

End of Life

Patient Centered Communication

Bruce P. Bates, D.O., CMD

Certified - Family Medicine

Certificate of Added Qualification - Geriatric Medicine

Certificate of Added Qualification - Hospice and Palliative Care

Purpose Statement

*(objectives)

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?

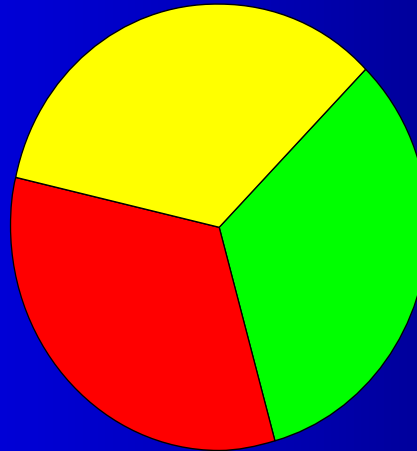
- Unequivocal cases of medical futility are rare
- Miscommunication, value differences are more common
- Case resolution more important than definitions
- Trust Based Outcomes – changes in the extended family and change in relationship care from “the old time GP” Dr. Welby

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?

- To The Talk?

- THE TALK

- The Talk

- The Talk

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)

e)

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

I A T P

IT'S ABOUT
THE PATIENT

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