End of Life

Patient Centered Communication

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Frame End of Life Care as a Health Promotion Goal
Explore Medical Futility
Propose a Process to Initiate End of Life Discussions
Consider Barriers to the Discussion of End of Life
Present End of Life Communication as Clinical Jazz
Case Example

72 year old with SDAT
NH X 3 years dependent 6/6 ADLs
Most hours Bed bound / fewer than 6 words
Lost weight – PEG
Hx: Recurrent falls – ORIF
3 episodes pneumonia O2 dependent
NOW WHAT?

Is this a case of Futility?

Time for

THE TALK
Paradigms of Futility

- Futility and Values
  - Futile in Relation to What?

- Futility and Statistical Certainty
  - How Probable is Probable Enough?

- Futility and Resource Allocation
  - Money, Organs, Beds, Drugs, Personnel
Definitions of Medical futility

- Won’t achieve the patient’s goal
- Serves no legitimate goal of medical practice
- Ineffective more than 99% of the time
- Does not conform to accepted community standards
Futility Judgment

“Physician’s may be best suited to frame the choices by describing prognosis and quality of life. Beyond that, they run the risk of giving opinions disguised as data”

- NEJM July 27, 2000
  Vol. 343, No. 4 pp. 293 - 296
Is this really a futility case?

- Unequivocal cases of medical futility are rare
- Miscommunication, value differences are more common
- Case resolution more important than definitions
- Trust Based Outcomes – changes in the extended family and change in relationship care from “the old time GP” Dr. Welby
There is a Reason
It is Called
“PRACTICE”

CLINICAL
JAZZ
Clinical Decision Making

- Patient circumstances
- Evidence from research
- Preferences, values and rights
Clinical Jazz

- Evidence is the background
- Practice is the improvisation
- When all else fails – practice in the interest of the patient
- The truth may be brutal – the telling of it should not be
End Of Life Care
As Health Promotion

Anticipatory Guidance – a Hall Mark of Primary care

Immunizations, Smoking Cessation, Health Screening, Sex Ed, Prenatal and more

Essential part of the medical home and the accountable care organization (ACO) concept

Why not end of life /goals of care?
The Death Panel aka Obamacare

Affordable Care Act provides for the discussion of end of life planning and advanced directive determination as part of care.
BARRIERS?

Humanistic Domain
- Initiating / Timing
  - Pt waits for doc
  - Doc waits for patient
- Truth Telling
  - Misinformation / Misunderstanding
- Maintaining HOPE
- Personal Discomfort with Topic
- Pt / Family Denial / Guilt
- Religious/cultural

Skill and Knowledge Domain
- Means abandonment
- Prognosis too uncertain
- Not my role
  - My job is cure
  - Nurse/Social Services better prepared
- Communication Skill level
- Skills in Palliative Care
- Resentment / Perception of Failure
Timing

Physicians/Midlevel
- 28% WHEN TX INEFFECTIVE
- 24% WHEN Dx MADE
- 41% WHEN ACTIVELY DYING
- OFTEN LATE
  - OVERESTIMATE LIFE EXPECTANCY
  - UNDERESTIMATE FUTILITY

Other Health Provider
- Nurse more likely to broach subject
- Social Services more likely to have the opportunity for the “teachable moment”
- Discharge planner more likely to have the opportunity to guide/refer
- MAY FEAR OVERSTEPPING BOUNDARY with doctor
Potential goals of care

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolongation of life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for families and loved ones
Advanced Care Planning
(= Anticipatory Guidance = Health Promotion)

Note to chart
Patient letter
Five Wishes
Living Will
Durable Power of Attorney
DNR DNH CMO

HAVE THE CONVERSATION
“THE TALK”
Importance of Goals of Care

- Most people **Want to Know** if facing a serious illness
- Strengthens the provider-patient relationship
- Fosters collaboration with colleagues
- Establishes an appropriate allocation of resources
- Permits patients, families to plan, cope
Goals may change

- Osteopathic Principles make very clear the distinction of caring for disease and caring for the patient who has disease – A.T. Still
- Some goals take precedence over others
- The shift in focus of care
  - Requires the patient (Guardian) to understand
  - is gradual
  - is an expected part of the continuum of medical care
7 STEP FRAMEWORK TO COMMUNICATE BAD NEWS (as if it were that simple)
1. Create the Right setting

- Quiet – private
- Allot enough open time
- Have a single medical spokesperson
  - Secondary support / backup may be needed
- Determine the right people are present
  - Family clergy guardian other
2. What Does the Patient (surrogate) Know

- Establish Patients Knowledge and Understanding
- Assess ability to comprehend
- Correct misunderstanding
- Reschedule if unprepared or unresolvable conflict of info
3. How Much Does the Patient Want to Know

- Recognize patient preferences
  - May decline to know voluntarily
  - May designate someone to communicate on his/her behalf
  - Consider Power of Attorney or advanced directive – 5 wishes
Cultural differences

- Who gets the information?
- How to talk about information?
- Who makes decisions?
- Ask the patient
- Consider a family meeting
4. Sharing the Information

- Say it then  **STOP**
  - Avoid monologue - promote dialogue
  - Avoid Jargon and Euphemisms
  - Pause frequently
  - Validate understanding
  - Use Silence and Body Language

- Don’t minimize severity

- Implications of “I’m Sorry”
Language with unintended consequences - Negative

- Do you want us to do everything possible?
- Will you agree to discontinue care?
- It’s time we talk about pulling back
- I think we should stop aggressive therapy
- I’m going to make it so he won’t suffer
Language to describe the goals of care - positive . .

- I want to seek the most comfort and dignity possible until the day you die
- We will concentrate on improving the quality of your child’s remaining life
- Let’s discuss your needs and wants
Communicating prognosis

- Providers markedly over-estimate prognosis
  - Either way raises fears and stresses
- Helps patient / family cope, plan
  - increase access to hospice, other services
- Offer a range or average for life expectancy
Truth-telling and maintaining HOPE

- False hope may deflect from other important issues
- True skill to help find hope for realistic goals
- Hope may need to be re-defined in terms of goals – hope for care goal vs cure goal
5. Respond with Empathy

Patient / Family

- **Affective response**
  - Tears, Anger, Sadness, Love, Anxiety, Relief

- **Cognitive response**
  - Denial, Blame, Guilt, Fear, Shame, Rational Planning

- **Psychophysiologic response**
  - Fight / Flight

Provider

- **Listen Listen Listen**
- **Encourage**
- **Allow feelings - acknowledge**
- **Use non verbal communication**
- **Know thyself / own feelings**
- **Be Silent when appropriate**
6. Planning and Follow up

- Explore hopes, expectations, fears, needs
- Plan for next steps
  - Tests, treatment/non treatment, informed consent, second opinion, referral
- Sources of support
  - Medical spiritual social legal hospice
- Continuation of involvement
  - Care will continue even if not cure
7. Review / Revise

- Care is a continuum – goals and needs are in a dynamic flux of change
- Next appointment – contact information
- Be prepared to repeat info – all will not be heard
- Assess safety
- Assess support system(s) - formal and informal
Reviewing goals, treatment priorities

- Goals guide care – whose goal?
- Assess priorities to develop initial plan of care
- Review with any change in
  - health status
  - advancing illness
  - setting of care
  - treatment preferences
Determine specific priorities

- Based on Patient values, preferences, clinical circumstances
- Influenced by information from physician(s), team members, PATIENT and family

—Clinical Jazz
Summary

- Anticipatory Guidance
- Begin the Conversation Early
  - Keep seven steps in mind
- Understand the Clinical Jazz
  - Patient centered values and preferences and evidenced based medicine
- Revise and Renew
IT’s ABOUT THE PATIENT

They don’t care how much you know until they know how much you care