When Patients Make “Bad” Choices

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Objectives

Participants will:

• Appreciate the potentially conflicting goals of ethics/palliative care
  – With specific reference to patients you’ve treated
  – Identify distinct resolutions to this dilemma

• Reflect on what this dilemma says about us
Goal #1 of Palliative Care

• Respect for autonomy
  – “The patient’s goals, preferences and choices are respected within the limits of applicable state and federal law, within current accepted standards of medical care, and form the basis for the plan of care.” (National Consensus Project)
Goal #2 of Palliative Care

• Beneficence
  – “The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies.” (National Consensus Project)
  – May seem uncontentious, and unlikely to conflict with Goal #1
The Dilemma

- There are certain situations where the patient opts for a treatment course where (we think) the burdens outweigh the benefits
  - Must choose between respect for patient choice (autonomy) and minimizing suffering (beneficence)
  - Highlights that the goals of palliative care aren’t neutral – or universally accepted
Abuse of power:
- Nazi atrocities
- Unethical research (e.g., Tuskegee)
- Impaired professional
Cases that haunt me: B.W.

• Backstory
  – 62-year-old woman with metastatic colon cancer
  – S/P partial resection with open abdomen and multiple fistulae
  – Severe malnutrition and recurrent infections
  – Variable adherence to treatment plans
  – FULL CODE

• Narrative
  – Different philosophy of healing: “Rest makes me stronger.”
  – “Nobody expected me to make it this far.”
  – Willing to place a time limit on CPR
    • 30 minutes
Cases that haunt me: E.R.

• Backstory
  – 5-year-old boy with global developmental delay, sz d/o, and severe tracheo-bronchomalacia
  – Admitted to PICU with aspiration pneumonia and lung consolidation
  – Maximal respiratory and cardiovascular support
  – Mother unwilling to accept prognosis

• Narrative
  – Mother with very strong religious beliefs
  – Mother/MGM convinced God will save patient
  – Eventually told that CPR would not be offered
  – Refused d/c of ventilation, even after cardiorespiratory death
Good judgment comes from experience, and often experience comes from bad judgment.

– Rita Mae Brown
But could anything have been done differently, or better?
Why keep going?

• This is the only life/parent/sibling/child the decision-maker has.
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- Something external is driving the decision-maker.
  - For instance, spiritual beliefs
Role of spiritual beliefs

• **Basis**
  – Notion of “redemptive suffering”
  – Belief in miraculous cure
    • Not impacted by medical developments

• **Response**
  – Respect for spiritual beliefs
  – Clarification of religious tradition
    • E.g., extraordinary/ordinary distinction, or use of feeding tubes, in Roman Catholic thought
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• It is contrary to the patient’s value system to “give up.”
Do Not Go Gentle Into That Goodnight

Dylan Thomas (1914-1953)
Do Not Go Gentle Into That Goodnight

Dylan Thomas (1914-1953)
Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.
Though wise men at their end know dark is right,
Because their words had forked no lightning they
Do not go gentle into that good night.
Good men, the last wave by, crying how bright
Their frail deeds might have danced in a green bay,
Rage, rage against the dying of the light.
Wild men who caught and sang the sun in flight,
And learn, too late, they grieved it on its way,
Do not go gentle into that good night.
Grave men, near death, who see with blinding sight
Blind eyes could blaze like meteors and be gay,
Rage, rage against the dying of the light.
And you, my father, there on the sad height,
Curse, bless me now with your fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light.

Do Not Go Gentle Into That Goodnight
Were more anti-palliative care words ever written?
Avoiding the dilemma

- **Objective**
  - Verify that the decider has all the facts
  - Clarify ethical landscape
    - Especially re: withdrawing and withholding

- **Subjective**
  - Life inventory
  - “Five things that matter most”
  - Addressing feelings of failure and of “giving up”
Clinician Responses to Requests for Nonbeneficial Treatment

1. Refuse on the basis of futility
   – May be institutional

2. Refuse on the basis of professional objection
   – Likely will lead to severing of physician-patient relationship

3. Provide treatment, however grudgingly
Problems with invoking “futility”

- Futility
  - Lack of consensus as to definition of “futility”
  - Medicolegally precarious
    - “To date, in nearly every known case in which the patient has sought treatment and the doctor has objected on the grounds that the treatment offers no medical benefit, courts have found in favor of the patient.” *(American Journal of Law and Medicine)*
  - May make patient feel that treating them isn’t worth the trouble
  - Determined patient may simply seek a more willing physician
Futility’s Many Definitions

Futility has a “variety of meanings ... including the narrow sense -- physiologic inefficacy and inability to postpone death -- and a broad sense -- inability to prolong life for a time, inability to maintain an acceptable quality of life, very low probability of achieving any one of the foregoing.”

Younger, “Who Defines Futility?”
*JAMA* 1988
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Problems with every definition

- **Physiologic futility**
  - The procedure *definitely* won’t achieve its goals
  - Yet: when do we ever say “never”?*

- **Probabilistic futility**
  - The procedure is very *unlikely* to achieve its goals
  - Yet: probability is in the eyes of the beholder

- **Qualitative futility**
  - The goal may be achieved, but the outcome may be perceived as insignificant
  - Yet: bald value judgment
Medical Futility in End-of-Life Care (AMA, 2005)

When further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure. However, there are necessary value judgments involved in coming to the assessment of futility. These judgments must give consideration to patient or proxy assessments of worthwhile outcomes.
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Problems with claiming professional (conscience) exception

- May make patient feel abandoned
- Eliminates possibility of future advocacy
- Minimizes palliative options in the face of a burdensome treatment plan
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Not an original conclusion

By sometimes agreeing to provide futile CPR, we send a message to our communities not that clinicians can be bullied into performing procedures that good medical judgment would oppose, but that our hospitals are invested in treating patients and families with respect and concern for their individual needs ... Providing nonbeneficial CPR can be an act of sincere caring and compassion.

Robert Truog (NEJM 2/11/10)
More than just what to do

How do we provide burdensome treatment that goes against every fiber of our being?

Why is this so hard for us?
“The fiber of our being”

- We’re comfortable with (and conversant in) death
  - And we try to get everybody else to be, too
- We’re empathizers
  - We recognize the reality of suffering, and we know what to do about it
- We pride ourselves on being excellent communicators (and persuaders)
- We like to think our assumptions are universally held, and so don’t constitute biases
This dilemma might say more about us than about “them”
Listen to patients, because they’ll tell you not only what’s wrong with them, but also what’s wrong with you.

– Walker Percy, *Love in the Ruins*
We’re comfortable with death

- But some have never been, and don’t ever want to be

  Do not go gentle into that good night,
  Old age should burn and rave at close of day;
  Rage, rage against the dying of the light.

- An outlook developed over a lifetime
We’re empathizers

- We say we recognize “total suffering,” but could we have blind spots?
  - Do we recognize the suffering of a patient who is spared burdensome procedures at the very end, but is confronted by feelings of failure every moment that precedes it?
  - Could this be “intractable” suffering?

*Grave men, near death, who see with blinding sight
Blind eyes could blaze like meteors and be gay,
Rage, rage against the dying of the light.*
We pride ourselves on being excellent communicators

• And we might feel like we’ve failed when we can’t persuade a patient to adopt a less burdensome course

• Arguably, it’s harder to fail at beneficence (which is our bread-and-butter) than at autonomy
  – The temptation of futility and “slow codes”
Our supposedly “universal” assumptions

• Stated
  – Patients make their own decisions (autonomy).
  – We help minimize suffering (beneficence).

• Tacit
  – Life should not be preserved at all costs.
  – We can talk patients into the “right” course of action.
  – The best response to terminal illness is peace-making.

*Good men, the last wave by, crying how bright
Their frail deeds might have danced in a green bay,
Rage, rage against the dying of the light.*
A potential response
Acknowledge our own feelings

- Palliative care clinicians are willing to enter into suffering
  - We signed up for this job, after all
- But seemingly *needless* suffering is even harder
  - So this is where *we* need a lot of support
Our failure is cognitive, not professional

- The patient’s insistence on a burdensome course doesn’t mean that we’ve “failed” to effect a good outcome
  - It’s a sign that we’ve failed to recognize that what we think is best for the patient, just isn’t what they think is best for themselves.
  - And autonomy can be a rather frustrating principle to honor.
Ironic, isn’t it?

- Palliative care spends a lot of its time trying to convince patients (and other clinicians) that the human body doesn’t always do what we wish it would.
- And now “the enlightened few” are confronted with the same conclusion, this time about the human soul.
Maintain relationship

• Patients can always change their mind, and often do.
  – And if we’re beside them, we can help them chart a different path.
  – Another manifestation of the vagaries of the human soul.

• Fundamental reason not to refuse treatment based on professional objection.
Concluding thoughts

• It still isn’t easy.
  – Kind of like watching a train bear down on a stalled car.

• It is an opportunity for us to learn a lot about ourselves, and to push our limits.

• Maybe, at the end of the day, the best we can do is share with the patient how hard this is for us.
  – They’ll know how much we care.
  – They’ll know we’re ready to help, if they’ll let us.