

# Discussing Treatment Preferences When Patients Want "Everything"

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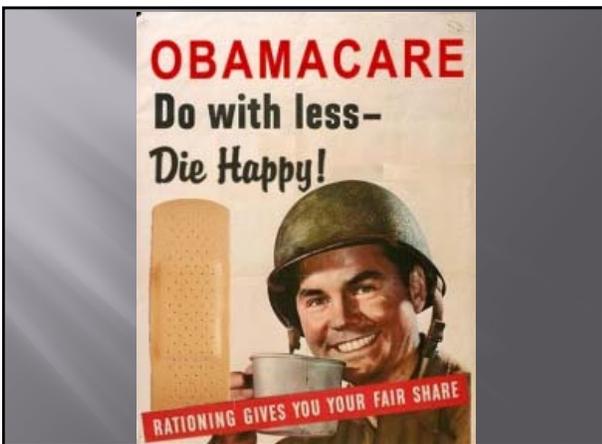
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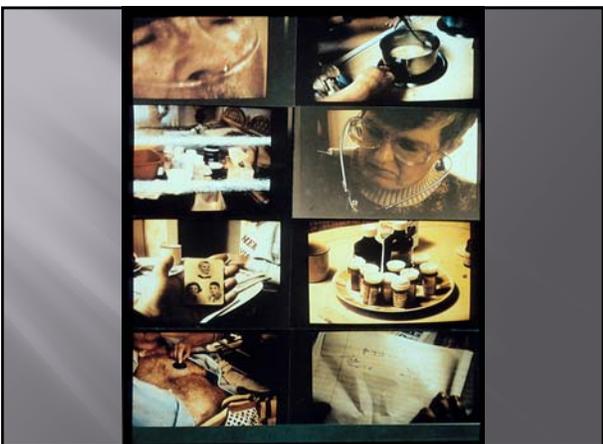


*Dr. Quill has no significant conflicts of interest  
to declare*

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### Background Data: General Medical Care

#### Medical breakthroughs

- Much of our living longer comes from public health and prevention
- New treatments that prolong life substantially for populations are rare
- Medial exaggerations on the evening news
- Substantial money at stake in treatments of marginal benefit
- Some of our interventions have potential to prolong dying

#### Cultural context

- Even with the Affordable Care Act, ~30 million Americans uninsured
- Fear of death; lack of cultural sophistication
- Politicization of healthcare reform (socialize medicine vs "death panels")
- No discussion about limits in health care reform

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### Background Data: Palliative Care

Inadequate pain and symptom management

Inadequate physician training in palliative care

Economic incentives promote over-treatment (once into care)

Physicians overly optimistic prognostication

30% completion of advance directives

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### Definition of Terms

**Palliative Care:** biological, psychological, social, and spiritual care of patients with serious illness

**Goal of Palliative Care:** to produce the best possible quality of life for the patient and family, to assist with medical decision-making, and to provide extra support

**Hospice:** Medicare sponsored program dedicated to provide palliative care for terminally ill patients and their families

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### Some Data from Hospice

Serves about 35% of patients who die in the US

Has broadened admission criteria to serve a wide range of patients

Length of stay tends to be short for those referred

- Median length of stay is about 3 weeks
- Mean length of stay is about 2 months
- About 1/3 are on the program for less than a week

Satisfaction levels are generally very high once on the program

Much variation between sites and regions of the country

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### Palliative Care is Often Not End of Life Care

Many patients seen are cured or have a normal life span

Making informed decisions about disease-directed treatments

Exploring the full range of treatment options

- Aggressive treatments including dialysis, VADs, etc
- Palliative treatments along side disease directed treatments
- DNR/DNI
- Hospice

Symptom reduction, physical / emotional functioning, spiritual well-being

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### Conceptual Shift for Palliative Care

#### Disease-Directed Therapies



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### Unlike hospice, palliative care allows for:

- Simultaneous treatment of underlying disease
- Acute hospitalization including intensive care if needed
- Palliation along side the most aggressive disease treatment
- Much more prognostic uncertainty

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### Patients and Families Who Request "Everything"

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### Key Transitions Where "Everything" Might be Requested

- New diagnosis
  - Evidence-based treatment
  - Watchful waiting
  - Benefits and burdens of treatment
- Treatment not working
  - Evidence-based second line
  - Balance of benefits and burdens
  - Always includes palliative care
- All evidence-based treatment not working
  - Experimental treatment
  - Always includes palliation
- Hospice care
  - Living life fully
  - Minimize suffering

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### Potential Contextual Issues for Patients

- Lack of trust the healthcare system
  - Patients who have lacked basic healthcare in the recent past
  - African Americans, Hispanics and other underserved groups
- Lack of acceptance of one's own finitude
  - Religiously based
  - Personal or family based
- Wish to keep fighting (medically) to the end
  - Equate limit setting with "giving up"
  - Have family obligations as parents, mates,...

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### Potential Meanings of "Everything"

- ...any possibility of prolonging life regardless of suffering
- ...reasonable change of prolonging life
  - but not if it increases suffering
  - even if it causes a modest increase in suffering
  - regardless of its effect on patient suffering
- ...maximum relief of suffering, even if it might shorten life

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### Potential Meanings Underlying Requests for "Everything"

- Affective
  - "Don't give up on me."
- Cognitive
  - "I did not really understand I was that sick."
- Spiritual
  - "Only God can decide when it is time for me to stop."
- Family
  - "My family (husband, parents, children) will never let me go."

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### Clinical Context for "Limit-Setting" Discussion

Medical options becoming more limited

- Failed usual medical treatments
- Impending decisions about invasive treatment with marginal benefit

Medical perception of diminishing returns on treatment

- High suffering and poor prognosis
- Desire to protect patient, family (and ourselves)

Thoughts about futility and causing harm without benefit

- Hard to define with 100% certainty
- Almost always involves a value judgment

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### Before Initiating a "Limit-Setting" Discussion

Make sure all treating teams are "on the same page"

Make sure the main treating physician is in agreement

Decide who is the best clinician to initiate the discussion

- Primary treating subspecialist
- Primary care physician
- Palliative care specialist

Decide who should be there for the discussion

- Include key clinicians (if possible)
- Include key family members
- Include key others from the patient's and family's world

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### Initiating a Limit-Setting Discussion: Step 1

Hear (or re-hear) the patient's story of illness

- Allow patient and family to fully express themselves
- Include what they have been told about treatment options and prognosis
- Patients and families who do not feel "heard" are less receptive to new ideas and recommendations

Information gathered is needed to articulate a treatment philosophy and recommendations that make sense to patients and families.

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### Propose a Philosophy of Treatment: Step 2

*"Given what I have learned about (the patient's) goals and priorities, and what I know about his medical condition and treatment options, I would propose that we..."*

- *"...try any treatments that have a good chance of helping him, but avoid those likely to increase his pain and suffering"; or*
- *"...shift gears toward doing everything we can to keep him comfortable, but avoid any treatments that would add to his suffering"; or*
- *"...keep doing everything that has any chance at all of helping while at the same time try to keep his pain and suffering at a minimum."*

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### Recommend a Plan of Treatment: Step 3

Once you have agreement about a treatment philosophy, then make specific recommendations about what to do and what to avoid

*To give him his best chance at turning this around, but also avoiding treatments that would only hurt him, I would recommend:*

- *Continuing the ventilator and all other treatments we have started for now, but if his heart were to stop, I would recommend against CPR (mechanical ventilation, dialysis) as that would only hurt him without any real chance of bringing him back.*

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### Respond to Emotions: Step 4

Acknowledge

- *"I can see that this conversation is very upsetting to you."*

Legitimate

- *"This news about his condition would be upsetting for anyone."*

Explore

- *"Tell me what is the most upsetting part for you."*

Empathize (if you genuinely feel it)

- *"I can imagine hearing this news for the first time would be devastating."*

Support and nonabandonment

- *"We are going to work this process through with you no matter what happens"*

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### Define Differences: Step 5A

- Problem / prognosis
  - With and without treatment; understanding probabilities
- Goals of treatment
  - Balance of quality of life and survivorship
- Methods of treatment
  - Disease-directed and palliative
- Conditions of treatment
  - Hospitalization, commitment
- Relationship
  - Level of commitment, across settings, contingencies

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### Negotiate Differences: Step 5B

- Understand and review common ground
- Brainstorm and invent new solutions for solving differences
- Avoid power struggles
- Give in if it is not critical
- Propose a "time limited trial"
- Take a timeout
- Get a second opinion

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### "Both/And" Conversation: Hoping and Preparing

- "Lets hope for the best..."*
  - Join in the search for medical options
  - Open exploration of improbable/ experimental Rx
  - Ensure fully informed consent
- "...attend to the present..."*
  - Make sure pain and physical symptoms are fully managed
  - Attend to depression and any current psychosocial issues
  - Maximize current quality of life
- "...and prepare for the worst."*
  - Make sure affairs (financial/personal) are settled
  - Think about unfinished business
  - Open spiritual and existential issues

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### Conversation Confounders

- Emotionally charged
  - Anxiety, fear, denial, overwhelmed
  - Terror management: Fear of death
- Complexity of information
  - Desire to be informed; remember little
  - Framing effects (Tversky) ; internet; multiple providers
- Optimism, pessimism and realism in presentation
  - Hanging of crepe vs. over-emphasize the positives
  - *Hope for the best; prepare for the worst.*
- Specialization, fragmentation and lack of standardization
  - Absence of big picture view; need for a navigator
  - Trust and guidance

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### Nonabandonment: A Critical Value for Clinicians

- Who will the main treating physician for the patient and family through their entire illness?
- A commitment to:
- pursue all reasonable disease-related and palliative options
  - get help when the path is uncertain
  - be honest with compassion about what is truly happening
  - see the process through wherever it goes

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### Two Recent Illustrative Cases

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### Case Number 1

45 year old woman with widely metastatic non-small cell lung cancer, unresponsive to third line therapy

- Unable to eat or drink due to nonsurgical intestinal obstruction
- Severely malnourished, receiving central hyperalimentation
- Had "beaten" two other cancers in the past (breast and thyroid)
- Teenage children at home
- Did not want to talk prognosis, and wanted "everything"

Palliative care consult was reluctantly accepted to help manage symptoms of pain, nausea and vomiting

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### Case continued

Consulting team initially focused on symptom management

- Pain controlled with intravenous methadone
- Nausea and vomiting treated with steroids and venting gastrostomy

Initial time spent hearing her story and gaining rapport

- She was a "fighter" and still thought she could "beat this"
- She had been told things were "hopeless" with her earlier cancers

10 days later, as she got sicker, we proposed a philosophy

- "We want to continue to look for any possible treatment that would help you, but we also want to avoid any treatments that would only harm you."
- "Given that, we will continue to look for treatments to help you, but set a limit on CPR and breathing machines as we feel that would only hurt you."
- Patient agreed with the recommendation, and we stopped asking

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### Case continued

We continued to provide aggressive disease management and intensive palliative care

- She did not want to talk about dying or preparing psychologically
- But she was willing complete her will, make arrangements for her children

We continued to treat complications as they arose

- Initially she hoped to get strong enough for more chemotherapy
- She then hoped to get stable enough to go home

Eventually she became much less responsive

- We shifted to a purely comfort-oriented approach with family consent
- She died peacefully in the hospital several days later

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### Case 2: When requests for "everything" persist...

An 80 year old African American patient with widely metastatic lung cancer who has been fully treated over two years...

- Essentially bed bound
- Weighted 80 pounds
- Eating and drinking small amounts
- Not strong enough for further disease-directed treatment
- Still "full code" and not wanting any limits on treatment

After hearing his story and developing a relationship, we recommended "continuing to look for any treatments that might help, but avoid those that would only hurt", and recommended DNR/DNI

- Despite repeated attempts to set limits, patient would not set any limits
- Patient and family eventually felt we were not listening to them

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### A "Harm Reduction" Strategy

After a good faith effort to protect patients from treatments that appear (to us) to do more harm than good:

- Clearly acknowledge and adhere to the patient's philosophy
- Stop regularly discussing setting limits on treatment,

Address the treating team's discomfort and disapproval

- Communicate the reasoning behind the decision
- Work on other achievable goals (pain management, support, treatment)

Still use clinical judgment to define limits of treatment

- Don't offer or discuss truly ineffective treatment (true futility)
- Consider stopping code after one cycle if patient does not respond

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### Return to the case

Disciplined ourselves to stop asking or recommending limits

- Worked hard to repair our relationship with the family
- Began to work on palliation and treatment at the same time

Worked hard with staff to explain our strategy

- They felt they were abusing the patient
- Required reassurance about the possibility of time limited CPR
- Recommitted to caring for the patient and family

Patient coded in the hospital and CPR was stopped after 5 minutes based on medical futility

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### If requests for "everything" persist...

Continue the search for effective disease-directed therapy...

- A genuine search for evidence-based treatments that would make a difference
- An exploration of experimental therapies

Simultaneously provide the best possible palliative care

- Pain and symptom management
- Support for patient and family

Attend to the support of your staff, your team and yourself

- These cases can be fundamentally upsetting to all involved

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### The Bottom Line

When patients ask for "everything" that should be the beginning and not the end of the conversation

Always start by hearing the story of illness from the patient and family, including experiences, values and priorities

Jointly define a treatment philosophy which takes into account the patients values in context of their clinical situation

Recommend specific treatment plans and limits that are consistent with the patient's philosophy and clinical realities

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### The Bottom Line

Try to find common ground when there are differences

Use a harm reduction strategy when patients still insist on treatments that appear to not be in their best interests

Palliative care should always be part of the treatment plan even if no medical limits are set

Support your staff, your team and yourself when encountering patients and families who seem to be requesting harmful treatments

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### Questions and Comments

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