Difficult conversations
with seriously ill people & their loved ones

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Objectives

- Identify common pitfalls of communication with the seriously ill & their families
- List five core skills for communicating with the seriously ill & their families
- Demonstrate ways to effectively communicate about limiting aggressive care

"Grave Words"

A Case

- 67 year old man with stage IV adenocarcinoma of the lung & brain metastases, admitted with post-obstructive pneumonia, doing well on IV antibiotics.
- Four chemotherapy trials did not succeed.
- You are the nurse & they tell you about planning a trip to California for a second opinion on further treatment options.
- You also learn that his daughter is hoping he can live to see the birth of his first grandchild (she is recently married, not yet pregnant.)
- The patient tells the chaplain that he strongly believes God will help cure him.

A Case

- The hospitalist who does not know the patient notices that there are no advance directives in the chart & that the patient is "full code".
- He walks in & asks: if your heart stops, what would you like us to do?
- The patient is in rage, calling his daughter to come & get him.
- The hospitalist orders a new MRI of the brain, concerned about new frontal lobe metastases causing emotional volatility.

What went wrong?

Brainstorming

What went wrong?

- A person with complex medical, social & emotional considerations being asked to make an important decision by someone he doesn't know.
- The patient is a father who's daughter hopes he will live to a milestone, a man of deep religious conviction who hopes to live as long as his God will allow.
- The patient clashes with a medical system that is pressuring him to give simple "yes, no" answers to very charged decision making questions.
- His readiness to engage in the hospitalist's agenda is not considered.

Communication patterns in health care

- Talking too much (more is NOT better)
- Focusing on the medical facts
- Overemphasizing cognitive communication
- Not exploring patients' values & attitudes
- Avoiding patients' affective concerns
- Not assessing patients' readiness & understanding
- Not acknowledging loss, uncertainty, ambivalence, & conflict

*The problem with communication ... is the **illusion** that it has been accomplished.*

GEORGE BERNARD SHAW

Attitudes & Assumptions

- No training is needed
- Communication equals transfer of information (thus it is a cognitive interaction)
- Facts are more important than relationships
- Communication is an event rather than a process

The challenge

We are untrained in complex communication, yet expected to

- Develop a relationship
- Explain biomedical science
- Use clinical judgment
- Be hopeful yet realistic
- Provide counseling
- Assist with complex decision making

Core concepts: Communication

- Communication is the fundamental tool we use in health care
- Successful health outcomes depend on good communication
- Communication failures account for nearly 100% of what goes wrong in healthcare

Negotiating a shared meaning is the essence of communication

Communication leads to community, that is, to understanding, intimacy & mutual valuing.

ROLLO MAY

- Communication is a procedure
- It requires no less skill than performing surgery
- Health care workers with good communication skills have higher work satisfaction

Core skills: Communication

1. Body language
2. Listening
3. Ask-tell-ask
4. Recognizing the key components
   - Cognitive
   - Affective
5. Self awareness

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Core skill No. 1

AKA: Park your little…

No. 2: Active Listening

- The most important communication tool
- Allows provider to know the "whole patient"
- The goal: learn what it is like from the patient's & family's perspective
- Shows patients & families that their concerns are heard

Active Listening

Let the patient / family talk without your

- ☐ Interruptions
- ☐ Advice or suggestion
- ☐ Pointing out the positive
- ☐ Sharing your own experiences
- ☐ Analysis
- ☐ Giving your own insight
- ☐ "Fixing" the problem

Many attempts to communicate are nullified by saying too much.

ROBERT GREELEAF

Listening exercise

- ☐ Ground rules
  - ■ Comfort
  - ■ Confidentiality
- ☐ Break to groups of 2
- ☐ A: Talk about a major loss you had
- ☐ B: Practice your ability to
  - ■ Listen
  - ■ Use nonverbal cues
- ☐ 2 minutes than switch roles

Debrief

A

- ☐ Did you feel listened to?
- ☐ What were the cues?

B

- ☐ How did it feel to be silent?
- ☐ What happened when you broke your silence?

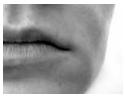
"Tell me more"

When the conversation is getting stuck

- ☐ Information
- ☐ Emotion
- ☐ Meaning

It is the province of knowledge to speak & it is the privilege of wisdom to listen.

Oliver Wendell Holmes



No. 3 Ask-Tell-Ask

- Ask– for the patient & family story
  - Pearl: open ended questions
- Tell– deliver your message
  - Pearl: limit the amount of information
- Ask– for patient & family response
  - Pearl: demonstrate empathy

We create meaning by telling ourselves stories.
Storytelling is the DNA of all communication & meaning.

onethousandandone.com.au

No 4. Cognitive & Affective

- Cognitive = conscious intellectual component
  - Thinking, reasoning, judging
- Affective = involuntary emotional component
  - Anger, sadness, love, anxiety, relief

Affective Response

- Identify & explore the affect
  - "You seem angry (worried, upset) about this. Can you help me understand what's going on for you?"
- Acknowledge the probable source of affect & connect it with its source
  - "You've been through a lot. No wonder you're feeling like this."

Exercise

- "Fishbowl role play" – moderators
- Three minutes
- Audience:
  - Observe for the Ask-Tell-Ask
  - Identify the cognitive & affective elements
  - What would you do differently
  - How would you improve on it

Debrief

- Physician
- Patient
- Observers

- How did it go?
- What were you trying to accomplish?
- What did you do?
- How effective was it?
- How did it feel?

Emotions matter

- Emotion can derail cognitive understanding
- Emotional integration creates value, meaning & leads to action
- We value cognition over emotion
- We often avoid or dismiss emotion
- Tracking & using emotional data gives valuable information we can use to tailor the encounter
- We are often limited by our capacity to tolerate strong emotions

When dealing with people, remember you are not dealing with creatures of logic, but creatures of emotion.

Dale Carnegie

No 5. Self awareness

- We all bring our attitudes, knowledge, & skills into the encounter
- We also bring a personal agenda, assumptions, & expectations
- Not to mention our emotions, fears, anxieties, personal losses, etc.

Lack of self awareness

Results in some common behaviors

- Making assumptions about what the patient & family knows & doesn't know
- Focus on interventions without trying to understand the patient's preferences or rationale
- Launching into your agenda without assessing patient & family
- Push them to talk / make a decision on your schedule

Lack of self awareness

Results in some common behaviors

- Ignore your own emotions
- Ignore patient & family emotions
- Demonstrate distancing behaviors when they show emotions
- Respond to emotion by offering aggressive or unnecessary care
- Feeling you are responsible for maintaining the patient's hope
- Feel &/or express frustration with those that make a choice that diverges from your recommendation

Your lack of self awareness will

- Adversely affect the encounter
- Put patients & families at risk
- Cause unnecessary suffering
- Put you at the risk for burnout

Exercise

Audience

- Take 3 minutes & write down 5-7 emotions / attitudes / skill deficits that limit your ability to communicate with the seriously ill & their families

Core concepts: Limiting aggressive care

- Huge decision rooted in a sense of failure
- For patients & families, medical decision making is anything but medical
- Emotional, relational, & social elements influence decision making
- Conflict, ambivalence & uncertainty are the norm

The challenge

- We perceive that
  - Medical factors guide medical decisions
  - Our job is largely information transfer
    - "If I educate the patient or family well, they will make a rational decision"
- From the patient's & family's perspective
  - Social, emotional, & relational factors dominate over medical issues
  - Decisions are primarily based on non-medical issues

Readiness

- Patient & family readiness to engage in the HCP' agenda is rarely considered
- The patient & family do not have to be ready for the reality of bad news, death or decision making
- The result is a conflict with the medical system

Ineffective communication patterns

- Discussing treatment options before identifying goals
- All you need is "code status"
- Discussing palliative care when things are going badly
- Tying treatment options & relief of suffering to prognosis

Dangerous assumptions

- The other person has the same information
- The other person is ready
- The agenda is clear to all
- Controlling the future with decisions made now
- Simple answers & solutions to complex situations

Assumptions are the termites of relationships.

Henry Winkler

Core skills: Limiting aggressive care

- The ability to be in the presence of strong emotions, yours & of patients/families
- The ability to tolerate uncertainty
- Using a positive attitude & language
- Most successful when evolves around patient goals & values

Limiting aggressive care

- Positive framing: most effective & appropriate care options at this point
- What we can do & will do
- Explore emotions & provide support
- Convey non abandonment
- It takes time to cognitively & emotionally adapt to the reality of decline & death

Language is key

"We are going to treat the suffering caused by serious illness"

as opposed to

"We should do *only* supportive care because prognosis is poor"

"Allow natural death"

as opposed to

"Do not resuscitate"

Fishbowl role play

- Ground rules:
  - Comfort
  - Confidentiality
- 5 minutes
- 2 audience volunteers
  - Provider
  - Patient

Debrief

- Physician
- Patient
- Observers

- How did it go?
- What were you trying to accomplish?
- What did you do?
- How effective was it?
- How did it feel?

Summary: Communication

- Good communication starts with self awareness
- Shared meaning is the essence of communication
- Listening is the most important communication skill
- Words are powerful & healing

- *There is no greater agony than bearing an untold story inside of you.*

  Maya Angelou

- *Words are, of course, the most powerful drug used by mankind.*

  RUDYARD KIPLING

Thank you!

Your questions & comments are welcome

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