The Art & Science of a Good Family Conference

ALMDA Annual Meeting
Sandestin, FL
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Outline

1. Purpose of the family conference
   - What, why, & how
2. Keeping ‘comfort’ in LTC
   - The *raison d'être* of family conference
3. Prognosis: why include it
4. Who can make decisions about care
5. Summary & Pearls

Life is too short!!

1. Purpose of Family Conference

- **WHO** should be included:
  - MD, RN, + SW? [depends on circumstances]
  - DPOA/Proxy + any other family members

    [generally more is better – rational can persuade irrational - but not always!]
- **WHAT** should be discussed:
  - History/background - clarify
  - Goals of care based on information and prognosis
  - Establish POC based on goals
- **Document** preferences/choices

…Purpose…

- When: should be within 1-2 wks of admit
  - But can be at any point during stay
  - May need to be repeated (abbreviated)
- Where: separate meeting room usually
  - ? in resident's room - ?include resident ??
- How long: 15min up to 1hr – *depending*!!!

Purpose: **why !**

- Sets the 'tone' [& goals] for future care
  - What are 'we' trying to do for resident (goal)
  - Avoid futile/unnecessary interventions & hospitalizations
  - Reduce unrealistic expectations
- Establish *therapeutic* relationship w/ family
  - 'what I would do if caring for my mother'
- Document ! – Document ! – Document !
  - Prevent medical-legal sphincter spasms

What Should be Discussed

General Topics:

- History & why admitted to SNF/LTC
- Patient's health/diseases
  - Trend over 6-12mo - ? Downward spiral
  - How many life limiting diseases do they have
- Legal aspects – Living Will, DPOA/Proxy ?
- What does patient & family want – same?
- Goals of care – based on hx and patient values
  - comfort emphasized; avoid futile care
- Prognosis – for each disease
- Care preferences based on goals & prognosis
  - Results in "POLST", ACP…

…**What** Should be Discussed

Specific Interventions [ACP]:

- AND/DNR – Allow Natural Death ?
- Myths of EOLC [later]
- PEG ?
  - HDC [Hypodermoclysis – subQ fluids] ?
- NATH – No Admission to Hospital ?
- No ORIF [e.g. fix fx hip] ?
- No Abx for pneumonia/other ?
- Dialysis ?

…What to Discuss

- *Physician* as teacher/educator !
- Handouts of relevant topics
  - *Informed Decisions: a checklist for residents/sponsors/families* = guide for ACP
    - Handouts & References listed [articles found at comfortcarechoices.com]
- Internet references
  - Links & handouts on comfortcarechoices.com

Handouts for Families [and staff!]

- *Goal Focused Care: how to choose the most appropriate healthcare while in Long Term Care (LTC) ;*
- *Making Choices – Choosing Comfort When There is no Cure*
- *Allowing for Natural Death – Myth & Reality*
- *Polypharmacy*
- *Drug Holidays*
- *When to consider, No Admission To Hospital*
- *Feeding Tubes - Myths & Realities*
- *Dehydration & Starvation – Myths & Realities*
- Comfortcarechoices.com
- nursinghomecompare.com.

How to Discuss

- *Introductions - shake hands with everyone !!!*
  - *Who are you and what's the purpose of meeting*
- *Review history, diagnoses [especially LLD's]*
- *Does resident have an Advance Directive?*
  - *Is there a DPOA or HC Proxy?*
- *Ask about patient & family goals, based on above*
- *Explain treatment options and prognoses*
- Taking notes? Sitting together. "Eyeballing."
- Speaker phone for *seagull offspring*?
- *Ask – Tell – Ask* method
  - What have they been told already?

…How to Discuss

- Active listening
  - Paraphrase what they said
- Because discussions can be difficult and emotional, may offer family time to decide, if needed, then call back or meet again.
- Skillful guidance re shared decision-making
  - Make recommendations
    - ***What I would do if this were my parent !***

…How to Discuss

- Help them stay in perspective
  - Can't cure the disease, so what's best?
  - Will treating other problems cause ultimately more suffering?
    - E.g. CAD/A.Fib. w/ Alz.Dementia
- Offer best and worst case scenarios?
- Negotiate a Plan of Care
  - Emphasize it can be changed !
  - What would family want if they were resident

2. Keeping ‘Comfort’ in LTC

- Comfort Care is Palliative Care
  - PC is what you will be providing!
  - Almost every LTC resident is PC appropriate i.e. comfort focused (SNF is often not)
- EOLC Myths

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 v Hospice

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*]

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."

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*

  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.]*

Why PC so beneficial?

Implementing PC principles in LTC helps to…

- Stop all/most non-comfort tx/meds
  - May not survive long enough for med benefit !
- 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

Historically, always had PC:

Physician's Traditional Role = PC

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

- anonymous 16th century aphorism [?Hippocrates]

Palliative Care helps *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…

Then, knowing Prognosis & Goals can help preserve Hope while avoiding Futile Care

Use the family conference to educate families and help avoid futile care.

Decisions: Goal Focused

What are ‘goals’?

- A result or end we want to reach.

Why set goals of the medical care?

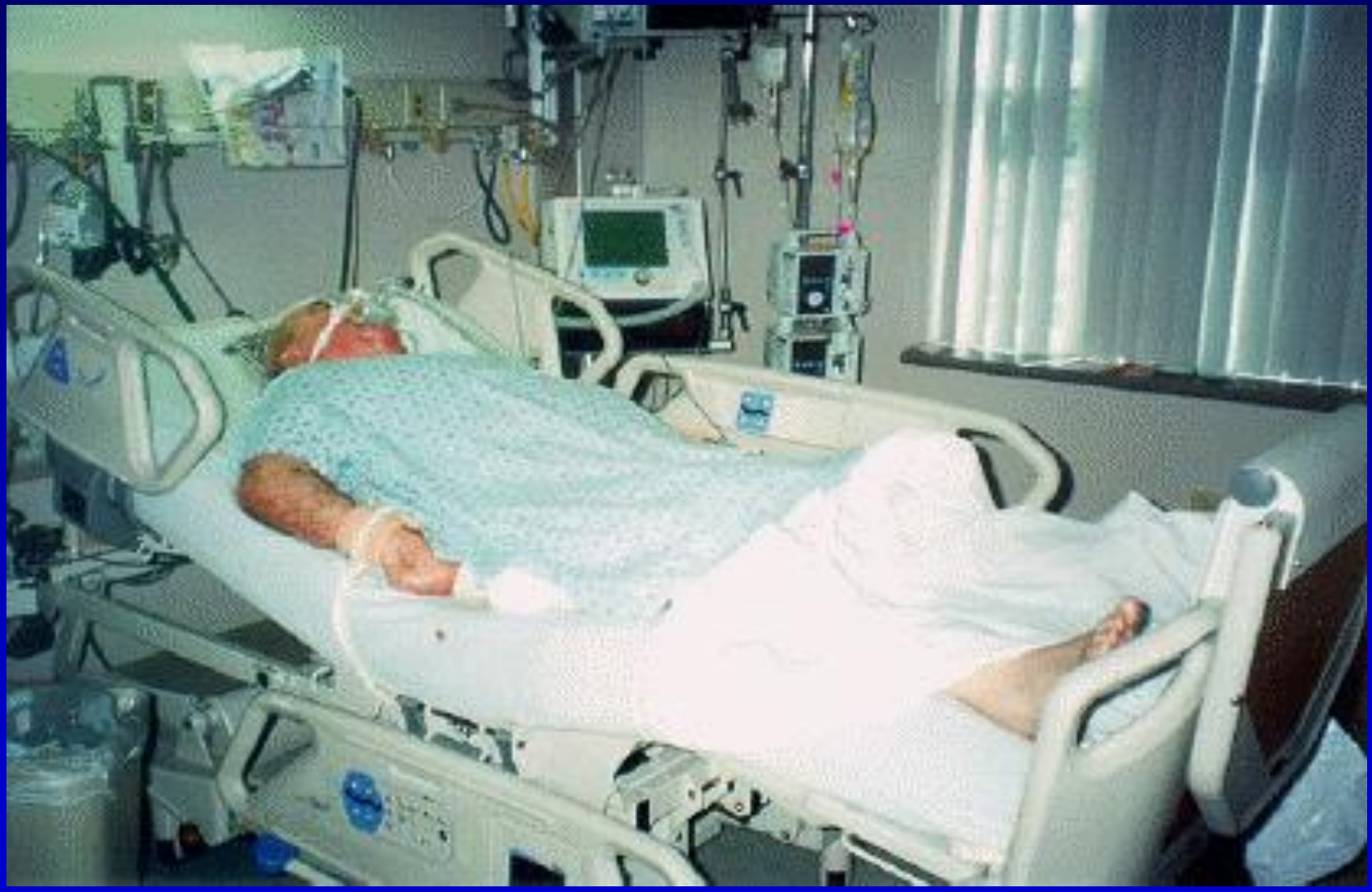
- Care goals shape expectations & priorities
- Goals often depend on understanding risks & benefits of options and on prognosis
- Goal-Focused care means choose only that care which will help reach a goal !

If patient and provider don’t know the goal and prognosis, how can we establish an appropriate plan of 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?



Avoiding Futility: which are life-sustaining v. comfort treatments?

- Resuscitation
- Elective intubations
- Surgery
- Dialysis
- Blood transfusions, blood products
- Opioids
- Diagnostic tests
- Artificial nutrition, hydration
- Antibiotics
- Other treatments
- Future hospital, ICU admissions

Educating families & avoid futile care:
Myths of CPR

- Really discussing what to do when someone is ‘dead’!
  - No breathing, No pulse
  - i.e. we are trying to revive the ‘departed’ !
- What is the success rate of CPR on TV?
  - 67% !! *[Diem. NEJM 1996]*
  - *Gives public unrealistic expectations*

CPR Myths & Reality

CPR **Reality**:

- Started 1959: intended for “healthy” middle-aged
  - To rescue them from death, not fix underlying problem or improve comfort or function !
- Only 0-17% over age of 70 survive CPR – only to die a prolonged death in hospital
- Usually considered “heroic measures”
- Ribs/sternum break & pneumonia often develops
- Incompatible with a peaceful death
  - Means giving up the goal of a peaceful end !!

Tribble BT. DNAR: More than code or no code. AAHPM bulletin. 2008

…**CPR** Myths & Reality

…CPR **Reality**:

- Seniors' bodies have little reserve and rarely return to pre-CPR health status
- For the few seniors who 'survive', CPR usually still ends in traumatic death or placement on machines
- Example of interview?

Avoiding Futility: More EOLC Myths

1) Dehydration is painful
2) We cannot allow someone to starve to death
3) Feeding tubes prevent aspiration

Avoiding Futility: Stopping Artificial feeding, hydration

- Difficult to discuss
- Food, water are symbols of caring
- Myths of starvation & dehydration
- Address misperceptions
- ANH [Artificial Nutrition & Hydration]
  - ANH is Not Food ! It is a Medical Treatment !

…EOLC ***Realities***

1) Dehydration improves comfort [ketosis & endorphins]
   - Do you want to die a ‘wet death’ or ‘dry death’
2) People do not “starve to death”

   We allow them to die naturally from the disease !
3) PEG’s increase aspiration risk x 4

McCann. Comfort care for terminally ill patients. JAMA. 1994
Christakis. BMJ 2000;320][Benkendorf. Prehosp EmCare 1997
Koretz R,et al. Am J Gastro. 2007

Preferences – Potential Last Resort Options to "keep mom comfortable"

1. Accelerating opioids for pain or dyspnea
2. Stopping life-sustaining therapy
3. Voluntarily stopping eating and drinking
   [VSED]
4. Palliative sedation
5. [Physician-assisted death]

Preferences – Palliative Sedation

- Symptoms uncontrolled: give enough drug (morphine/haldol/phenobarb) to control symptoms or induce unconscious state
  - PPS = Proportionate Palliative Sedation
  - PSU = Palliative Sedation to Unconsciousness
- Principle of double effect and unintended consequences
- Document family choice, based on goals

3. Prognosis: why important to include

Definition:

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

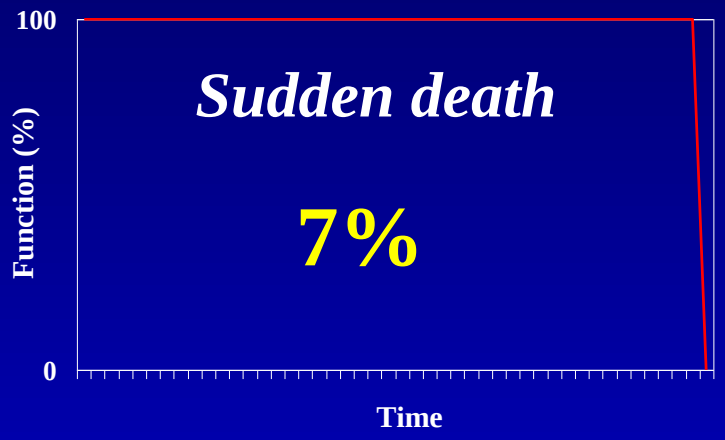
- Root word = "fortune telling" or "knowledge of the future" [*nosis*]
- Biblical reference: Psalm 39:4 "Lord, make me to know mine end, and the measure of my days; that I may know how frail I am."

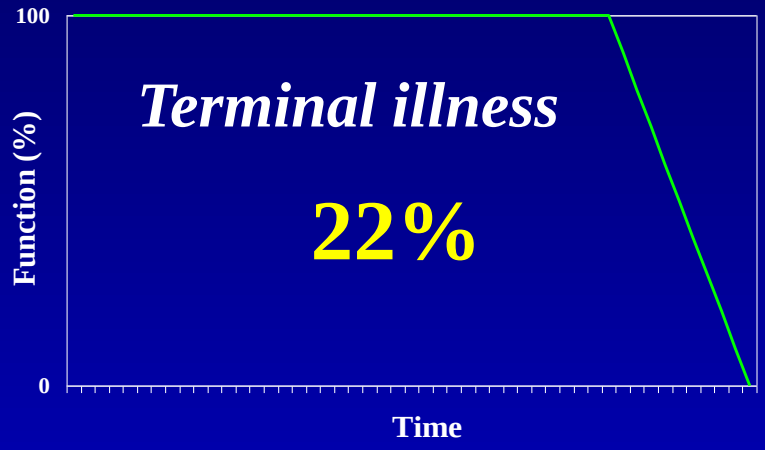
Prognosis: When is an illness "terminal" ?

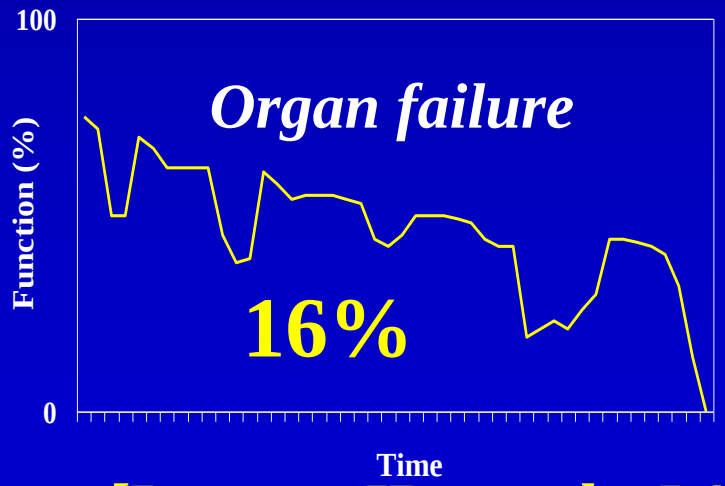
- "Terminal" = incurable + progressive + prognosis <6-12mo

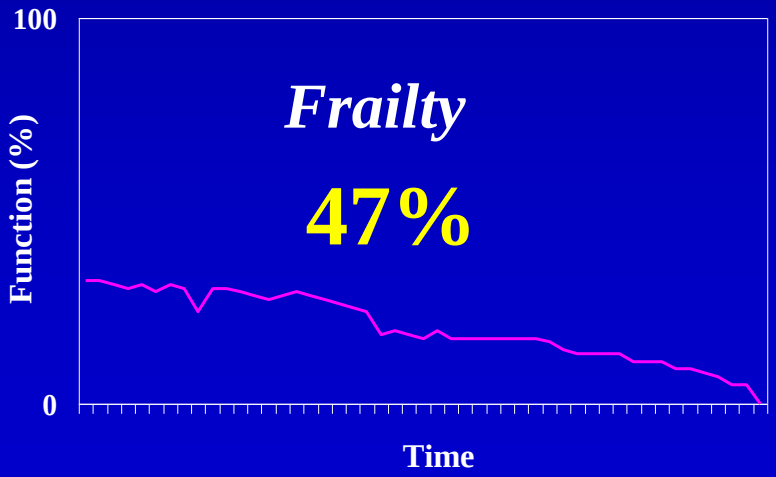
- Pattern of dying has changed over the years
  - 1900: 90% died quickly, from infections or accidents
  - 2011: only 10% die quickly; 90% die of "chronic" diseases

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 interfered and:
  - 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, AICD'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 (e.g. 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 4 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
- Letting go of misleading *healthy parent memory (especially for dementias)*

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

Choose your values & life !

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?"

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' – "death anxiety"

  - 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*

. 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 [related to inappropriate hospice referrals]

[from NHPCO guidelines]*

Non-Cancer Diagnoses Prognosis

Important factors for <6mo [hospice *status*]:

- ADL's – progressive debilitation
  - Assistance for all ADL's
- Recurring hospitalizations
- Downward Spiral ?! – wt. loss ?
- Disease-specific considerations
  - Less accurate than with cancers

e.g: *dementia [look on website for others, or handouts]*

Eligibility (for hospice status): ***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

Informed Decisions/choices Example

- 78 year old woman w/ Alzheimer's & CHF
- 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
  - If pneumonia – no antibiotics !
  - If fx hip – no ORIF; only M&M

Family Conference Summary:
How to Avoid Futile Care & Prevent Suffering

1) Clarify hx/status of each condition and prognosis
2) Determine goals – longevity v comfort

   e.g. Ask re ACP & DPOA; tell re CPR; ask re choice.
3) Explain the options, risks, & prognosis for each choice (for comfort related information go to comfortcarechoices.com) – educate them & make an informed choice
4) Make a recommendation (skillful guidance)

4. Who can make decisions re preferences?

- Patient
- Guardian
- DPOA w/ medical component
- Spouse
- Adult children – eldest
- Not a ‘simple sponsor’

Try for family consensus !

5. Summary & Pearls

- Family conference critical to ‘best care’ and to family & staff satisfaction
- Medical technology forcing EOLC choices
- Use goal-focused checklist - don’t miss topics
- Educate families via conference
- PC improves QOL - comfort-focused
- Hospice is PC for the last 6mo of life

Summary & Pearls

- Important factor in prognosis is ADL function & wt. loss – rate of decline & ‘Spiral’
- Knowing prognosis helps make more informed decisions and avoid futile care/suffering

Pearls: Avoid miscommunication

Information Resources EOLC Discussions

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

Thank You !

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

- Maxine

Enjoy yourself while you can !