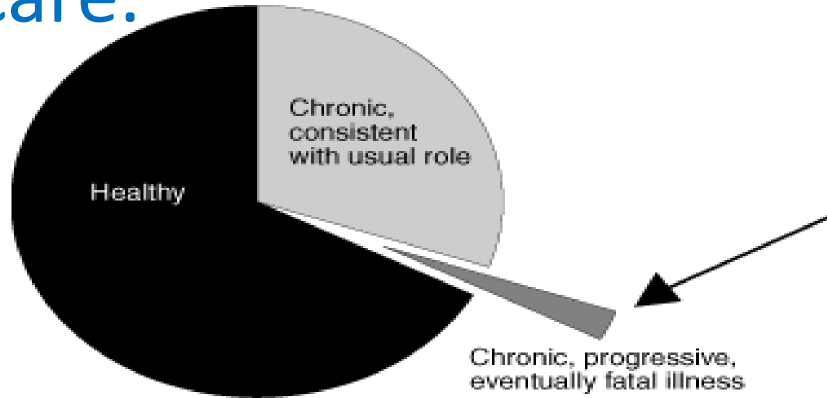
- The when is not so binary in primary care.
- “seek[ing] to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure.”

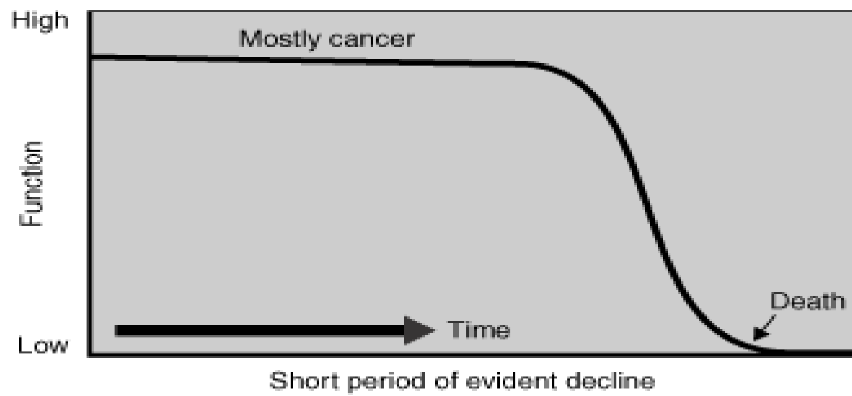


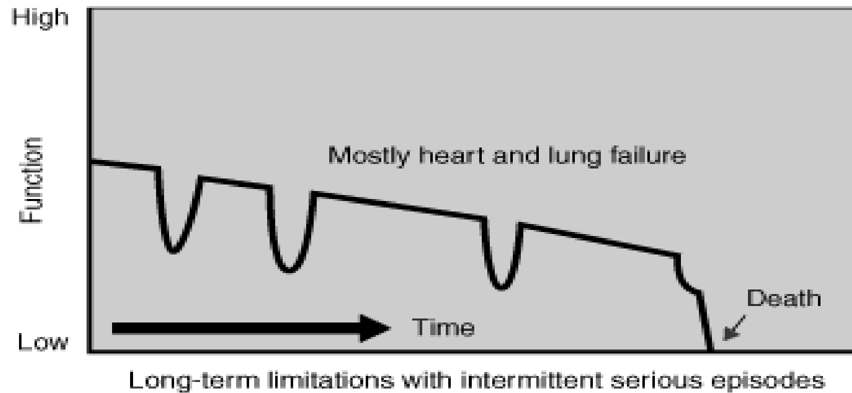
the essential skill is to recognize when key issues in palliative care present themselves, because this often occurs long before a specialized palliative care service (such as hospice) is involved.

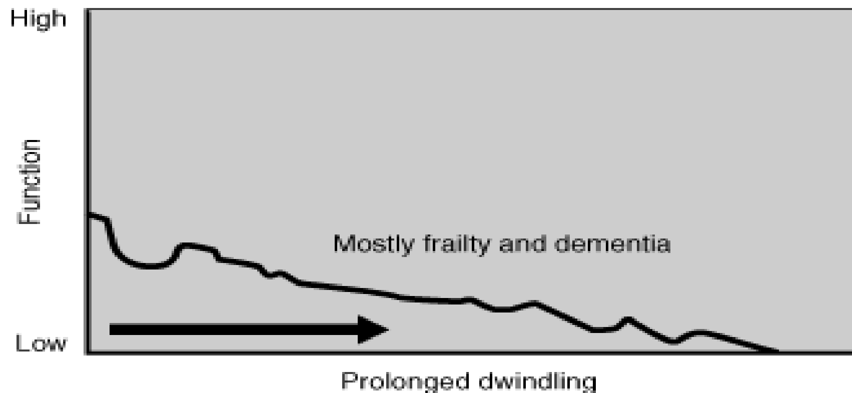
When?

Look for markers for when palliative care should become a central feature of standard medical care.









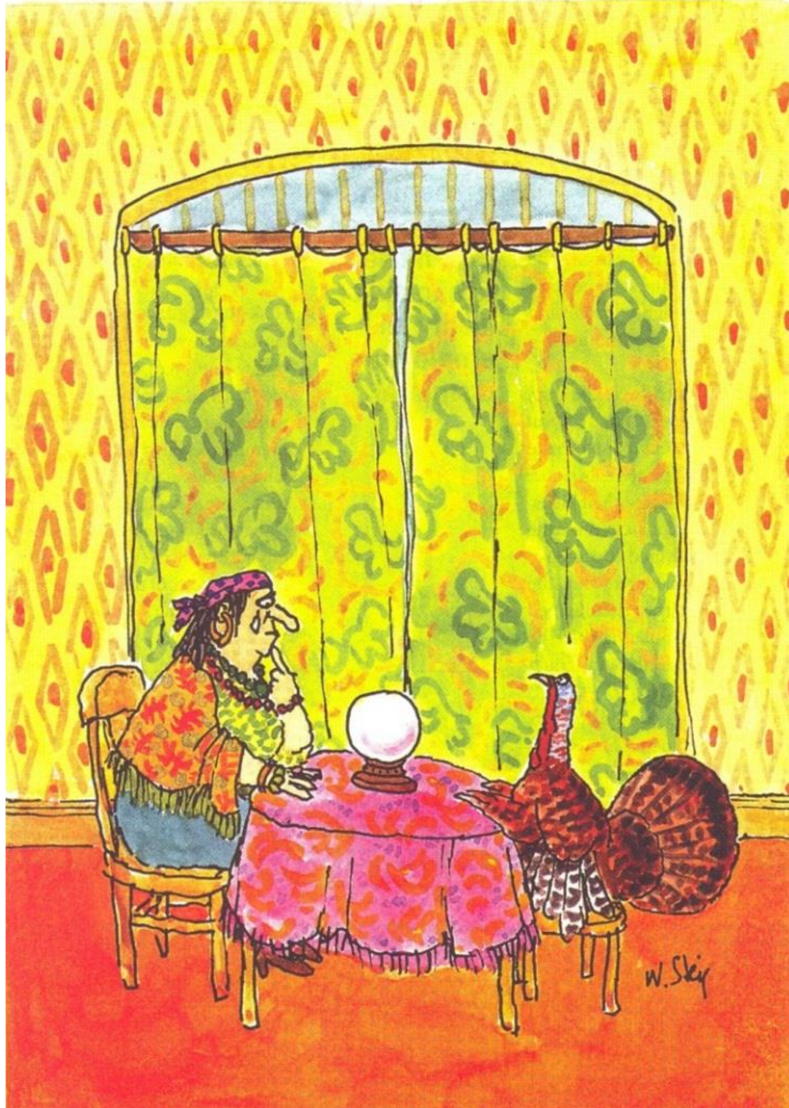
The prognostication problem.

Lunney JR et al. JAMA 2003;289(18):2387-92

"I'm right there in the room, and no one even acknowledges me."

Determining Prognosis

Why don't we do it?



- Fear extinguishing hope
- Feel we lack accurate tools
- Time-consuming
- Lack Education
  - Prognostic tools
  - Communication
- Hard place for lots of us to go
- Optimism and Avoidance

Majority Really Dislike Prognostication

Characteristic	Freq (%)
"Stressful" to make predictions	**60.4**
"Difficult"	**58.7**
Wait to be asked by patient	**43.7**
Believe patients expect too much certainty	**80.2**
Error will result in loss of patient confidence	**50.2**
Should avoid being specific	**89.9**
Inadequate training in prognostication	**56.8**

What do you mean, “terminal” ?

- What does it mean if physicians say the patient’s condition is “Terminal”? How many weeks to live on average?

- 13.5 +/- 11.8 weeks to live
  - Varied from 1 to 75 weeks
  - <4 weeks (28%)
  - Bimodal 68% <16 weeks (peak at 8 weeks)

    32% >/= 16 weeks (peaks at 24)

Adjusting for other factors, physicians with more years of practice held definitions of terminality that involved shorter expected survivals

How Good Are We?

HChristakis, NA. Extent and determinants of error in doctors’ prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000;320:469-473.

- At the time of hospice referral, MD asked for a Clinical Prediction of Survival
- Only 20% accurate (within 33%)

- Overestimated survival by a factor of 5! *(but consistently)*
  - Upper quartile of practice experience were the most accurate.
  - ***Increased duration of relationship meant decreased accuracy (!!!)***

Criteria for a PC Assessment

At the time of Admission

A potential life-limiting condition *and…*

- Primary Criteria (global indicators)
  - **The "surprise question" (SQ) – *You would not be surprised if the patient died within 12 months or before adulthood***

  - Frequent admissions
  - Admission for difficult-to-control symptoms
  - Complex care requirements (home vent)
  - Failure to thrive (function, nutrition, cognition)

When? How about now? Tap on the shoulder

BestPractice Advisory -

Research Recruitment (1)

Provider Feedback

Potential Research Study: Meta-LARC Advance Care Planning

Your patient has an ACP Score of 2 or 3, which indicates that he/she might benefit from advance care planning based on their age, co-morbidities, and/or hospitalizations. Your patient may also be a candidate for the Meta-LARC study Serious Illness Care Planning (SICP) conversation.

If you had an ACP(SICP) conversation with your patient today, please select "Send" to notify the Study team, allowing them to contact your patient about the Meta-LARC study.

If you are planning to have an ACP(SICP) conversation at a future clinic visit, please select the "Did not discuss with Patient" Acknowledge Reason.

Link to the Serious Illness Conversation Guide (SIC)

Send | Do Not Send | Send this advisory via In Basket

Acknowledge Reason

Did not discuss with Patient

Accept | Dismiss

Ok so now we know when. But What? Be the guide…

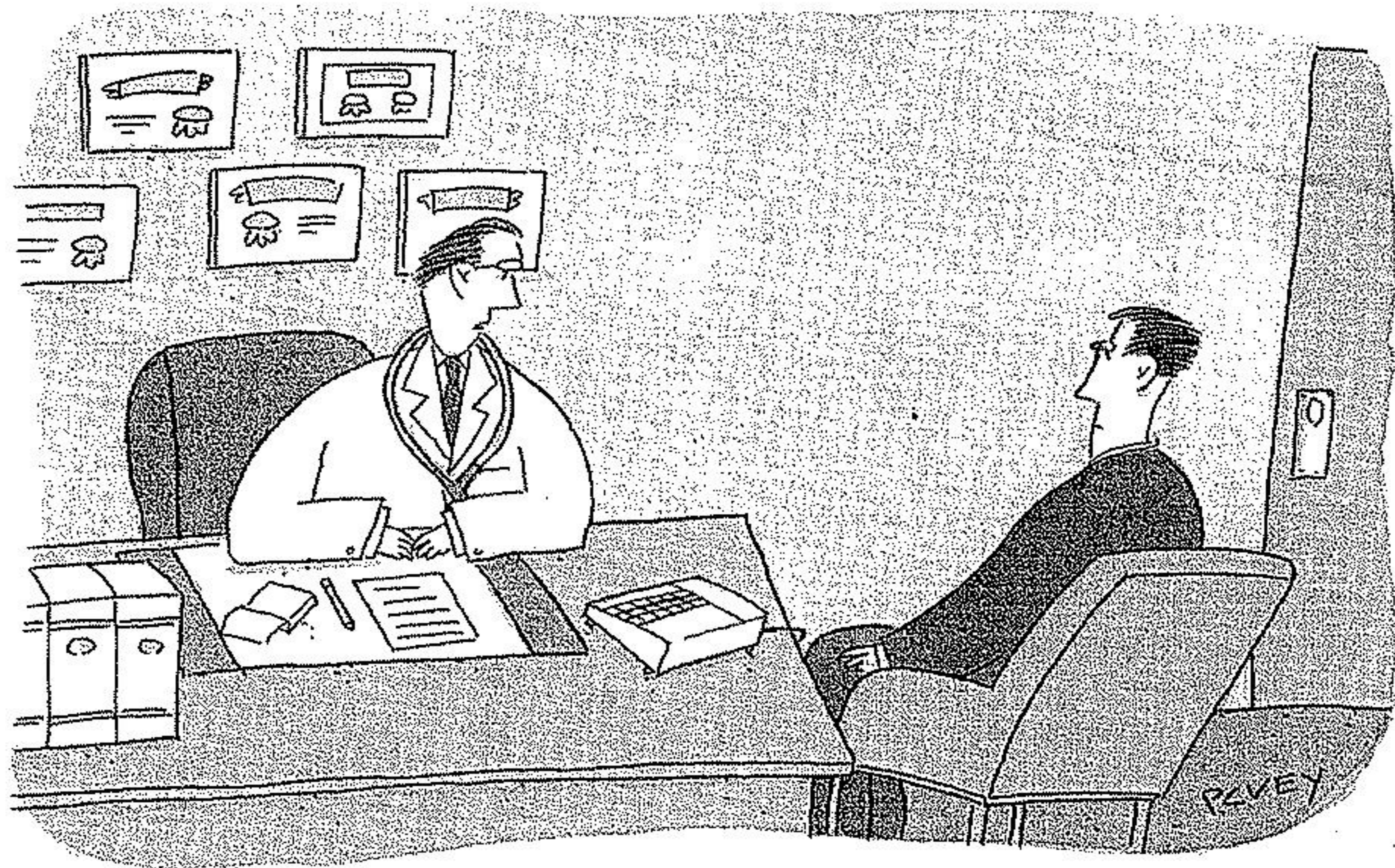
"It is thornlike in appearance, but I need to order a battery of tests."

PCP can know the system

- important role in ensuring that “the system” does not get in the way of personalized care.
- hospital-oriented care focuses on acute exacerbations of illness, rather than on an integrated approach incorporating preventive, curative, and palliative care.
- In SUPPORT trial, the strongest predictor of hospice use was the number of hospital beds in the region. (not patient prognosis or physician knowledge of patient preferences for end-of-life care)
  - more hospital beds- more in hospital deaths.
  - Primary care providers should remain alert to this powerful influence of care systems

What?

- Cognitive skills such as differential diagnosis or evaluating published evidence
- Comfort and confidence with symptom management
- Also requires affective skills, such as communication and emotional support

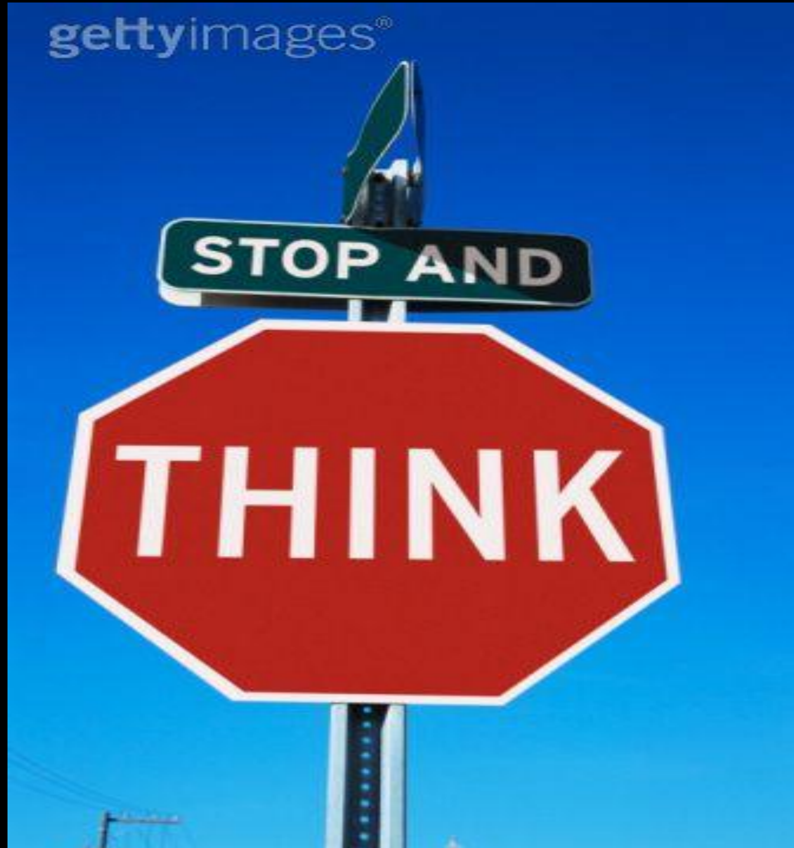


"There's no easy way I can tell you this, so I'm sending you to someone who can."

ROLL

STOP

WOULD I BE SURPRISED?



Take the catalog out of your bag!

DROP

- ASK: What do you understand about what is going on?

"What's the matter?" medicine vs.

"What matters to you?"

ROLL

(with the conversation and with the patient)

CORE FOUR

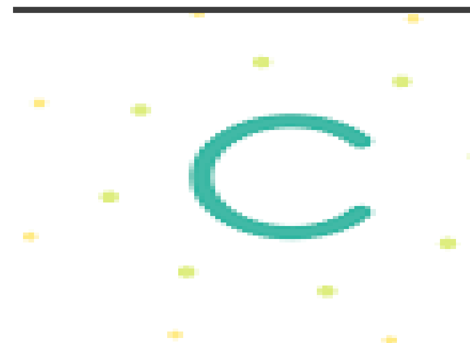
- Do they know their prognosis?
- What are their fears?
- What are their goals?
- What are the tradeoffs they are willing to make?

VITAL talk

Respecting Choices®
ADVANCE CARE PLANNING

Communication

ARIADNE LABS



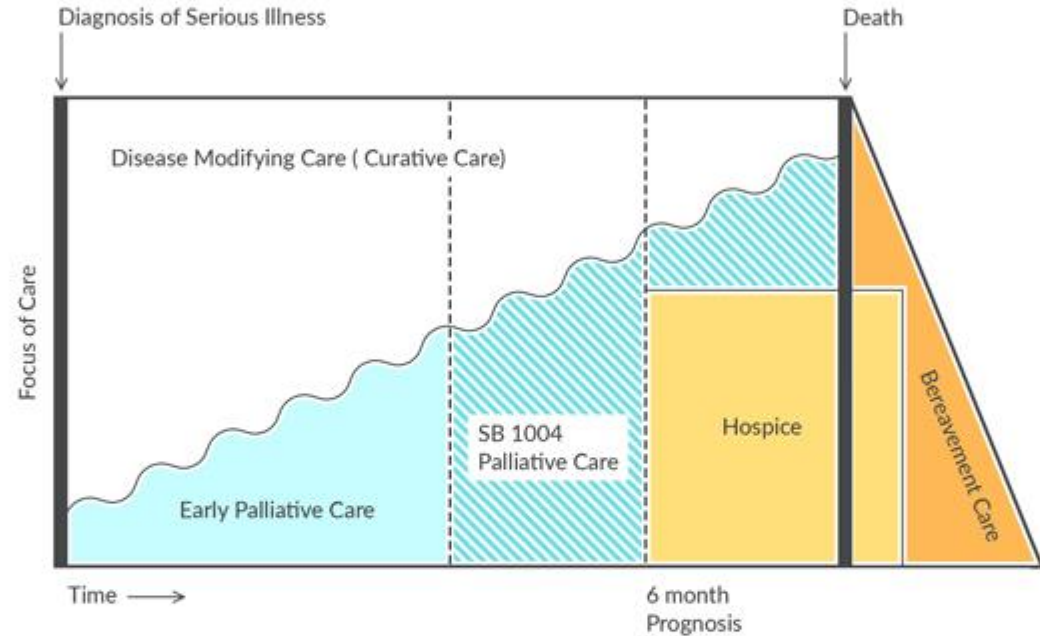
Communication
SKILLS PATHFINDER

The one-door portal for clinician
communication skills training

communication-skills-pathfinder.org

Making it happen- Palliation through legislation!

- SB 1004 (Hernandez, Chapter 574, Statutes of 2014) requires the Department of Health Care Services (DHCS) to "establish standards and provide technical assistance for Medi-Cal managed care plans to ensure delivery of palliative care service
- DHCS contracted with the California State University Institute for Palliative Care to fund palliative care training for qualified Medi-Cal providers and their clinician staff.



Task Sharing and Shifting

- Professional designation is less important than competencies
- Have been shown to be safe and effective ways to improve access to some PHC services. (hypertension diabetes mellitus, pre-natal, asthma, epilepsy, anxiety and depression, and screening for oral and cervical cancer)
- They can also include opioid therapy for moderate or severe pain due to advanced cancer by specially trained nurses and pharmacists.
- Thus, appropriately trained and supervised non-physician health workers, including CHWs, can have important roles.
- i.e Duke DOC project on ACP using SW

Expand the reach- using community health workers

- Ongoing care for patients with well controlled symptoms related to serious, complex or life-limiting health problems
- CHWs provide surveillance and emotional support as often as daily
- Visits as needed by a nurse, doctor, social worker or trained lay counsellor from the clinic with basic training in palliative care
- Nurse and possibly also a doctor, social worker or lay counsellor with basic training in palliative care provide outpatient care and possibly home visits as needed

Medical Orders for Scope of Treatment (MOST) form

HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Medical Orders for Scope of Treatment (MOST)

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. **When the need occurs, first follow these orders, then contact physician.**

Patient's Last Name:

Effective Date of Form:

Form must be reviewed at least annually.

Patient's First Name, Middle Initial:

Patient's Date of Birth:

Section A — *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ **Attempt Resuscitation (CPR)**

☐ **Do Not Attempt Resuscitation (DNR/no CPR)**

When not in cardiopulmonary arrest, follow orders in **B, C**, and **D**.

Section B — *Check One Box Only*

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **Full Scope of Treatment:** Use intubation, advanced airway interventions, mechanical ventilation, cardioversion as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. **Transfer to hospital if indicated.**

☐ **Limited Additional Interventions:** Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation or mechanical ventilation; also provide comfort measures. **Transfer to hospital if indicated. Avoid intensive care.**

☐ **Comfort Measures:** Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in current location.**

Other Instructions ____

Section C — *Check One Box Only*

ANTIBIOTICS

☐ **Antibiotics if life can be prolonged.**

☐ **Determine use or limitation of antibiotics when infection occurs.**

☐ **No Antibiotics** (use other measures to relieve symptoms).

Other Instructions ____

Section D — *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: Offer oral fluids and nutrition if physically feasible.

☐ **IV fluids long-term if indicated**

☐ **IV fluids for a defined trial period**

☐ **No IV fluids** (provide other measures to ensure comfort)

☐ **Feeding tube long-term if indicated**

☐ **Feeding tube for a defined trial period**

☐ **No feeding tube**

Other Instructions ____

Section E — *Check The Appropriate Box*

DISCUSSED WITH AND AGREED TO BY:

Basis for order must be documented in medical record.

☐ Patient

☐ Parent or guardian if patient is a minor

☐ Health care agent

☐ Legal guardian of the person

☐ Attorney-in-fact with power to make health care decisions

☐ Spouse

☐ Majority of patient's reasonably available parents and adult children

☐ Majority of patient's reasonably available adult siblings

☐ An individual with an established relationship with the patient who is acting in good faith and can reliably convey the wishes of the patient

MD/DO, PA, or NP Name (Print):

MD/DO, PA, or NP Signature (Required):

Phone #:

Signature of Person, Parent of Minor, Guardian, Health Care Agent, Spouse, or Other Personal Representative
(Signature is required and must either be on this form or on file)

I agree that adequate information has been provided and significant thought has been given to life-prolonging measures. Treatment preferences have been expressed to the physician (MD/DO), physician assistant, or nurse practitioner. This document reflects those treatment preferences and indicates informed consent.

If signed by a patient representative, preferences expressed must reflect patient's wishes as best understood by that representative. Contact information for personal representative should be provided on the back of this form.

You are not required to sign this form to receive treatment.

Patient or Representative Name (print)

Patient or Representative Signature

Relationship (write "self" if patient)

SEND FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED

- More than a DNR order
- Guide care even when patient has not arrested
- Options to receive or withhold treatments
- Avoid inappropriately limiting or providing other types of treatments

MOST is . . .

https://www.wakeahec.org/CourseCatalog/CASCE_courseinfo.asp?cr=40327

- Optional
  - Won’t work for everyone
  - Another instrument to help honor patient wishes
- Identifiable
  - Bright pink color
- Flexible
  - Accept or reject medical treatments
  - More than resuscitation preferences
- Portable
  - Travels with the patient
  - Directs care in a variety of settings
- Medical Order
  - Immediately directs care
- Reviewed Regularly
  - Annually
  - Changes in health status
  - Admissions/discharges
  - Changes in preferences

Teaching it forward

IV.B.1.e).(2) Residents must learn to communicate with patients and families to partner with them to assess their care goals, including, when appropriate, end-of-life goals. (Core)

IV.C.7. Residents must have at least 100 hours (or one month) or 125 patient encounters dedicated to the care of the older patient. (Core)

Does not specify how

Incorporating Palliative Care into Primary Care Education

Susan D. Block, MD, George M. Bernier, MD, LaVera M. Crawley, MD, Stuart Farber, MD, David Kuhl, MD, William Nelson, PhD, Joseph O'Donnell, MD, Lewis Sandy, MD, Wayne Ury, MD, for the National Consensus Conference on Medical Education for Care Near the End of Life

- Each medical school needs coherent plan for teaching palliative care in primary settings.
- Oversight body responsible for reviewing PC content in curriculum
- Primary Care conferences and CME should include palliative care as core content
- Faculty development programs i.e. Project on Death in America Faculty Scholars, MCW, Harvard med school division of medical ethics
- Promote linkages of community hospices as educational settings

"I was able to get in one last lecture about diet and exercise."

Suggestions

1. Prognostication- Encourage use of markers for when palliative care should become a central feature of standard medical care.
   - ❖ Data analytics to identify patients with high need. Use BPA or lists to providers
   - ❖ Criteria for automatic eligibility for higher levels of service (i.e. acp visit, navigator, home based services)
2. Communication skills- Incentivize or require additional training and facilitate funding for technical assistance.
3. Legislate to ensure availability of services and to enhance technical support (ie. Medi-Cal)
4. Reimbursement for interdisciplinary home based services.
5. Foster Team based care- Support interprofessional approaches to broaden the personnel and skill sets involved in primary care for serious illness. (i.e. support home based services, ACP activities billable even if carried out by qualified RN/ SW/NA)
6. Efficiency vs empathy- Value based contracts allowing for more time with patients.

Suggestions, cont'd

7. Promote and Incentivize behavior- Measure, Report and Reward (% of appropriate patients with ACP on file, benchmark DSR, symptom scores or other patient reported quality measures such as QOL.)
8. MOST form portability- require uniform acceptance? MOST form education- require evidence of training for licensure/registration- (like opioid CME)
9. NCAFP and other professional organizations include pc topics on CME / conferences.
10. integration of basic training in palliative care into undergraduate medical, nursing and pharmacy training.
11. GME- encourage adoption of WHO practices and requirement of hospice/palliative care experiences.
12. Promote/Reimburse Utilization of technology (telemedicine, project Echo) to enhance access to specialist palliative care consultation and education.
13. Needs assessment- Inventory of statewide community based palliative care services
14. Continued study of most effective means of integration. MetaLARK study (team vs provider), Dr Kimberly Johnson ACP study- PCORI

Thank you!

Go Heels!