Unrealistic Expectations in LTC: how to manage them

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Outline

1. Defining 'expectations' and 'unrealistic'
2. LTC facts & LLD's
3. Are families 'unrealistic' re 'best care'?
   - potential barriers – society, family, providers
4. Is there a solution?
   - What do patients/families really want
   - Information - prognosis in LTC
5. Helping families/staff make decisions

1. Definitions*

- *Expectations* – belief that something will happen
- *Unrealistic* – not able to see things as they really are; *belief based on what is wanted or hoped for rather than possible or likely*

**[M.Webster]*

…Definitions

- LTC/NH – a public or private residential facility providing a high level of long-term personal or **nursing** care for persons (such as the aged or the chronically ill) who are unable to care for themselves properly. *[M.Webster]*
- LLD [Life Limiting Disease] – a disease which, on its own, will eventually cause death; e.g. cancers, CHF, COPD, dementia.

…Definitions

Goals of Medicine/Nursing:

1) To prevent & relieve suffering.

Cassell. *The nature of suffering.*

2) To *Do No HARM.*

Maxim: *Primum non nocere = first, do no harm.*

?Hippocrates: "to abstain from doing harm"

2. Facts about LTC*…

- LTCF = 16,100 w/ 1.7M beds @86% full
- ALOS = 835days [2.4yr]
- ALOS for those who die in LTC = <2yr
- LTCF = home to 4% of seniors 65+
  - 65% +/- of residents have Dementia Dx
- Cost = $225/d or $6844/mo semi-pvt;
  $253/d or $7698/mo pvt.

** from CMS /link*

…LTC Facts

- Major LLD dx in NH: dementia [65%]; CHF; COPD; Cancer; ***Geriatric Syndrome***;
- Top dx lawsuit *paid* claims 2008-18 *[SVMIC]*
  - Injuries at facility
  - Failure to dx/tx orthopedic injuries
  - Unanticipated death
  - Failure to dx/tx other diseases
  - Failure to dx/tx vascular diseases/PU

3. Why are some so unrealistic??

- Are unrealistic expectations common???
  - Legal case […preventable DU & death]
- Why? Perhaps due to impact of multiple Barriers to good care:
  - society
  - healthcare system
  - Family
  - MD/NP/RN

Examples

Mom/Dad:

- Should never have a fall or injury
- "Cannot die before me"
- Cannot have morphine
- Needs every one of her pills
- Should not lose any weight
- Need to be 'fixed'! Why can't you fix this?

Lawsuit: Unrealistic Expectation ?

- 88 yof w/ Alz.Dementia x 5yrs; CHF/DM2/ OAB/OA/OP/H.Thyroid/etc = *Geriatric Synd*.
- Hx falls pre-LTC and falls in NH w/ fx hip
- Post op: delirium; pain; BB; losing wt; acquires PU; dies 1 mo.later.
- Dtr sues for 'allowing' mom to fall, not preventing fx, and causing pain and death.

Contributing Barriers: Society's…

- "McDonald's medicine" attitude
  - Fast, cheap, easy access, quality
- Obsession with medical technology and health perfection – *can cure everything*?
  - Medicalization of society [read *Limits to Medicine: **Medical Nemesis**, the Expropriation of Health. 1975. Ivan Illych*]
- Lack of experience with EOLC
- Unrealistic expectations promoted by
  - "pill for every ill" [TV & big *Pharma*]
  - Legal colleagues - plaintiff ads

Barriers: Healthcare…

- Provider "death anxiety"
  - Lack of training, experience; personal discomfort
    - *Learned helplessness – reluctance to discuss EOL*
  - Misunderstandings and avoiding patients
  - EOLC myths
- MD reimbursements
  - 'interventions' > bedside communications EOL
  - Few incentives to have 'conversation' [e.g. not *death panels* !!] – finally have 99497 *Advance Care Planning*
- Business model > medical model
  - *Maximize services even if no evidence of benefit*
  - 'Fraudulent' practices [e.g. some hospice/LTCF]

Barriers: FAMILY …

- Myths – fears of pain, addiction, starvation, EOLC
- "Selfishness" – loneliness, 'be orphaned'
  - *Mom can't die before me??!!*
    Can't let go of memory of once 'healthy parent'??
- Financial – need mom's SS check ? [or $ intention]
- 'Entitled' to max care regardless of cost
  - If had to pay, would still demand it??
- Guilt & unrealistic expectations…
  - Children's guilt – not available? Regrets?

…& [unrealistic] Expectations

- Technology today can cure everything?!!
  - *Death anxiety – if Christian, why fear…*
  - Expect doctor to 'do something'
    - Dr. trained to "rescue" everyone …
- **Dangers of technology: now have many toxic 'somethings'** available for treatment
  - Need to use least toxic – *First, do no harm!*
  - *'AND'*, choose comfort focus goal

. . . Modern Medicine Barriers

- MD/NP: Lack skill negotiating goals of care, treatment priorities [& compassion?] [e.g. "The Doctor", 1991]
  - Technological imperatives – reflex use because it's there & 'pressured' to "do something" [futile Rx]
  - **Remedy?** *Consider the Conversation 2: stories about cure, relief, and comfort [2014] - How Doctors Die: It's Not Like the Rest of Us, But It Should Be*
- Does dependency on modern medicine:
  - Lead to futile care and increased suffering? [see Gwande's *Being Mortal*]
  - resulting in our 'abandoning' loved ones to medical care ?...

What's Best?

"… 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

4. Is there a Solution?

- What do families/patients really want
- What do they 'need' to know from us
  - Attitude/goal shift?
  - Does prognosis help?
- How do we help them
  - Negotiating - handouts, time

What people want to know [about prognosis]

- 80% patients want to know [from their doc]
- But, many doctors won't give an estimate
  - Tend to be overoptimistic [x 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

- 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*

What about attitudes…

- A need to put dying in context
  - We will all die [seniors accept this better!!]
  - Fear, hope, distress, suffering, peace are all determined by the disease and the whole person/family
  - Suffering can be relieved by a bond w/ a caring physician/provider/carer – supporting the whole person through a crisis

…& using Palliative Approach to…

- Overcome barriers/attitudes
- Clarify patient/family goals
- *Avoid EOL situations created by medical technology that prolongs suffering, dying and requires difficult decisions*
- Overcome beliefs in EOLC myths

…Why important? Because…

- 61% of terminally ill suffer pain during their last months of life [*Annals IM 2015*]
- LLD Patient & family preferences!
- Who wants to cause/prolong suffering in those w/ LLD?
- But, our poor prognostication leads to futile interventions…

So, what can we do?

- Educate caregivers (staff/ families) & patients about their diseases and prognosis…

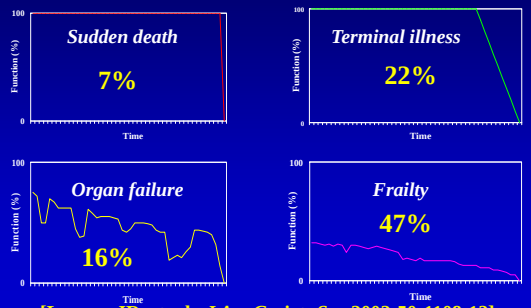
What does 'Prognosis' mean

- 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]

Prognosis: Time of Death Myth

Myth: 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 forces families into unwanted decision-making:
  - IV's, PEG's, Vents, abx, ICD's,
- Are families and doctors 'playing God' by interfering?

Prognosis: 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 only "*M&M's*" ! *[story]*
  - Developed pneumonia – no antibiotics !

Choose your values & life !

Our 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."

Factors affecting Prognosis:

Comorbid conditions:
- Age, ADL's, CV disease, DM2, nutrition

Tempo – speed of progression = *trend*

ADL & intake – rate of decline

Agendas – non-acceptance, mistrust, costs

Will to live vs 'given up' ?

Family expectations – 'cure' vs 'comfort only'

Intuition [caregiver/MD/NP]

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??

…Ca Prognosis

- Survival once become bedbound w/ Stage IV solid organ cancer:
  = 3 weeks avg.!!

Benefit:Harm if Stage IV Cancer

Prigerson study, JAMA 2015

- Stage 4 cancer patients, failed chemoRx x1, and QOL/QOD related to ADL function
- 158 received palliative chemoRx
- 154 received no more chemoRx
- No change in survival; worse QOL/QOD for chemoRx + better ADL's !!

Non-Cancer Diagnoses Prognosis

Important factors for <6mo:

- – ADL's – progressive debilitation
  - Assistance for all ADL's
- – Recurring hospitalizations
- – Weight loss
- – Will to live !
- – Disease-specific considerations
  - Less accurate than with cancers

General Guidelines in Decisions

- Since difficult to apply population-based prognostic statistics to individual, a guideline may help in making decisions
- Example: Cancer chemoRx questions

General Questions when considering Chemotherapy

- Would a diagnostic procedure help?
  [E.g. a liver biopsy]
  - – Can the patient tolerate the procedure?
  - – Would the procedure change the treatment?
- Would the chemoRx be palliative only?
- Burden v Benefit assessment – a patient-centered v disease-centered approach [will aggressive tx of disease cause patient suffering?]

Case example: ChemoRx Questions *

- 83 yof w/ met. Ca colon to liver, now postop hemicolectomy, w/ ascites
- CT = thrombosis of portal vein; pleural eff.
- Labs = abn.LFT
- Oncologist consulted and recommends chemoRx

[Selvaggi. AAHPM Annual Meeting 2011]*

…chemoRx questions

- Is the tumor a chemo-sensitive one?
  - Some cancers more chemoRx sensitive
- What benefit is chemoRx in an untreated patient with metastatic colon ca to liver?
  - Will it help relieve symptoms [pain, SOB, n/v]
  - [maybe, per oncology – might decrease liver size/ascites/effusions], but…

…chemoRx questions

- Will chemoRx improve quality & quantity of life?
  - [not per *Prigerson*]
- What are potential side-effects of chemoRx? How long & can they be controlled?
  - [depends on drugs – e.g. stomatitis, n/v, diarrhea, pancytopenia x 2-3wks]

Goal Focused Care

If the goal of medicine:

- 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

How do you want to live & die?

- Cancer pts who discuss EOLC wishes w/ MD have:
  - Less aggressive care/admissions to hospital
  - Improved QOL w/ more peaceful death
    - See article ----- *[Zhang]*
- Pts who choose hospice live ~29 days longer than those not in hospice *[Connor]*

Decisions Summary: How to Avoid Futile Care & Prevent Suffering

1) Clarify status of conditions and prognosis
2) Determine goals – longevity v comfort
3) Understand all the options & risks (read handouts, ask questions - for comfort related information go to comfortcarechoices.com) – make an informed choice…

Decisions: Myth of Informed Consent

What are 'goals'?
- A result or end we want to reach.

Why set goals of the medical care?
- Care goals shape expectations & priorities
- Goals may be dependent 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?

Deciding:

- Myth: patients make informed decisions.
- Ethical Question: Is the "road to death" undignified and more costly because patients [and their doctors], lacking relevant information (particularly on risks & benefits), make "un-informed" decisions which often result in futile interventions?

…Avoid Futile Care: Be informed

- Other information
  - Risk Charts for Men/Women – J Nat'l Ca Inst
  - Comfortcarechoices.com – R.Webb's website w/ info about EOLC and palliative care choices
  - Gerd Gigerenzer. *Calculated Risks. 2002*
  - *Expectations in LTCF*

Information for Families

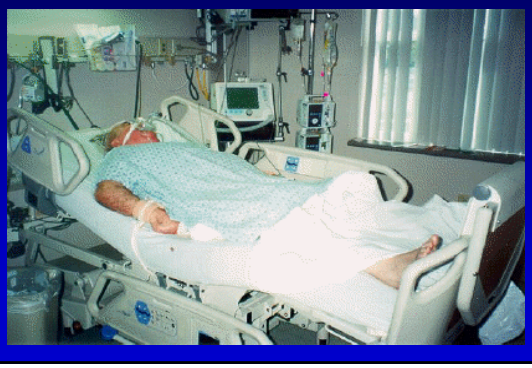
- ***Expectations in LTC (Long Term Care): What's realistic?***
  - Handout for families to help prevent unrealistic expectations, reduce suffering/harm, and minimize risk of unnecessary litigation
    - [can download from *Comfortcarechoices.com* website, or email me if want copy]

Can being realistic help?

Realisms from Ezekiel Emanuel [*Why I hope to die at 75.* The Atlantic. 2014]

- The "American immortal" – live 'better' to keep morbidities compressed into 'EOL' timeframe
- Although Americans living longer, now more incapacitated.
  - We've slowed dying process > slowed aging process
  - After 50, steady decline in productivity and activity
  - Functional limitation increased in men from 1998 (28%) to 2006 (42%)
  - Morbidity not compressed, but expanded – increase in years lost to disability as life expectancy rises
- How do we want to be remembered by our kids?
  - Good memories better than etchings of frailty and suffering

Futility – how do you want to die?



So…How do you want to live/die?

The Emanuel Option

- At age 75, will choose CCO - Comfort Care Only – accept only palliative Tx
- Stop:
  - All 'preventive tests/screenings
  - Non comfort drugs
  - Doctor visits routine
  - Abx for PNA – let it be 'old person's best friend'

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
- Important factor in prognosis is ADL function – rate of decline

Summary & Pearls…

- Make decisions based on goals and good information, not myths !
- Be assertive:
  - Encourage patients/families make decisions to prevent suffering; offer 'CCO' option
    - E.g. When patient/family want CPR: say 'no' ?
      - Can offer 'single precordial thump' compromise
  - Encourage other physicians/nurses to say 'no' to tx that causes futility/harm

…Summary & Pearls

- "Can you live w/ your decision?" - Be comfortable with it.
- As a family member: Is your decision based on what's best for the patient – or is 'selfishness' possible when having trouble 'letting go'?

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 !