Case #1 - AA

- AA is an 85 year man with metastatic lung cancer and renal failure who is in the intensive care unit on a ventilator
- He is unable to speak for himself, but his daughter is certain he would always want “everything” to extend his life, except...
- His wife had a severe respiratory illness requiring a tracheostomy, and died shortly thereafter, so he would “never want a tracheostomy”
- He has been on the ventilator for over 3 weeks, and the ICU team clearly recommended a tracheostomy, which the daughter flatly refuses
- Palliative care consulted on the case, recommended setting other limits which the daughter refused, and suggested an ethic consultation
Case #2 - BB

- BB was a 45 year old fiercely independent man who had surgery and radiation for a brain tumor in his early 20’s
- He was cured and did very well leading a very active and full life
- About 8 years ago he began to develop slow deterioration of his brain and his physical functioning with a process similar to ALS such that he now needed help with almost all of his ADL’s.
- He saw correctly that he was progressively losing his independence, and wanted to know what options he had for potentially ending his life
- He consulted with palliative care and discussed potential future options
- Two years later he was ready to end his life, and ethics was consulted

Traditional medical priorities

- Focus primarily on underlying disease
- Careful attention to the basic physiology
- Heavy reliance on technology and biological treatment
- Life prolonging if possible
- Death as the enemy

Additional Palliative Care Priorities

- Relief of suffering
- Attention to pain and symptoms
- Person-centered
- Family and social context
- Spiritual and religious
- Acknowledgement of death as part of the life cycle
Additional palliative care values

• Individual autonomy

• Patient and family centered

• Partnership

• Nonabandonment

Principle-Based Ethics

• Autonomy
  - Respect self determination

• Beneficence
  - Promote well-being

• Nonmaleficence
  - Do no harm

• Justice
  - Protect vulnerable populations
  - Provide fair allocation of resources

Limits of a principle-based approach

• Principles vary in importance between individuals

• Principles sometimes conflict with one another

• Weight and meaning of principles may vary between cultures and between individuals

• Process of getting clear direction and closure from a principled discussion sometimes unclear
Limits of patient autonomy

Reaction away from paternalism
Independent choice
- Closer to abandonment
- Deprived of physician expertise
- Lack of thought and commitment to "best course"

Recommendation and choice
- Utilizing medical expertise and...
- Patient/family values and priorities
- Guidance and choice

Importance of relationship

Caring-Based Ethics

Relationship
Virtue
Narrative
Partnership
Nonabandonment

PARTNERSHIP
Critical Elements

• Understand commonness and differences
• Sharing of expertise
• Mutual influence and understanding
• Negotiation of differences
• Ultimately patient-centered
PARTNERSHIP
Sharing Power and Expertise

• Patient
  – Personal experience
  – Personal values
  – Personal meaning of interventions

• Physician
  – Medical knowledge
  – Personal medical experience
  – Access to medical interventions

PARTNERSHIP
Recommendation and Choice

• Good and bad paternalism
• False autonomy: independent choice
• True autonomy
  – Information and expertise
  – Physician experience and recommendation
  – Patient choice
• Mutual influence

Role of the Palliative Care Consultant

• Dual responsibilities
  – Patient/family
  – Referring Clinician
• Distinct from primary medical provider
  – Solely responsible to patient/family
  – Boundaries jointly negotiated
• Potential conflicts
  – Restrictions on involvement by referring clinician
  – Symptom management vs. goals of care
  – Potential disagreement with overall plan of care
Usual Reasons for Palliative Care Consultations

- Assist with
  - Pain and symptom management
  - Goals of treatment discussions
  - Added support for patient and family
  - End-of-life decision-making

- Sometimes it also includes
  - Mediation among conflicting forces
  - Request to take over attending role (hospice patients)

Usual Reasons for Ethics Consultation

- Assistance with conflict resolution
  - Between providers and patient/family
  - Within families
  - Within or between treatment teams
  - Within a person (ambivalent or unclear)

- Uncertainty about decision-making roles
  - Who is the rightful decision-maker?
  - How should the person make the decision?
  - Does the decision-maker have capacity?
  - Resolving disagreement about best interests

Reasons for Ethics Consultation

- Unclear treatment goals and options
  - Help deciding among reasonable treatment options
  - Treatment offered/encouraged against patient values
  - Requested treatments not part of usual practice
  - Difference of opinion about benefits and burdens

- Clarification of medico-legal questions
  - Do legal precedents have application in this case?
  - Do you want (or need) formal legal input?
Overlap between ethics and palliative care

• Goals of treatment discussions
• Assistance with conflict resolution
• Added patient, family, staff support
• Involvement in difficult end-of-life decisions

Some important distinctions between ethics and palliative care consultations

• Who can request a consultation?
  – Palliative care consult requested by patient’s attending physician
  – Ethics consult can be requested by any member of the healthcare team or patient or family (requestor’s identity can be kept confidential)

• How is the consult paid for?
  – Palliative care paid for by billing insurance
  – Ethics consults are not billed (to patient or insurance); consultants’ time is usually supported by the healthcare organization

Some important distinctions between ethics and palliative care consultations

• Usually team based
  – Palliative care team usually includes physicians, nurse practitioners, nurses, social workers, chaplain, bereavement coordinator
  – Ethics team potentially includes multi-disciplinary clinicians, legal experts, administrators, non-medicine representatives

• Family/clinical team meetings common
  – Palliative care always includes direct assessment of the patient/family, and often meets with members of the clinical team(s)
  – Ethics will usually include a wide range of data gathering, usually including patient/family but often includes a wide range of providers and others
Some important distinctions between ethics and palliative care consultations

- **Medical decision-making authority**
  - Ethics teams make non-binding recommendations, but do not have final decision-making authority
  - Palliative care team is most often consulting, but sometimes takes on attending role (usually for some patients who transition to hospice)

- **Types of decisions addressed**
  - Ethics teams address decision-making processes, goals and boundaries, but usually not specific clinical treatment details
  - Palliative care addresses some of the same issues if straightforward, and frequently include specific, detailed palliative treatment recommendations

Define Areas of Agreement and Disagreement

- **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

Negotiate Differences

Fisher, Ury and Patton: *Getting to Yes*

- 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
Some Legal Myths

- Forgoing life sustaining therapy for an incapacitated patient requires knowledge of his or her actual wish.
- Risk management must be consulted before artificial hydration and nutrition are stopped.
- If physicians order high doses of opioids and/or sedatives to treat intractable suffering, they are at risk for legal prosecution.
- No legally available options are available to address intractable suffering outside of Oregon, Washington, Missouri and Vermont.

Some Legal and Ethical Truths

- Because of legal fears, patients are at much higher risk of under-treatment for their suffering than over-treatment.
- Ethics and legal consultation is highly advisable if treatment withdrawal decisions are being contemplated in patients who have never had capacity.
- Your best protection against legal intrusion is to discuss difficult cases with your team, get ethics consultation on uncertain cases, and carefully document what you are doing.

A Practical Approach

- Clinical Issues
- Patient / Family Preferences and Values
- Palliative Care Issues
- Ethical and/or Legal Dimensions
Step 1: Clinical issues

- What is the medical problem?
- Is it acute, chronic, reversible, critical?
- What are the probabilities of success with treatment?
- What if the plan of treatment is unsuccessful?
- How can the patient harm be minimized?
- Is there agreement among treating teams about these issues?

Step 2: Patient / Family Preferences and Values

- Is the patient medically and legally capable of giving consent?
- If so, what has (s)he expressed about treatment preferences?
- If not, has (s)he expressed prior preferences (formally or informally)?
- If incapacitated, is there a surrogate (who is using appropriate standards?)
- If never capacitated, are there special standards that apply?
- In sum, is the patient’s right to choose being honored to the extent possible?

Step 3: Palliative Care Issues

- Are the patient’s pain and symptoms being fully addressed?
- Are the psychosocial and spiritual dimensions of suffering being considered?
- Are the patient’s (and family’s) personal values being fully integrated?
- Are there significant barriers to or conflict about addressing patient suffering?
- Is the patient’s prognosis understood and being considered fully?
- Are there grounds for recommending a given treatment approach?
Step 4: Ethical and/or Legal Dimensions

- Are there family issues overly influencing treatment decisions?
- Are there provider issues overly influencing treatment decisions?
- Are there confounding financial and economic factors?
- Are there underlying religious or cultural factors?
- Are there problems of allocation of resources?
- Are the underlying legal implications of treatment decisions?

Return to Case 1 – AA the patient whose daughter is refusing tracheostomy but wanting everything

- Step 1: Clinical Issues
  - Patient (daughter) wanted full aggressive Rx but no tracheostomy
  - Tracheostomy is clearly indicated for continued mechanical ventilation
  - Patient will die without ventilatory support
  - Patient will eventually develop major problems from oral ventilation
  - Standard of care is clearly for tracheostomy if full aggressive Rx
  - Full aggressive Rx not standard for untreatable metastatic lung cancer
  - Patient’s prognosis is also poor with full support, but he will die almost immediately if ventilator withdrawn

AA the patient whose daughter is refusing tracheostomy but wanting everything else

- Step 2: Patient / Family Preferences and Values
  - Patient can no longer speak for himself
  - Patient has clearly expressed wishes to avoid tracheostomy
  - Not clear he was envisioning this scenario
  - Daughter is not a formally named proxy, but is the logical (and legal) surrogate decision maker
  - Daughter appears to have patient’s best interests and values in mind
• Step 3: Palliative Care Issues
  – Patient is sedated, and probably not acutely suffering
  – Patient’s quality of life seems poor to staff
  – Daughter believes that patient would make tradeoff of some suffering for continued life – he was always a “fighter”
  – Strong consensus among staff that recovery impossible and that treatment is “futile”
  – Daughter believes that the patient could recover despite being told repeatedly that he could not
  – Daughter would never forgive herself if she allowed Rx to stop

• Step 4: Ethical and/or Legal Dimensions
  – Staff feel they are causing harm to the patient
  – Daughter feels she is protecting and advocating for the patient
  – Scarce resource questions very active among staff
  – Patient has medical insurance coverage which is paying for treatment
  – Reality check – patient is alive and would have died if recommendations were followed
  – No basis for going to court in the absence of public policy

• Questions and discussion...
“Resolution” of the Case

- Daughter was doing her best to advocate for the patient
- Although avoiding a tracheostomy did not make sense medically, it did make sense given the patient/family experience
- Unilaterally stopping treatment based on futility was not an option (though if the patient lived in Texas it might have been)
- No legal/ethical basis for unilaterally overriding the daughters decision
- Team needed to do their best to provide continued ventilation through the current ET tube, try to prevent damage (if possible), and prepare the daughter if and when predicted complications came to pass
- Palliative care team helped support the staff

Any additional questions or comments?

Return to Case 2 – BB the 45 yo man with ALS like syndrome from prior radiation therapy

Step 1: Clinical Issues

- Progressive neurological deterioration very likely to continue
- No medical treatments available to reverse the process
- Full palliative care in place to minimize symptoms and suffering
- Progressive loss of control and independence was his worst nightmare
- Patient had full mental capacity, and did not appear depressed (a psychiatric consultation was obtained to be certain)
- In exploring his last resort options, the only one that made sense in his circumstance was voluntarily stopping eating and drinking
  - No life sustaining treatments to stop or to aggressively palliate
  - No severe immediate suffering to sustain
  - Physician assisted suicide illegal in NY, and even if legal he would not qualify
BB the 45 yo man with ALS like syndrome from prior radiation therapy

• Step 2: Patient / Family Preferences and Values
  – Patient valued his independence and autonomy
  – He had adapted to his disability more than he could have imagined
  – He had been considering last resort options for 2 years
  – He would have preferred the option of physician assisted suicide if available in New York State
  – He had capacity for consent, confirmed by a psychiatrist and by ethics
  – He was fully aware of his alternatives, including continuing palliative treatments which he had been doing for 2 years since initial consult
  – His family supported his decision

• Step 3: Palliative Care Issues
  – He had been working with palliative care for 2 years
  – His treatment was devoted exclusively to his quality of life
  – His pain and symptoms were well managed, and psychosocial and spiritual issues were addressed; he was not depressed
  – He saw his quality of life diminishing as his functional status declined
  – He understood that his function was going to progressively worsen
  – Maintaining independence was at the core of quality of life for him

• Step 4: Ethical and/or Legal Dimensions
  – No major family or social issues confounding the decision (except that his home aides were totally opposed to the decision)
  – Economic issues were also not relevant
  – Religious issues were also not relevant for him
  – His decision making capacity was confirmed by multiple sources
  – The option of stopping eating and drinking in his circumstance is legal (though never tested), though still ethically controversial
  – Needed to explore if this could occur in our inpatient palliative care unit or a local inpatient hospice unit since home would not work
BB the 45 yo man with ALS like syndrome from prior radiation therapy

Questions and discussion...

Resolution of the Case:
- We explored with the staff on the palliative care unit and hospital administration if they would support this process
- Make sure his immediate family would be supportive
- Arranged admission to the palliative care unit, and put him on inpatient hospice there
- Made sure he understood the challenge of fully stopping drinking
- Very meaningful 2 weeks in the hospital "saying goodbye"
- Symptoms were well-palliated
- Died peacefully on the unit

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