“It’s All in God’s Hands”

Understanding and responding when this statement arises in medical decision making discussions
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Case 1; Act 1

Ms. Edi’s Story:
“She’s not born again,
but we’re hoping for a miracle.”
Intersecting Frames of Reference

- Patient’s
- Provider’s

Our Encounter
Provider’s Perspective
Dealing with emotional content of cases

- Identify **Risk Factors** that predispose to emotions adversely affecting patient or provider
- Monitor for **signs/behaviors and symptoms/feelings** affecting patient care
- Identify **sources** of the emotion
- **Name/accept/normalize** the emotion
- **Reflect and respond** constructively to the emotion

Provider’s Perspective
Dealing with emotional content of cases

- Constructive response to presence of emotion
  - Consider implications/consequences of behaviors
  - Think of alternative outcomes
  - Consult trusted colleague
  - Choose professional behaviors
  - Step back from the situation to gain perspective

Patient and Family Perspectives

Internal Influences

- Distrust of medicine
- Flawed understanding of palliative philosophy
- Religious beliefs
- Cultural and language issues
- Unresolved grief and loss experiences
- Guilt
- Fear
- Previously held expectations

Patient and Family Perspectives

External Influences

- Media images/information
- Family influence
- Religious directives, doctrine and leaders
- “Professional” advisors outside the team
- Tendency towards litigation

What does it really mean?
“It’s all in God’s hands.”

- Do EVERYTHING! God will determine the outcome
- Passive decision making styles - not making a decision IS a decision
- When advance directives are NOT in place and the family is afraid to decide
- General disagreement with “medicine”
- God “owns” the body- we won’t interfere with God’s doings
- Sanctity of life vs. quality of life??
What does it really mean? “It’s all in God’s hands.”

- Belief in miracles
- “I’ve beat it before”
- Inability to tolerate ambiguity: everything should be black/white.
- Avoidance expressed in religious language
- Mistrust because of past discrimination
- Belief that suffering has redemptive value
- Respect for Mystery
Styles of Religious Coping

- Passive Deferring/Pleading Style
- Self-Directed Style
- Active Surrender Style
- Collaborative Style

Religious Coping

- Passive Deferring/Pleading Style
  - Control is centered in God
  - Miracle-pleading
  - God makes things happen for a reason
  - RISK: lose faith or blame self/other when miracle doesn’t happen

Religious Coping

• Self-Directed Style
  – Control is centered in self; God is passive
  – God gives people tools and resources to solve problems for themselves
  – RISK: too many factors are beyond our control, therefore can result in self/other blame and depression

Religious Coping

- Active Surrender Style
  - Control is centered in efforts to work through God
  - The responsibility for problem-solving is surrendered to benign Being
  - RISK: lower self-esteem, but higher acceptance of outcome

Religious Coping

- **Collaborative Style**
  - Control is centered in mutually active, partnership-relationship between God and the individual
  - “God and I will make it through...God will help me figure out what to do.”
  - This style consistently points to constructive coping with stress.

FOUR EXPECTATIONS

- **AUTOGENESIS:**
  “I am the master of my fate.”

- **SYNERGISM:**
  “I am in tune with the infinite.”

- **EMPATHY:**
  “God experiences WITH me.”

- **MONERGISM:**
  “God worked a miracle IN me.”

Let’s take a step back: some principles to consider when any patient or family is making a decision…

- Ethical Issues: autonomy
- Legal issues: Capacity vs. competence
- Medical Futility issues
Medical Ethical Considerations:

- The principle of autonomy
  - An adult with full capacity to decide has a “full and perfect right” to determine what can be done to his or her body.
  - Recognized in ethics, medical practice, and law.

Capacity vs. Competence

- **Decision making capacity**: the ability of a patient to make decisions for a specific medical intervention
  - Performed by Physician and Health Care Team

- **Competence**: Global decision making ability involving multiple aspects of daily living
  - Determined only by a court of law
Is Our Patient Decisional?
Bedside Method of Evaluating Capacity

- Can the patient *receive* information?
  - must be awake, not necessarily oriented to person, place, time and situation.
- Can the patient *process* the information?
- Can the patient *communicate* his or her preferences?

Decision-Making Capacity: Things to look for

- Understanding
- Task-specific
  - “sliding scale view” demands a higher level of certainty when the decision carries risk of greater harm
- Logical
  - Severe depression or hopelessness may make some cases very difficult, consult psychiatry for help with this.
- Time-specific
- Consistent

A decisional patient may choose:

- **INFORMED REFUSAL:**
  - Based on autonomy, patients may refuse any procedure, treatment, or even the advice of their physicians.
  - “The fact that this refusal is seen as ill-advised or even irrational by the physician does not counter moral, social, and legal norms which hold that competent patients have the right to determine their destinies”.

- **INFORMED CONSENT:**
  - Review risks, benefits, alternatives of medical procedure or therapy.

Medical Futility Issues

- Families insist on futile treatment when:
  - Disagreement re: prognosis
  - Rejection of physician authority
  - Distrust of Western medical systems
  - Belief in Miracles

Medical Futility Issues

● Ineffective Tactics:
  – Using “facts”: the disagreement is NOT about facts but about values
  – Saying that miracles are impossible: try to reframe the miracle
  – Using the family’s religious terms to get them to agree with the plan can be manipulative
  – Pressing the issue over and over: try LISTENING!

Medical Futility Issues

What to do?
- Clarify patient’s concerns/beliefs/needs
- Acknowledge importance of religion
- LISTEN!
- Identify common goals of care
- Mobilize support for the patient and family

Acknowledging and Reducing An Inherent Power Differential

- On whose ground are we meeting? (physically and ideologically)
- Whose vocabulary is primary here?
- Social or historical context of this encounter?
- How have I been trained to see this person and this “population”?

Acknowledging and Reducing An Inherent Power Differential

- Who calls for/facilitates the meeting?
- Who speaks first? Who listens?
- Does the patient speak for self? Who does?
- Who determines who speaks for the patient?

RESPECT, REVERENCE, COMPASSION, CURIOSITY

- Acknowledge that provider’s past experience will influence the encounter
- Use open-ended questions
- Use clear, non-technical language
- Use translator services
- Involve the pt’s own spiritual guide
TOOLS

- Review Goals of Care
- Reframe possibilities in the POSITIVE
- Plant seeds for further discussions
- Build an alliance with the patient and family
TOOLS

- Create a safe place for the discussion both physically and emotionally
- Document communications frequently
- Continue to inform and educate the patient and family
- Consider unarticulated grief or guilt
- For an impasse: consider ethics consultation
Recognize where the patient is and go one step beyond, offering hopeful reframing of “It’s in God’s hands”

Remember: two opposite strong beliefs cannot be held by a person at the same time: “I’m going to live to 85” may not be possible with a terminal diagnosis
TOOLS

- LISTEN!!! At least four times longer than you speak.
- Always remember to debrief with the care team.
Taking a Spiritual History

- S: Spiritual Belief System
- P: Personal Spirituality
- I: Integration with spiritual community
- R: Ritualized practices and restrictions
- I: Implications for medical care
- T: Terminal events planning

What’s my Line?

- When the patient or family is depending on a miracle (medically inexplicable event) and their assumption is that God works mostly through miracles.
What’s my Line?

- When the patient refuses to give up on the God of Faith. To withhold interventions would be premature therefore “Let’s wait on God”.
What’s my Line?

- When the patient says, “Preserve life at all costs.”
What’s my Line?

- When the patient believes in the redemptive value of suffering.
...and...when in doubt...

- It’s okay to be the “dummy” and walk on through the land mines.
  - Don’t take yourself too seriously.
Questions to ponder upon…

- In the end, is everything *really* out of our hands anyway?
- Does trying to plan/discuss/anticipate everything not honor the *mystery* of death?
- TIC/TOC, Living/dying, Problem/solution: Ultimately we want our patients to have the experience of caring so that they can conceive a solution
We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.

T.S. Elliot