Guidance of Patients and Families: Palliative Care

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The presenter has nothing to disclose.
Objectives

Provide an opportunity for therapeutic catharsis for the physician involved in this difficult conversation

Provide a framework for how to approach difficult conversations
Objectives

Dispel two common myths about palliative care.

Myth #1: What the patient wants matters most

Myth #2: There is no crystal ball
Case History

- The patient is an 78 year old woman with a history of HTN and a prior CVA from which she substantially recovered.

- She was brought to the ER with a history of deteriorating mental status, and worsening L-sided hemiparesis.

- Family stated she typically becomes non-verbal and confused like this when she has a UTI or pneumonia.
Case History

- The patient was discharged back to her nursing home with a feeding tube.
- Dx: Metabolic Encephalopathy
- One day after discharge she was sent back to the ER as she was again poorly responsive. UTI was suspected.
- When she began extensor posturing a follow up CT scan was ordered.
MD: So…

The reason I brought you all in here is… what I am sorry to have to say is that your Mom has suffered this catastrophic stroke, and really, I think there is no chance that she can survive… and probably what she would want is to be made comfortable.
A Care Conference was Held
The Family’s Response
Oh, I know what you are trying to do. You just want us to murder our Mom.
This is way too soon
She had a stroke before and got better.
You can’t be completely sure she won’t recover, right? RIGHT??
This is ObamaCare, right? RIGHT??
You’re fired
Multiple Choice Question #1

What should the doctor say next?

a) If you are so smart why didn’t you go to medical school?
b) Are you challenging my integrity???
c) Fired? Is that a promise or a threat?
d) I can certainly arrange for another doctor to assume responsibility for your Mom’s care.
The most important goal in every difficult care conference

Make sure that the family is happy
to see you the next time you meet
FACT or MYTH??

What
the patient and family
want matters
most
Traditional Approach to End-of-Life Decisions

Discussion of very specific treatments in the language of preferences

- Do you want a feeding tube?
- Do you want to be resuscitated?
  - chest compressions?
  - Intubation?
  - Cardioversion? (if so how many Joules?)
It’s not what the patient “wants” that matters most.

Everyone “wants” to live.

No one “wants” to die.
Be careful of false choices

Do you want a feeding tube?
Of course. I don’t want to starve.

Do you want to be resuscitated?
Of course. I still want to live.

Do you want hospice?
End of Life Decision Making
A qualitative study

- (Subjects) were concerned primarily with the outcomes of serious illness rather than the medical interventions that might be used, and defined treatments as desirable to the extent they could return the patient to his or her valued life activities.
It’s not what the patient “wants” that matters most

Prognosis matters first.
Will I get better?

Preferences follow.
If I can get better, then I want treatment.
Why are end-of-life discussions so difficult?

the widespread and deeply held desire not to be ……
Why are end-of-life discussions so difficult?

the widespread and deeply held desire not to be ……

…the one who tells the patient they are going to die.
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
A book I highly recommend

...And a time to die

How American Hospitals Shape the End of Life.

Sharon Kaufman
Physicians want to avoid the guilt and personal responsibility of authorizing death or being seen as the “cause” of death.

(So they…) ask the patient if “he wants” to (change goals) and end his life.

(The question makes) the patient responsible for choosing or not choosing death.
Why are end-of-life discussions so difficult?

the widespread and deeply held desire not to be …..

DEAD.

Finucane TE.  
“Goals of Care” Discussions

Euphemism for saying “you are dying.”

- Doctor: “What are your goals? What do you want?”
- Patient: “My goal is to live. I want to live.”
- Doctor: “Well, what about other goals?
- Patient: “Other than living? So are you telling me that I’m dying?”
- Doctor: “Oh. Did I forget to mention that?”
Palliative Care: Providing Guidance

- Careful assessment of prognosis
  - If prognosis uncertain probably premature to expect family to make big decisions
- Share this information with family
- Follow emotions
- Await consensus on prognosis
- Only then offer recommendations
Sometimes Care Conferences are easy

- Doctor: Thank you for coming. I know it has been a very difficult few days for you.
- Family: Yes it has.
- MD: I know that you have heard a variety of things from different staff here. What I would like to do first, before I share some of my thoughts, is hear from you what you understand about your mother’s condition.
Sometimes Care Conferences are easy

- Family: Well I understand that she has had a very large stroke
- MD: (silent, nodding)
- Family: and there is very little chance that she will recover…
- MD: (silent, nodding)
- Family: she would never want to live like this
- MD (silence shaking head no)
Sometimes Care Conferences are easy

- Family: What do we do now?
- MD: Is there anyone else that needs to be here?
- Family: My brother will be here this evening.
- MD: What I recommend is that once your brother arrives we proceed with removing the breathing tube....
- Family: Thank You
There is no crystal ball. Therefore, doctors are unable to provide accurate estimates of prognosis.
Multiple Choice Question #2

How over-optimistic are doctors about prognosis when they refer patients for hospice care?

- a) 50%
- b) 100%
- c) 200%
- d) 500%
How good are doctors at predicting the future?

- Christakis N BMJ. 2000
- Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study.
- 343 doctors, 484 patients referred to hospice
- Median survival was 24 days.
- 20% of predictions were accurate
- 63% were overoptimistic by a factor of 5.3.
At OHSU we are pretty good at prognostication

- Incorporating Routine Survival Prediction in a Palliative Care Service.
  - 429 pts. age 63, 48.5% cancer, med surv 18 d
  - 59 % of predictions accurate
  - 5/264 pts predicted to die < 30 d lived > 6 Mth
  - 17/165 pts predicted to live > 30 d died < 1 wk
Prognosis in Neurological Diseases can be complex

- Advanced ALS
  - Feeding tube, ventilator = years
  - No life support = months
- Anoxic Coma vs Traumatic Coma
- Can prognosticate re types of deficit
  - Unable to speak
  - Unable to use L side
  - Will require considerable assistance
Case History-Epilogue

- Her attending not fired and was allowed to continue serving as the patient’s doctor
- Day 14 Trach/PEG, (after abundant institutional angst)
- Day 21 Transfer to LTAC Hospital
- Day 25 Readmission  Temp 34 BP 70/30
- Dx: Sepsis
A Care Conference was held

Family said: it would be their mother's wish to treat for possible infection with antibiotics and proceed with pressors. I urged them to reconsider this decision to no avail.

We discussed goals of care as well as the situation we were in.

Daughters were not comfortable withdrawing care.
Case History-Epilogue

Per Discharge Summary

The family wished to transition her to comfort care. She passed away peacefully shortly thereafter with family by her side.
Case History-Epilogue

- Dx: Autonomic Dysregulation
- FSH 4 LH 1
- Hypernatremia from Central DI
- Heating blanket to maintain nl temp
- Untreatable
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