The Art of Prognosis: when to ask for hospice

Hospice of the Valley w/
Decatur General Hospital
Decatur, AL

Dr. Robert Webb, MD, ABHPM

Medical Director of Hospice of the Shoals, & of the Palliative Care Service of ECM Hospital, & for Glenwood Rehab

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Outline

1. Definitions: hospice v palliative care
2. Prognosis: why do we need to know it
3. Regulations & Myths governing Hospice
4. Hospice Eligibility: general
5. Cancer Diagnoses & Prognosis
6. Non-Cancer Diagnoses & Prognosis
7. Summary & Pearls

1. Definitions

Hospice: A Medicare benefit providing palliative care* for those certified with a terminal disease and less than 6 mo. to live if the disease "runs its usual course".

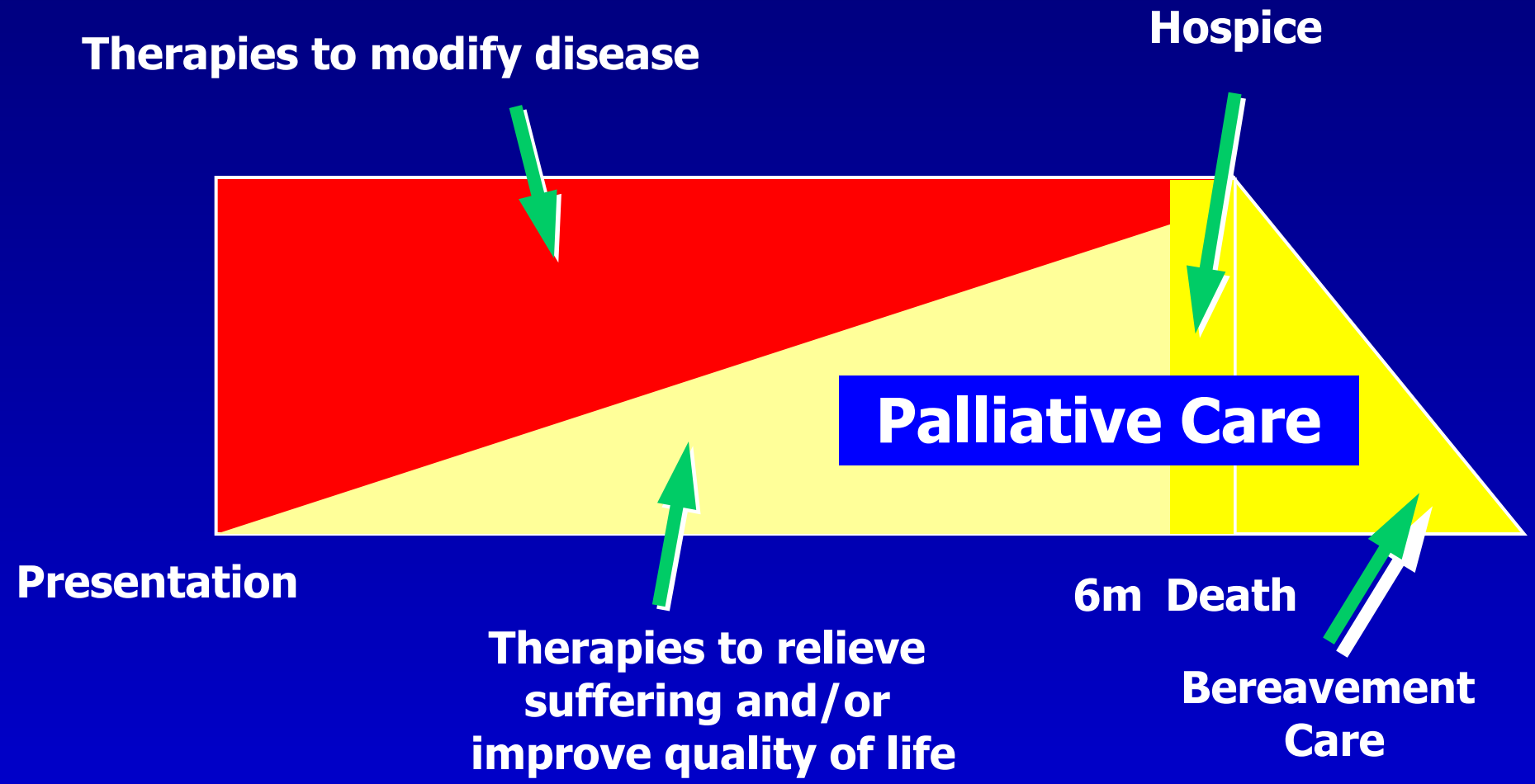
– It is "palliative care for the last 6 mo. of life."

*Palliative care is interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families.

- It can be offered while receiving usual appropriate medical curative therapies, and

- is NOT only for those who are dying [that's *hospice*]

Palliative Care's Place in the Course of Illness



Palliative Care is Comfort-focused

1) Helps patients clarify their goals in the face of a LLD*, to make informed decisions and avoid non-beneficial treatments; which…
2) Improves their quality of life so they can live comfortably (soothing symptoms) as long as possible; and then,
3) when they are at the very end of life, PC ensures a natural death w/ comfort and dignity.

*LLD = Dementias, cancers, end-stage organ disease (e.g. lung/ heart/renal/liver), ALS, AIDS

PC & Hospice Benefits

- PC does NOT accelerate dying
  - Cost Savings Impact Study 2009 at ECM
    - patients in both the control group (94%) and the PC consult group (100%) died in the same 12 mo.

and…

- PC improves survival & QOL in lung cancer
  - Patients receiving chemotherapy and PC lived 3mo longer (11.6mo v 8.9mo) than those on just chemoRx. *[Temel. NEJM 2010.]*

and…

…PC & Hospice Benefits

- Cancer pts who discuss EOLC wishes w/ MD have better QOL and lower costs in final wk of life
  - Less aggressive care/admissions to hospital
  - Improved QOL w/ more peaceful death

  ** Zhang B. Health care costs in the last week of life. Arch Intern Med. 2009*
- **Pts who choose hospice live ~29 days longer than those not in hospice**

  ** Connor S. Comparing hospice & non-hospice patient survival among patients who die within a three-yr window. J Pain Symptom Manage 2007*

Why so beneficial?

Implementing PC principles can help to…

- Stop all/most non-comfort tx/meds
- Aggressively control symptoms which helps them to feel better and eat/socialize/exercise more and fight illness
- Encourage patient/family-driven goals
  - Avoid futile/unnecessary treatment & hospitalizations
- Encourage EOLC planning
  - helps accept limits to life

  [that confronts the *illusion of certainty*…]

Historically, always had PC:

Physician's Traditional Role = PC

- To cure sometimes
- To relieve often
- To comfort always

- anonymous 16th century aphorism [?Hippocrates]

A Purpose of Palliative Care & Hospice: avoid "Futile" Care!

Futile Care is:

- "when desired goals not met or desired results cannot be achieved" [qualitative], or
- "clinical care that has a <1 - 5% chance of survival" [quantitative]

[Davila F. The infinite costs of futile care… Physician Exec. 2006.]

[Schneiderman L. Beyond futility to an Ethic of Care. Am J Med. 1994; 96:110-14.]

Avoid Futility: Goal Focused Care

If the goal of medicine is:

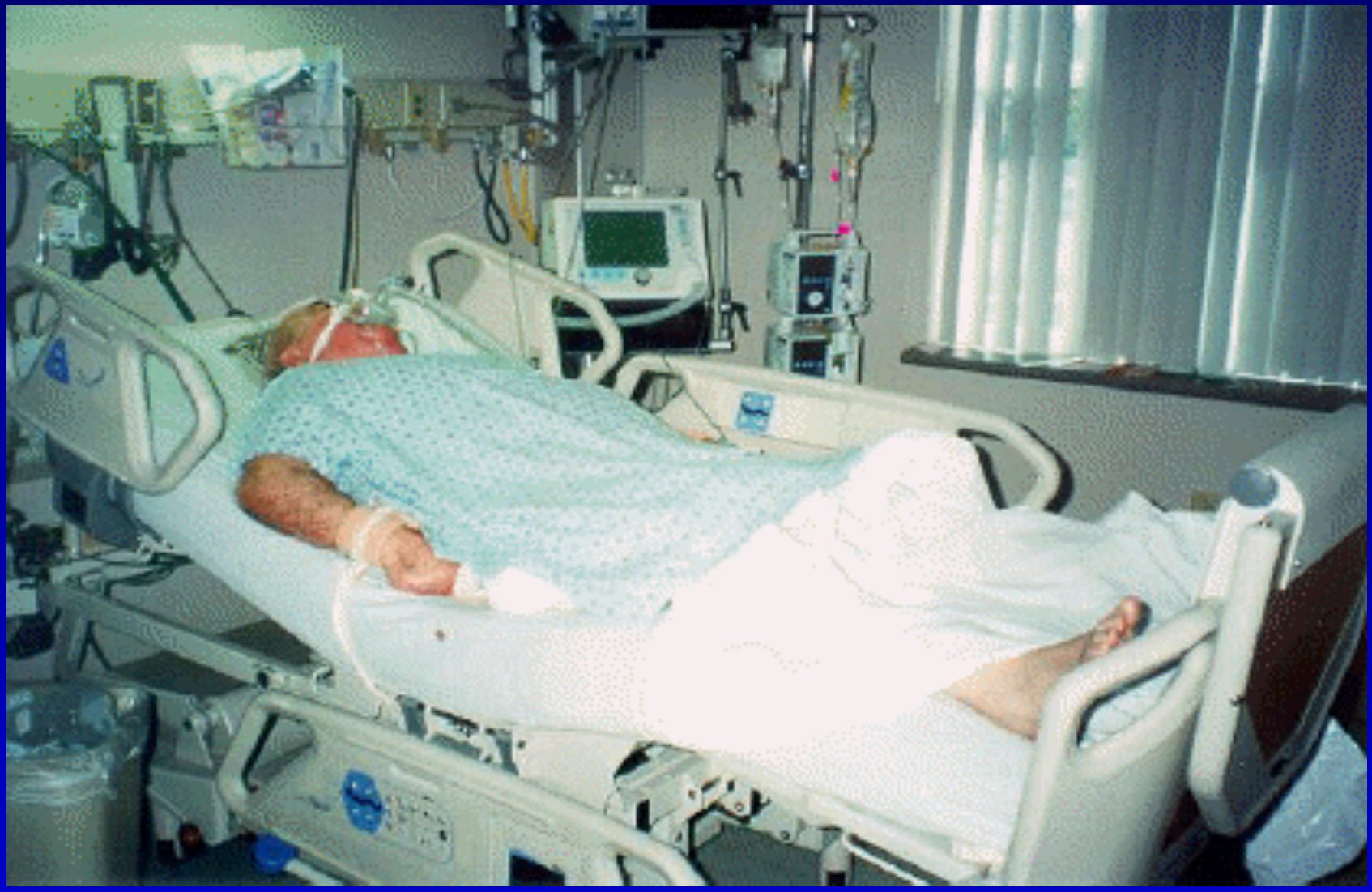
- to prevent and relieve suffering!

Knowing Prognosis can help preserve Hope while avoiding Futile Care

Avoiding Futile Care - cont'd

- Should Never Hear "There's nothing more we can do" !!!!
- Base choices on Goals
- False hope is worse than 'no hope' !
- Never lose HOPE – that at least good will come from decisions; that no one will be abandoned

Futility – how do you want to die?



Decisions Summary: How to Avoid Futile Care & Prevent Suffering

1) Clarify status of conditions and prognosis
2) Determine goals – longevity v comfort
3) Explain the options & risks (for comfort related information go to comfortcarechoices.com) – make an informed choice
4) Make a recommendation…

2. Prognosis: Definition & Why

- a forecast of the probable course and outcome of a disorder. *[Dorlands]*

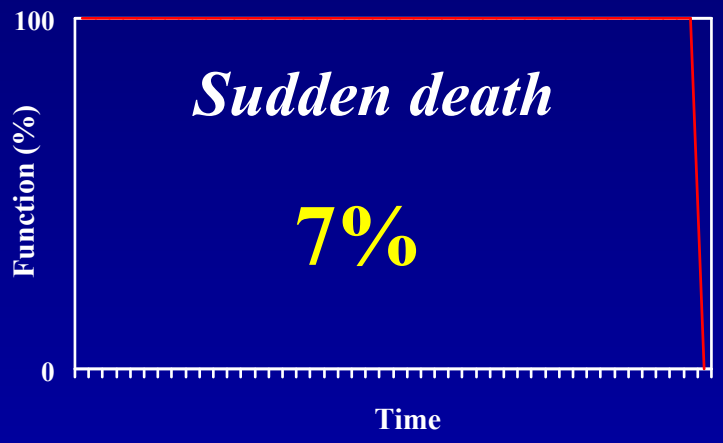
- Root word = "fortune telling" or "knowledge of the future" [*nosis*]
- Biblical reference: Psalm 39:4 "Lord, make me to know mine end, and the measure of my days; that I may know how frail I am."

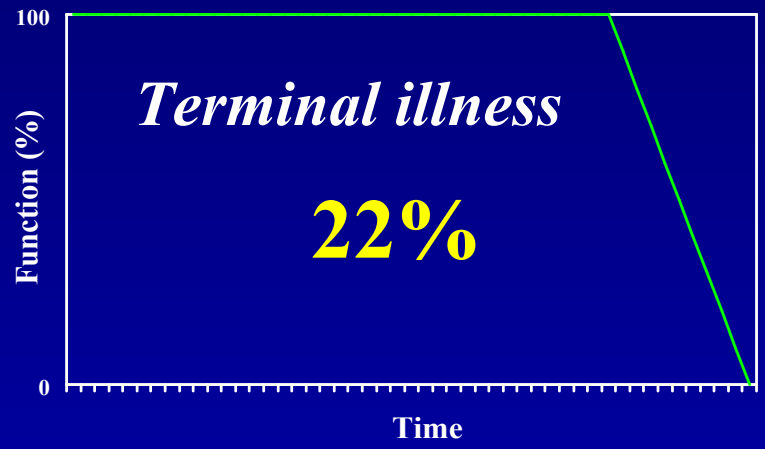
Prognosis: When is an illness "terminal" ?

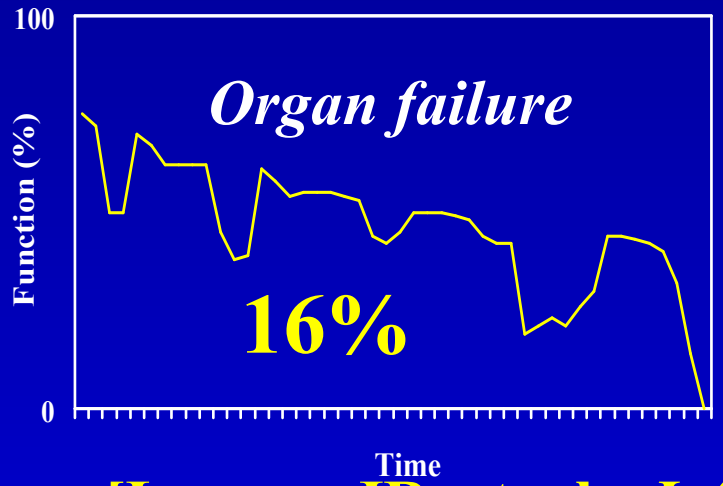
- "Terminal" = incurable + progressive + prognosis <6-12mo

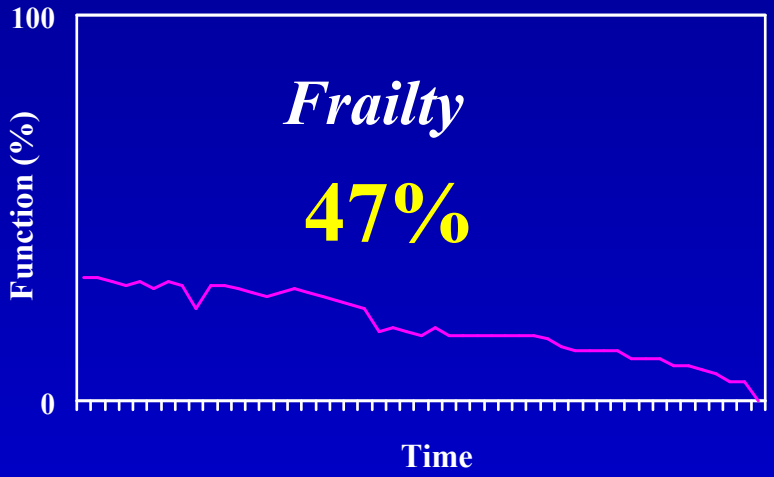
- Pattern of dying has changed over the years
  - 1900: 90% died quickly, from infections or accidents
  - 2011: only 10% die quickly; 90% die of "chronic" diseases

Terminal Trajectories









[Lunney JR, et. al. *J Am Geriatr Soc* 2002;50:1108-12]

Time of Death/Prognosis Myths

- Myth #1: It doesn't matter what we do because people will die 'when God decides'

- Reality: Medical technology:
  - has created situations which keep people alive;
  - often causes suffering and prolongs dying;
  - now requires us to make decisions re medical 'interventions':
    - IV's, PEG's, Vents, abx, ICD's,
  - Are families and doctors 'playing God' by interfering?

…And

- Myth #2: doctors cannot predict death or outcome with any reasonable certainty

- Reality: for many patients, an educated estimate can provide helpful guidance…

Why do we need to know prognosis?

1) Administrative/insurance reasons
2) Medical decision making by physicians
3) Patient/family decision making
   - Avoid “abandoning”

1) Why: *administrative* reasons

Prognosis determines eligibility for funded services (Medicare's definition of hospice):

"an individual is considered to be terminally ill if the medical prognosis is that the individual's life expectancy is six months or less if the illness runs its normal course."

2) Why: *medical* decision making

Knowing prognosis helps:

- providers determine what treatment options to offer and what advice to give.
- change focus to 'whole person' – not just a diagnosis for one damaged organ

One of the traditional duties of a doctor

- diagnosis, etiology, treatment, prognosis

…knowing prognosis may avoid Non-Beneficial or Futile Care

- Because technology has created situations:
  Providers now face decisions of "how many and what kind of interventions are needed"
- During EOLC, we can be primary cause of suffering or, primary cause of its relief !

3) Why: *patient* decision making

Knowing prognosis allows for patient & family to make more informed choices, related to:

- Medical issues [such as side-effects]
- Financial concerns
- Social & cultural situations
- Personal values
- End-of-life planning

Informed Decisions/choices Example

- 78 year old woman w/ Alzheimer's
- Prognosis: terminal – avg = 4.5yrs
- Values: dignity and comfort and knowing family as long as possible
- Advance Directive: no *artificial* support
  - Wanted "M&M's" only
  - Developed pneumonia – no antibiotics !

Personal Values: avoid futile care & abandonment?

"… they saw finally that in their attempt to help they had not helped but only complicated his disease beyond their power to help. … Loving him, wanting to help him, they had given him over to "the best of modern medical care"—which meant, as they now saw, that they had abandoned him."

– Wendell Berry, *Fidelity*, 1992

How good is prognostication?

- Several prognosis/performance scales
  - Karnofsky score
  - Palliative Performance Scale
  - ECOG [Eastern Cooperative Oncology Group]
  - Disease specific scales
- Physician accuracy & judgment
  - "would you be surprised if this patient were still alive in 6-12 months?"

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity level Evidence of disease	Self-care	Intake	Level of consciousness	Estimated median survival in days (a)	(b)	(c)
100	Full	Normal *No disease*	Full	Normal	Full	NA	NA	108
90	Full	Normal *Some disease*	Full	Normal	Full			
80	Full	Normal with effort *Some disease*	Full	Normal or reduced	Full			
70	Reduced	Can't do normal job or work *Some disease*	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework *Significant disease*	Occasional assistance needed	As above	Full or confusion	29	4	
50	Mainly sit/lie	Can't do any work *Extensive disease*	Considerable assistance needed	As above	Full or confusion	30	11	41
40	Mainly in bed	As above	Mainly assistance	As above	Full or drowsy or confusion	18	8	
30	Bed bound	As above	Total care	Reduced	As above	8	5	
20	Bed bound	As above	As above	Minimal	As above	4	2	6
10	Bed bound	As above	As above	Mouth care only	Drowsy or coma	1	1	
0	Death							

ECOG Staging (Cancer only)

- Metastatic [i.e. Stage IV] and failed chemoRx
- Eastern Cooperative Oncology Group
  - Stg I - ambulatory, active, mild symptoms
  - Stg II - in bed <50% of day, more symptoms
  - Stg III – in bed >50% of day [= 3-6mo. survival]
  - Stg IV – bedridden, total care [= <3wks avg survival]
- III & IV: usually have symptoms: losing wt, dysphagia, anorexia, dyspnea, dry mouth

Prognosis Accuracy Poor

- Physicians are poor prognosticators
  - Accurate only 20% of the time
  - 63% overly optimistic

  Why? - fear of withholding hope
  - death is the 'enemy'
  - lack of experience = *uncomfortable*

[Christakis. BMJ 2000;320][Benkendorf. Prehosp EmCare 1997]

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

Do people want to know prognosis?

- 80% patients want to know [from their doc]
- Many doctors won't give an estimate
- Tend to be overoptimistic [factor of 5]
- Population-based stats often not helpful when determining prognosis for individual

Christakis NA. Death Foretold: prophesy and prognosis in medical care. 1999. Univ. Chicago Press.

Fine JW. The Art of Prognosis. Hospice of Michigan.

What do Patients & Families with Serious Illnesses Want [i.e. their goals?]

- Pain and symptom control
- ***Avoid prolongation of the dying process***
- Achieve a sense of control, & Hope
- "Beat the prognosis"
- ***Included in decisions & to be listened to***
- ***Honest information***
  - Everyone wants adverse event info [1/100,000 - Ziegler. Arch Intern Med 2001]

* *Singer et al. JAMA 1999;281(2):163-168.*
* *Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics*

3. Hospice: Regulations + Myths

Admissions:

- Pt must be evaluated within 48hrs of referral
- Primary doctor & medical director must sign

Certifications [i.e. that <6mo life expectancy]:

- Initial certification (90 days) by PMD & M.Director
- 2nd 90 day recert by M.Director
- 3rd recert (@ 180days, for next 60days) requires face-to-face visit by M.Director [or CRNP]
- Subsequent recerts q 60days – "unlimited"
- Must include written narrative

Hospice Regs

Discharges:

- Patient must be discharged if not declining or not likely to die in next 6mo.
  - Patient/family can appeal discharge [AQAF]
- Patient can 'revoke' hospice at any time
  - To go with another hospice; or moving;
  - To resume 'curative' therapies

Hospice Regs

- NOT required to provide 24hr personal care
- Usually doesn't cover "non-terminal" therapies or drugs
- In NH, hospice responsible for POC and must ensure NH staff oriented to hospice
- Obligated to provide grief support for 13 months after the death

Myths about Hospice

Myths:

i. There are ‘two’ kinds of hospice
ii. Patient must have DNR [AND]
iii. They cannot be admitted to hospital
iv. Patients must be discharged if they don’t die in <6mo.

Hospice Realities/Facts

i. Only 'one' kind of treatment hospice
   - there are "Not-for-profit" & "For-profit" businesses

ii. Patients do not need a DNR/AND
   - But, mixed messages - false hope - ?fraud

iii. Patients can be admitted to hospital
   i. Hospice related dx
   ii. Non-hospice problem

iv. After the initial 6 mo. certification, if the doctor believes death will still occur within the next six months, patients can continue in hospice

4. Hospice General Eligibility *

- Medicare beneficiary, entitled to Part A;
  - Or: have another insurance contract; indigent
- Certified as having life expectancy <6mo "if illness runs its normal course." [by PMD and hospice Medical Director]
- Patient waives rights to all curative care for the terminal illness

* *Eligibility and Guidelines for Determining Prognosis taken from NHPCO*

When to ask for Hospice?

- Estimated life expectancy less than 6 mo + criteria present
- Cure no longer possible or made decision to stop attempted cure
- Symptoms [e.g. pain, shortness of breath] not controlled and hoping to relieve suffering - "tired of fighting it"
- Don't leave it "too late"
  - 35% patients die in <7days from admission *[2008]*

Hospice Eligible Diseases

- Cancers
- ALS [Amyotrophic Lateral Sclerosis]
- CVA [Stroke & Coma]
- Dementia
- General Debilitation
- Heart
- HIV/AIDS
- Lung
- Liver
- Renal

5. Cancers: prognosis & eligibility

- When to begin hospice, determined by individual cancer prognosis, and by speed of decline in ADL's

Factors affecting Prognosis:

Comorbid conditions:

- Age, ADL's, CV disease, DM2, nutrition

Tempo – speed of progression

Agendas – non-acceptance, mistrust, costs

Will to live vs 'given up' ?

Family expectations – 'cure' vs 'comfort only'

Intuition

Cancer Prognosis <6mo if:

- Malignant hypercalcemia [S. Ca++ >11]
- Extensive liver mets/failure
- Malignant pleural effusion
- Brain mets [usual = <8mo]
  - Rx steroids only = 1-2mo
  - Rx WholeBrain Rtx = 3-6mo
  - Rx Surg + RTx = 10-16mo?

Three common cancers

Cancer	5 year survival
• Lung	1% (distant mets)
•	13% (overall)
•	35% (localized)
• Breast	18% (distant)
•	75% (overall)
•	90% (early stage)
• Prostate	31% (distant)
•	73% (overall)
•	85% (localized stage)

[Davita]

Examples of "Curable" Advanced Malignancies

Malignancy	5 Year Survival
• Acute myeloid leukemia	23%
• Stage IV Hodgkin's lymphoma	56-89%
• Stage IV aggressive non-Hodgkin's lymphoma	44-87%
• Testicular germ cell tumors	48-91%
• Colon cancer, resectable solitary liver metastasis	25%

Metastatic Cancer Patient Survival with Treatment

Cancer Type	1 Year	Median* (mo.)
• NSCLC	33-51%	7 – 31
• Breast	~70%	23 – 26
• Prostate (Hormone refractory)	~70%	7 – 40
• Colorectal	36%-40%	18 – 24
• Pancreatic	27%	6 – 12

*Median survival data from optimal treatment in clinical trials

6. Non-Cancer Diagnoses: prognosis & eligibility *

- Prognostication much more difficult than with cancers
- Need to adhere to national guidelines/ criteria *
  - Avoid potential OIG investigation and charges

[from NHPCO guidelines]*

Non-Cancer Diagnoses Prognosis

Important factors for <6mo:

- ADL's – progressive debilitation
  - Assistance for all ADL's
- Recurring hospitalizations
- Disease-specific considerations
  - Less accurate than with cancers

Will cover 3: *dementia, gen. debilitation, pulmonary*

[look on website for others, or handouts]

Eligibility: ALS (Lou Gehrig's Disease)

Must fulfill 1, 2, or 3.

1) Impaired breathing [all present in prior 12mo]
   - VC <30%;
   - Dyspnea at rest;
   - declined ventilator
   - O2;
2) Rapid progression of ALS & nutrition [all present]
   - From independent walk & ADL's to w/c or BB + assist
   - Normal speech to barely intelligible
   - Normal diet to pureed
   - Oral intake insufficient to sustain life
   - no PEG
   - Continuing wt loss
   - Evidence of dehydration/hypovolemia

ALS cont'd

3) Rapid progression of ALS [above], and Life-threatening complications [1 of]:
   i. Recurrent aspiration pneumonia
   ii. Pyelitis
   iii. Sepsis
   iv. Recurrent fever after antibiotics

Eligibility: Stroke & Coma (acute)

- Coma, persistent vegetative state >3days
- Severe myoclonus >3days
- Persisting Coma after 3 days, w/ any 4 of:
  - Abnormal brain stem response
  - No verbal response and No response to pain
  - S.Creatinine >1.5mg/dl
  - Age >70
- Dysphagia sufficient to not sustain life
  - PEG declined or not a candidate
- MRI/CT suggesting decreased survival
- NIHSS helpful re prognosis

Stroke & Coma (chronic)

- Karnofsky <50 [PPS <50]
- Wt loss >10% in 6 mo; or, Albumin <2.5
- Meets criteria for Dementia
- Age >70
- Medical complications
  - Aspiration pneumonia
  - Pyelitis/sepsis/fever after abx
  - Refractory Decubiti stg 3-4

Eligibility: ***Dementia***

FAST [Functional Assessment Staging Scale] = 7c

- 7a – speaks < 6 intelligible words /day
- 7b – speaks only 1 word clearly/day
- 7c – bed-bound (2 person max. assist OOB)
- 7d – cannot sit unsupported
- 7e – no longer smiles
- 7f – cannot hold head up

AND…

…Dementia eligibility

AND, at least one of following in prior 6mo:

- COPD
- CHF
- Recurrent aspiration pneumonia
- Decubitus ulcers Stg.3-4
- Age >70
- Serum albumin <2.5
- Progressive wt loss >10% previous 6mo
- Recurring fever after antibiotics; septicemia; pyelitits

Eligibility: ***General Debilitation***

- Have a life-limiting condition
- Patient accepts comfort focus only
- Documented clinical deterioration in ADL, or

  Documented wt loss >10% in prior 6mo.
  - may be supported by albumin <2.5gm/dl]

Eligibility: Heart Disease

- Class IV by NYHA
  - Symptoms at rest [angina, dyspnea]
- Supportive documentation
  - SaO2 <89%/RA - EF <20%
  - CP.Arrest - V.arrhythmias
  - Unexplained syncope - cardiogenic brain embolism
- Receiving optimal treatment
  - ACE inhibitors
  - Diuretics/vasodilators
  - nitrates

Eligibility: HIV/AIDS

- CD-4 count <25, or viral load >100,000copies/ml
- Karnofsky score <50 [PPS <50]
- Chronic diarrhea, albumin <2.5, age >50; CHF
- Plus [one of opportunistic conditions]
  - CNS lymphoma
  - Wasting worsening
  - Persistent MAC bacteremia
  - Systemic lymphoma, failing chemoRx
  - Visceral Kaposi unresponsive to treatment
  - Cryptosporidium or toxoplasmosis

Eligibility: Liver Disease

- Not liver transplant candidate
- PT >5sec above control [INR >1.5]
- Albumin <2.5
- One of:
  - Refractory ascites or noncompliance
    - [to furosemide & spironolactone]
  - Spontaneous bacterial peritonitis
  - Hepatorenal syndrome
  - Refractory hepatic encephalopathy/noncompliance
  - Recurrent variceal bleeding despite tx

Eligibility: ***Pulmonary Disease***

- Dyspnea at rest; HR 100+/min; wt loss
  - Bed-to-chair existence, fatigue, cough
- FEV1 <30% expected [post-bronchodilator]
- Increasing ER visits/hospitalizations or decreasing FEV1 >40ml/yr
- Cor pulmonale [RHF]
- PO2 <55mmHg [SaO2 <89% on O2]
  - Or PCO2 >50

Eligibility: Renal Disease

- Patient decided to stop/forego dialysis
- S.creatinine >8mg/dl [>6 if DM]
- Creat.clearance [~GFR] <10cc/min
- Clinical signs of: uremia [confusion, n/v, pruritus, restlessness]; oliguria; hyperkalemia; uremic pericarditis; HR Synd; fluid overload

7. Summary & Pearls

- Prognosis is ‘medical meteorology’
  - ‘Fortune telling’ often inaccurate
- Knowing prognosis helps make more informed decisions and avoid futile care/suffering
- Medical technology forcing EOLC choices
- Most important factor in prognosis is ADL function – rate of decline

Summary & Pearls

- PC improves QOL, being comfort-focused
- Hospice is PC for the last 6mo of life
- Hospice requires certification of <6mo survival if disease runs usual course
- Hospice doesn't require DNR/AND order
- Patients can be in hospice >6mo
- Patients can be admitted to hospital

…Summary & Pearls

- Non-cancer diagnoses now the majority of hospice patients;
  - need good documentation to justify admission and recertification
- Hospice benefits patients/families more, when enrolled at least 3 mo

Information Resources for Hospice & Palliative Care

- OneSlideProject – engagewithgrace.org
- nhpco.org [National Hospice & PC Organization]
- CAPC [Center to Advance Palliative Care]
- Comfortcarechoices.com [RJ Webb's website]
- The Five Wishes – agingwithdignity.org
- Patient Decision Aids - http://www.npc.nhs.uk/patient_decision_aids/pda.php

Finally, learn from the mistakes of others

Will Rogers said…

- There are 3 kinds of men. The ones who learn by reading. The few who learn by observation. The rest of them have to pee on the electric fence for themselves.

- Never kick a cow chip on a hot day.

Thank You !

As you slide down the banister of life, may all the splinters point down!

- Maxine

Enjoy yourself while you can !