Inside the patient-physician encounter:
communication & value

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How is patient-physician communication related to value?
How is communication related to value?

- Transition conversations as an instructive paradigm
- What happens in current practice?
- A view from the patient’s perspective
- What gives patient-physician interactions value?
Transitions to end of life care

- Definition: a transition in goals of care conversation marks a change from...
- medical treatments given with the intent of disease modification to...
- treatments given with the intent of assuring comfort and preparing the patient and family for death
- An important interaction that defines value
Where do transitions occur?

Disease-modifying therapy

Palliative care

Diagnosis

Death

Desired outcome: smooth integration of disease-modifying therapy and end of life care
What is the problem?

Current practice seems ineffective:
• SUPPORT study: DNR 2 days before death
• Chemotherapy use increasing prior to death
  – Medicare pts with metastatic cancer: >20% started a new regimen within 2 wks of death
  – Oncology accounts for 40% Medicare drug costs
• Families remember being told “there is nothing more to be done”

JAMA 274:1591, 1995
JAMA 299:2667, 2008
Ann Oncol 15:1551, 2004
What happens in current practice?

“It’s the nightmare scenario”

 Patients don’t get information, or don’t believe it, or cope by avoiding, or don’t act on the information

 Doctors are hesitant to be frank, don’t manage the emotional content of the conversation, feel unclear about their role

 Systems give implicit, if unintended, messages about what kind of care is most important
Do transitions conversations matter?

- 332 patients identified prospectively
- Asked “Have you and your doctor discussed any particular wishes about the care you would want to receive if you were dying?”
- Yes/no: compared re
  - Distress/Depression \( p=\text{NS} \)
  - Accepts illness as terminal OR 2.19
  - Wants to know life expect OR 2.40

Wright et al, JAMA, 2008
Outcomes correlated with a transition conversation

• Medical care in **last week** of life
  – ICU admission OR 0.35
  – Ventilator use 0.26
  – Resuscitation attempt 0.16
  – Outpt hospice >1 wk 1.58

• Caregiver **bereavement**
  – Better QOL p=0.001
  – Felt prepared for death p=0.001
  – Regret p>0.001

JAMA, 2008
Doctors are ambivalent about talking frankly

- About 30% decline to give prognostic info
- Feel “damned if you do, damned if you don’t”
  - Negative feedback about ‘taking away hope’
  - Ditto about losing opportunities at end of life, yet confronting patients “hanging crepe” painful
- Mostly negative emotions associated with disclosing prognosis “the death sentence”
- Collusion “don’t ask, don’t tell”—or rather “don’t offer, don’t dwell"

BMJ 321:1376, 2000
Physician “factors” correlate with timing of hospice referrals

- 326 terminally ill cancer patients
- 258 physicians, 5 outpatient hospice programs
- Physician factors correlated with longer patient survival after referral (median 26 d)
  - MD referred >2 pts in previous 3 months
  - MD estimated survival accurately
  - MD specialty (internal med, geriatrics>oncology)
- Conclusion: physician skill counts

Cancer 94:2733, 2002
Does doctor discomfort translate to less discussion?

• Anecdotally, yes – "If I discuss anything about dying he becomes uncomfortable…so I change the topic to baseball"

• No empirical studies directly addressing this

• However, one study using simulated situations demonstrates that medical students have more positive affect if they conceal bad news—i.e., it's easier to lie

JAMA 286:2007, 2001
J Clin Oncol 26:1175, 2008
How do oncologists handle emotionally charged information?

[Diagram with text: 38F with AML, Dr pre-visit estimate of cure: 90-100%, Dr during consult: "So if you had 100 people, the survival curve drops down because people die of one thing or another, including relapse. That tends to level off at about 2.5 years after transplant and stays level after that. It's about 30% in your situation", Dr post-visit estimate of cure: 30%]
Patients find emotion overriding comprehension

• Pt post-visit qualitative interview (2 wks)
  – “after he said the 30% he just kept dinging along in his facts, and I was stunned. Literally, my note taking was completely done. All I wrote was 30% the rest of the time all over my paper. And I mean, I just couldn’t get past that point. I don’t know how to describe it”

• Pt immediate post-visit estimate of cure: 90-100%
How often do oncologists address emotion content?

- 51 oncologists
- 270 patients with advanced cancer
- 398 visits audiorecorded and coded
  - Empathic continuer
  - Empathic terminator
- Oncologists made empathic statements in 11% of conversations
- Conclusion: not very often

How much empathy does it take?

- 123 women who had breast cancer, 87 controls
- Randomized to one of two physician videos, one with 40 seconds of empathic language
- Women who saw the empathic video were significantly less anxious (p>.001)

J Clin Oncol 17: 371, 1999
Improving your communication skills

INTENSIVE RETREATS
for Medical Oncology Fellows

Anthony Back
Robert Arnold
Walter Baile
Kelly Fryer-Edwards
James Tulsky

NIH R25 CA92055
How do oncology fellows talk about transitions?

- 20 conversations randomly selected from 100
- Oncology fellows discussing transition with simulated patient
- Told that no further evidence based chemo available
- 20 minutes maximum
- Collected prior to intensive residential workshop on communication skills
Oncology fellows ‘make the case’ using scientific logic

- 19/20 conversations rely on scientific logic
- 1/20 elicited patient values first before discussing stopping palliative chemo
- “Of course, we also have third line chemo, single agent with different chemos, but the response rate is very low - 5, 10%...if we give you some more toxic chemotherapy and your response rate is very low, you have side effects and you’d be in the hospital again...at this point, the options for chemotherapy are very limited.”

Can oncology fellows improve how they talk about transitions?

Acquisition of communication skills relevant to transitions to palliative care

- Assesses patient understanding
- Elicits patient values
- Elicits patient concerns
- Respond to “How much time?”
- Respond to “Isn't there anything more?”
- Not offer unproven anticancer therapy
- Checks for understanding

% participants acquiring skill

30/77
49/80
29/69
50/87
26/62
29/69
15/92

Back, Arch Int Med 2007
What more skill sounds like

Pt: “Isn’t there anything more you can do?”

Dr [pre-Oncotalk] “You’ve had a lot of chemotherapy, haven’t you?”

Dr [post-Oncotalk] “There are more things we can do, yes. This has been a roller coaster ride for you hasn’t it?”

Dr: “I feel less flustered and my words are less tangled; I can focus on the person across from me and find out what they need from me in that moment—and that seems like progress.”

J Clin Oncol 24:3209; 2006
ONCOTALK

Teach

Improving oncologists’ communication skills

A faculty development program

FACULTY

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Kelly Fryer-Edwards, PhD
James Tulsky, MD

www.oncotalk.info

NIH R25 CA119019

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Do patients notice more skill?

- Oncotalk audiotapes of oncology fellows and standardized patients
- Patients with cancer listen with interviewer, comment on what they liked and didn’t like
- Compare pre- and post-Oncotalk
- Fellow must disclose news that chemotherapy isn’t working, no evidence based treatments left
- Pt: “Isn’t there anything else you can...
Wanted: empathy + guidance

• Subject: “...[the doctor] has to let him let his emotions run a little bit...personally, I would say, “Son of a bitch--now what do we do?”

• Patients want acknowledgment and guiding

• Substantial group concerned about framing by doctor
  – “I want to hear about options”
  – “It is excruciating to listen to the doctor evade the question”
  – “No leadership or guidance from the doctor”
Patients worry about being abandoned at the end

- “I think that it’s important that you still have that contact with them even though there isn’t anything they can do to make you better”

- “I need to be able to depend on my doctor…, ‘If I call you next week, doctor, will you see me right away?”
What they discovered: the importance of closure

• Spouse: “I realize that the doctor is busy….But he knew R. and I. We were together through the whole thing…it would’ve been nice just to hear from him…

• Oncologist: “I thought, ‘Oh, I should really call B.’ And then, didn’t, because I was just too busy. And then, I felt guilty that I hadn’t called her earlier and I didn’t know if it was appropriate…maybe it would just stir up emotional stuff…”

Arch Int Med, in press 2009
The consequences of marginalizing

• “Fighting On” Drazen et al, NEJM Jan 29, 2009

“We have to admit that our team was happy to see the woman leave our ICU. It was not that she no longer required ICU care; we simply could not face her in the morning with the optimism needed to convey to her that we were helping her achieve her goals. We worried that we were torturing her for little gain. Since her departure, we have not stopped questioning whether we, as her physicians, did right by this woman.”
What gives patient-physician interactions value?

- Some domains of value seen immediately
  - Access to biomedical therapies
  - Construction of hope
- Others discovered through experience
  - Defining quality of life
  - Information handling
  - Nonabandonment
- What’s missing: how do physicians talk about costs?
Implications for future studies on value

• How oncologists communicate creates a frame defining what’s important in cancer care

• Some aspects of value are evident to patients at the beginning of illness, others are discovered

• Communication is clinical work that is learned
A definition of value?

Value = (life extension) (life goals) (closure) (happiness) (QOL) (costs to self) (family costs) (societal cost)
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National Cancer Institute
National Institute of Nursing Research
Lance Armstrong Foundation
Project on Death in America
So, could we have all your stuff after you die?

Doctors without boundaries