Approaching Patients and Family Members Who Hope for a Miracle

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The lens of the provider
The lens of the family
“Yeah, but good luck getting it peer-reviewed.”
The Case
The Lung Mass
It’s Bad
The Mother:

“Do Everything...
I am hoping for a miracle”
The Physician
Fundamental Attribution Error
Behavior

Situational attribution

Dispositional attribution

Reaction

JERK
Why would a reasonable, rational, and decent person do that?

Paterson K et al. Crucial Confrontations. 2005
A Well Designed Question

• Should be clear and focused describing:
  – a patient or clinical problem
  – the intervention or exposure
  – Relevant comparisons
  – and the outcome of interest
Take a step back, why isn't a chaplain giving this talk?
A Well Designed Question

• Should be clear and focused describing:
  – a patient or clinical problem
  – the intervention or exposure
  – Relevant comparisons
  – and the outcome of interest
5 Questions
Question 1

- Among the general public, what is the prevalence of the belief in miracles or divine intervention?
Not an uncommon hope in general

• 79% of US population believe that “miracles still occur as in ancient times”
• Little difference based on age
• Majority of respondents from every major religion and those unaffiliated with any religion agreed

-- Religion among the millennials. Pew Research Center, 2010
A common hope in the context of health care?

- A patient in PVS could be saved by a miracle

- Divine intervention from God could save a person even if the physician told them “futility had been reached”.

A common hope in the context of health care?

- Survey of 1006 adult Americans and 774 trauma professionals
- A patient in PVS could be saved by a miracle
- Divine intervention from God could save a person even if the physician told them “futility had been reached”.

A common hope in the context of health care?

- Survey of 1006 adult Americans and 774 trauma professionals

- A patient in PVS could be saved by a miracle
  - 61% of public respondents
  - 20% of trauma professionals.

- Divine intervention from God could save a person even if the physician told them “futility had been reached”.
  - 57% of public respondents

Question 2

- Among Patients With Advanced Illness or Their Surrogates, What Is the Meaning of “Hoping for a Miracle” When Used in Medical Decision Making?
So What is Meant When Patients or Surrogates “Hope for A Miracle”? 
What is Meant by the Hope for a Miracle?

• A belief in a divine supernatural intervention that supersedes the laws of nature
• A manifestation of denial of impending loss
• An expression of hope or optimism about the possibility of unexpected recovery
• An expression of anger, frustration, or disappointment over certain aspects of medical care

• Sulmasy DP. South Med J 2007
• Delisser HM. Chest 2009
• Lo B, et al. JAMA 2002
"I sure hope the negotiations go well."
The role of health care providers in the hope for miracles?

• 1997 telephone survey of 1033 individuals living in the southeastern United States

• 88% respondents believed in religious miracles
  – 63% responding “definitely” in their belief.

• 80% said that they believed God acts through medical doctors to cure sickness
  – 49% reporting that they definitely believed

Question 3

• Among Patients With Advanced Illness or Their Surrogates, Does the Belief in Miracles or Divine Intervention Influence Medical Decision Making?
Miracles and Decision Making

• 68 African American and white patients with an advanced stage of lung or colon cancer

“To what extent do you believe in divine intervention or the possibility of a miracle that might change the course of your illness?”

Religious Coping and Decision Making

- 345 outpatients with advanced cancer followed from baseline interview until death
- 78.8% reported that religion helps them cope "to a moderate extent" or more
- High level of positive religious coping at baseline was significantly associated with the receipt of:
  - Mechanical ventilation during the last week of life (11.4% vs 3.6%)
  - Intensive life-prolonging care (13.6% vs 4.2%)
  - less advanced-care planning in all forms, including DNR orders, living wills, and DPOA-HCs

- JAMA. 2009;301:1140-1147.
Reluctance or Unwillingness to Believe Physicians

- 50 surrogates of critically ill patients given hypothetical prompts regarding their loved one
- 64% of expressed a reluctance or unwillingness to believe physicians' futility predictions
  - Futility = absolutely no chance of surviving hospitalization
- The four main reasons for this were:
  - Skepticism about physicians' prognostic abilities
  - A need to see for themselves that a patient was incapable of recovery
  - A need to triangulate multiple information sources before believing physicians
  - A belief that God could intervene to change the course of a hopeless situation

Reluctance or Unwillingness to Believe Physicians

• 1/3rd doubted a physician’s ability to predict futility based on religious grounds
  – More likely in a hypothetical scenario to request continuation of life support despite very poor prognoses.

What % of surrogates rely solely on the physicians estimate when determining prognosis?
Reluctance or Unwillingness to Believe Physicians

- Relied Solely on Physicians Estimates: 2%
- Did not rely solely on physicians estimates: 98%

Boyd et al. Crit Care Med, 2010; 38: 1270-1275
Reluctance or Unwillingness to Believe Physicians

• How surrogates estimate prognosis
  – Surrogates knowledge of the intrinsic qualities and will to live of the patient

Boyd et al. Crit Care Med, 2010; 38: 1270-1275
No matter what.

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  - Surrogates belief in the power of their support and presence
  - Surrogates optimism, intuition, and faith

Boyd et al. Crit Care Med, 2010; 38: 1270-1275
For 20% of surrogates, a faith in God overrode any other source of prognostic information

- Boyd et al. Crit Care Med, 2010; 38: 1270-1275
Tell us about the patient to find the best calculator

1. Where is the patient
   -- select --

refresh page

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Question 4

• Among patients with advanced illness or their surrogates who hope for miracles, does the support of spiritual needs by medical teams decrease the likelihood of aggressive end-of-life care?
Coping with Cancer Study

• 343 outpatients with advanced cancer followed from baseline interview until death

• Are they getting support?
  – 60% reported spiritual needs were minimally or not at all supported by the medical system
  – 54% reporting that they had not received pastoral care visits.

Coping with Cancer Study

- Does Spiritual Support by them Medical Team Impact Outcomes?
  - Full Sample:
    - Three-fold greater odds of receiving hospice care
    - No association with receipt of aggressive end-of-life care
  - High Religious Coping:
    - More likely to receive hospice care
    - Less likely to receive aggressive end-of-life care
The Nature of Suffering

The division of the human condition into what is medical (having to do with the body) and what is nonmedical (the remainder) has given medicine too narrow a notion of its calling.
Question 5

Among patients or surrogates who hope for miracles, is there a communication approach that decreases the likelihood of aggressive end-of-life care or improves bereavement outcomes?
Proactive Communication and Bereavement Brochure

• Family members of 126 dying patients in 22 French ICU’s

• Intervention
  – Proactive end-of-life conference
  – A Bereavement Brochure

VALUE communication system

(V) Value and appreciate what surrogates communicate
(A) Acknowledge their emotions with reflective summary statements
(L) Listen carefully
(U) Understand who the patient is as a person by asking open-ended questions
(E) Elicit questions.
“I really appreciate that you have told me about your hope in miracles, can you describe what a miracle look like to you”

“I see how hard this is for you”

“Tell me what your son enjoyed doing…”

“What would your son think of all this?”

“As you think about your son’s illness, what else do you hope for?”
Proactive Communication and Bereavement Brochure

• Conflict:
  – Increase in the number of relatives who eventually agreed with physicians after an initial disagreement regarding decisions to forgo life-sustaining treatments.

• Bereavement (90-day postmortem follow-up)
  – Decrease in symptoms of posttraumatic stress, anxiety, and depression.

"The soul is like a wild animal...tough, resilient, resourceful, savvy, and self-sufficient: it knows how to survive in hard places. Yet despite its toughness, the soul is also shy. Just like a wild animal, it seeks safety in the dense underbrush, especially when other people are around..."
“If we want to see a wild animal, we know that the last thing we should do is go crashing through the woods yelling for it to come out. But if we will walk quietly into the woods, sit patiently at the base of a tree...the wild creature we seek might put in an appearance.”

A Hidden Wholeness
To Sum Up

• Belief in miracles is common and likely impacts decision making at the end-of-life
• It is important to determine the meaning and significance of the “hope for a miracle”
• Good to get a chaplain involved, however spiritual support by other members of the medical team remains important
To Sum Up

• Proactive communication that VALUE’s what surrogates say may open lines of communication so all parties can appreciate the full range of options available, including those that ensure comfort while maintaining hope.
Palliative Care Rounds: Towards Evidence-Based Practice
Edited by Erik K. Fromme, MD, and Robert M. Arnold, MD, on behalf of Society of General Internal Medicine End-of-Life Interest Group

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"I think you should be more explicit here in step two."
Questions

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