Patient-Physician Communication about Therapy for Cancer: *Ethical Issues*

Neil S. Wenger, MD, MPH

UCLA Department of Medicine

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Value in Cancer Care

- Value of cancer care is the net benefit of the treatment in terms of the goals of the patient, accounting for the negative effects of the treatment across all patients and considering the cost of the treatment. Includes the value of having a treatment, opportunity cost of other treatments and closure, and potential alternative use of the healthcare resources.
- Focus on value implies the importance of outcomes for resources invested
  - Not wasting
  - Preserving resources for other valued activities
  - Elements of fairness

Case

- 55 year old man transferred to the ICU after complications of resection of a brain metastasis from NSCLC.
- Lawyer, married late, 4 year old daughter, never smoked. Traveled 40 miles to receive cancer care at academic center.
- 6/07 diagnosed with unresectable NSCLC with L mainstem bronchus and SVC compression.
- Responded to 6 cycles carboplastin/paclitaxel/bevacizumab and maintenance bevacizumab, most recently 10/08.
- 8/08 surveillance whole body PET negative
- 11/08 presented with altered mental status: MRI showed 2 right frontal brain mets. Hospitalized.

Case - II

- Hosp day 11 resection of brain mets, MRI suggests residual tumor
- Hosp day 16 intracerebral bleeding, worsening mental status, ICU team concerned care aggressiveness inappropriate
- Hosp day 27 cerebral imaging suggests tumor progression and fluid collections
- Hosp days 28 and 32 neurosurgical operative drainage attempts

Case - III

- Hosp day 47 worsening respiratory status, ICU team concerned patient will need intubation
- Wife talks with primary oncologist. Dire prognosis explained with progressive metastatic cerebral disease, unresponsive mental status, pulmonary infection with impending respiratory failure . Wife desired any available treatment. Erlotinib discussed but not recommended. “Around 10% chance of response with 2 month life extension” presented. Wife wants continued ICU care for patient to potentially benefit from erlotinib.

Case - IV

- Hosp day 53 imaging showed intracerebral tumor progression
- Hosp day 58 erlotinib liquid started via NG, until now patient was too unstable.
- Hosp day 62 worsening clinical status, hypotension, renal failure. Strained relationship between wife and ICU team. Discussions between wife and primary oncologist aim at comfort care.
- Hosp day 64 care goals change to comfort. Patient moved out of ICU.
- Hosp day 65 patient died comfortably with family at bedside.

Value in Cancer Care

- Value put into practice implies an identifiable metric
  - Transparency
  - Relevance
  - Appeal mechanism
  - Enforcement

  - After Daniels and Sabin

Clinical Impingements on "Value" in Cancer Care

- Use of treatments outside of RCT test conditions
  - These patient clinical characteristics are the basis of cost-effectiveness calculations
- Pressure to rescue in cancer care
- Effect of a rescue treatment on other aggressiveness of care treatment decisions
- *Who is "guiding" cancer care – that is ensuring the value of cancer care?*

Value of Erlotinib in Treatment of NSCLC

- RCT erlotinib v placebo in stage IIIB/IV NSCLC after failed 1st or 2nd line chemotherapy
- Response rate was 9% in the erlotinib group v <1% in the placebo group ($p<0.001$)
- Progression-free survival 2.2 months erlotinib v 1.8 months placebo (HR 0.61, $p<0.001$). Overall survival 6.7 months v 4.7 months (HR 0.70, $p<0.001$).
  - *N Eng J Med*. 2005; 353:123-32.
- Cost of erlotinib treatment $37,000
  - *Lung Cancer*. 2008;61:405-15.

Erlotinib Clinical Trial Inclusion Criteria

Inclusion Criteria	This Patient
18 years of age or older	Yes
ECOG performance status 0 - 3	No
Pathological evidence of NSCLC	Yes
Prior combination chemotherapy	Yes
No other malignancy	Yes
No symptomatic brain metastases	No
No clinically significant cardiac disease	Yes
No significant ophtho, GI abnormalities	Yes

Powerful Motivation to Rescue

- "Our moral response to the imminence of death demands that we rescue the doomed. We throw a rope to the drowning, rush into burning buildings to snatch the entrapped, dispatch teams to search for the snowbound. This rescue morality spills into medical care where our ropes are artificial hearts…..
- Should the Rule of Rescue set a limit to rational calculation of the efficacy of technology?"

  – Jonsen A. *Law Med Health Care*. 1986;14:172-4 quoted in the *J Med Ethics*. 2008;34:540-4.

Patients "Willing to Pay" In the Setting of Rescue

- Seriously ill patients willing to accept much more burden for a chance at benefit
  - Willing to undergo chemotherapy with substantial adverse effects for what chance of cure?

    1% - metastatic tumor patients

    10% - physicians

    50% - nurses

    50% - general public

  - Agrawal & Emanuel. *JAMA* 2003; 290:1075-82.

Cascade of Aggressive Care in the Setting of Rescue

Prognosis not discussed / decline not anticipated →

Patient deteriorates / next steps not discussed →

Clinical deterioration merits intensive care →

Organ failure merits more machines →

Ineffective care promotes undignified suffering →

↓ Healthcare morale, ↑Opportunity costs, ↑ Costs

Case 2

- 30yo M with AML s/p BMT had a complicated course with graft versus host disease.
- 7 months after BMT admitted to hospital with altered mental status. Diagnosed as status epilepticus. Two months of diagnostic procedures failed to distinguish opportunistic infection from immunosuppressant toxicity. Permanent coma: any reduction of 3 antiseizure medications yielded status.
- Infection → respiratory failure → renal failure
- Multiple specialists transiently at bedside: “Nothing irreversible”
- Hematology intermittently present, not directing care
- 5 months after hospital admission, patient bled out in ICU

Arguments Against Changing Treatment Indications in Rescue Cancer Care

- Virtue of a public decision making mechanism is impartiality and justice in balancing of interests
- Personal versus societal response
  - Not a reflection of the principles of fairness or equality
  - "Worst off" may not be the most "deserving"
- No clear "right" to be rescued
- In the setting of chronic illness, rescue may be the result of poor planning
  - Everyone dies, few require rescue
  - Physicians have a role in avoiding the need for rescue

Question Posed to Oncologists….

- "are we willing to restrict access to marginally beneficial cancer therapies because they are too costly for what they do?"
- "…the specific pain will be played out when…oncologists tell internet-savvy cancer patients that the new treatment for their cancer is not covered by their insurance…"

  – Ramsey SD. How should we pay the piper when he is calling the tune? *J Clin Onc*. 2007;25:175-9.

Medical Professionalism in the New Millennium: A Physician Charter

Project of the ABIM Foundation, ACP–ASIM Foundation, and European Federation of Internal Medicine*

- *Principle of primacy of patient welfare.* This principle is based on a dedication to serving the interest of the patient. Altruism contributes to the trust that is central to the physician-patient relationship. Market forces, societal pressures, and administrative exigencies must not compromise this principle.

- *Principle of social justice.* The medical profession must promote justice in the health care system, including the fair distribution of health care resources....

Medical Professionalism in the New Millennium: A Physician Charter

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- **A set of professional responsibilities**

- Commitment to a just distribution of finite resources. While meeting the needs of individual patients, physicians are required to provide health care that is based on the wise and cost-effective management of limited clinical resources. They should be committed to working with other physicians, hospitals and payers to develop guidelines for cost-effective care……

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….The physician's professional responsibility for appropriate allocation of resources requires scrupulous avoidance of superfluous tests and procedures. The provision of unnecessary services not only exposes one's patients to avoidable harm and expense, but also diminishes the resources available for others.

Valued Cancer Treatments at the end of Life?

- Multiple studies show that chemotherapy is not uncommonly given toward near death
  - 20% Medicare patients with metastatic cancer started a new chemotherapy regimen within 2 weeks of death
  - 43% of U.S. patients with NSCLC received chemotherapy within 1 month of death

But…some patients *want* treatments to the very end

Cancer	Patient preferences
Newly diagnosed solid tumors, UK	Elect treatment for 1% chance of cure, 10% chance symptom relief
Glioma, UK	Desired treatments even if no objective benefit - fully disclosed
NSCLC, Italy	Willing to accept even tiny benefit presented pessimistically
NSCLC, US	Median survival threshold of 4½ months if mild toxicity

Source: Matsuyama R, Reddy S, Smith TJ. Why Do Patients Choose Chemotherapy Near the End of Life? A Review of the Perspective of Those Facing Death. J Clin Oncol. 2006; 24:3490-96.

Relationship of Prognostic Guess to Outcome

Patient estimate of 6 month survival	Number (% of total)	Proportion favoring life extending rx	Proportion alive at 6 months
≥90%	543 (59%)	0.51	0.58
About 75%	238 (26%)	0.29	0.31
About 50-50	96 (11%)	0.29	0.21
About 25%	18 (2%)	0.31	0.33
≤10%	22 (2%)	0.21	0.14

Weeks JC, et al. *JAMA* 1998;279:1709-14.

Physicians Miss the Opportunity to Guide Cancer Care at the End of Life

- Prognostication difficult, prognosis uncommonly discussed, oncologists optimistic
  - But most patients want to know
- Inadequate empathetic communication
- Few discussions about adverse health states and the "Cascade of care"
- Minimal discussion about costs of care
  - Disclosure of personal gain, conflicts of interest
- *Guide cancer care decisions*
  - Many patients desire treatments for small potential gains

Box 2. Helpful Questions to Consider Asking About Palliative Chemotherapy

Treatment

What is my chance of cure?

What is the chance that this chemotherapy will make my cancer shrink? Stay stable? Grow?

If I cannot be cured, will I live longer with chemotherapy? How much longer?

What are the main side effects of the chemotherapy?

Will I feel better or worse?

Are there other options, such as hospice or palliative care?

How do other people make these decisions?

Are there clinical trials available?

- What are the benefits?
- Am I eligible?
- What is needed to enroll?

Prognosis

What are the likely things that will happen to me?

How long will I live? (Ask for a range, and the most likely scenario for the period ahead, and when death might be expected.)

Are there other things I should be doing?

- Will?
- Advance directives?
- Durable power of attorney for health care who can speak for me, if I am unable?
- Financial or family legal issues?
- Durable power of attorney for financial affairs?
- Trust?
- Family issues
  - Will you help me talk with my children?
- Spiritual and psychological issues
  - Who is available to help me cope with this situation?
- Legacy and life review
  - What do I want to pass on to my family to tell them about my life?
- Other concerns?

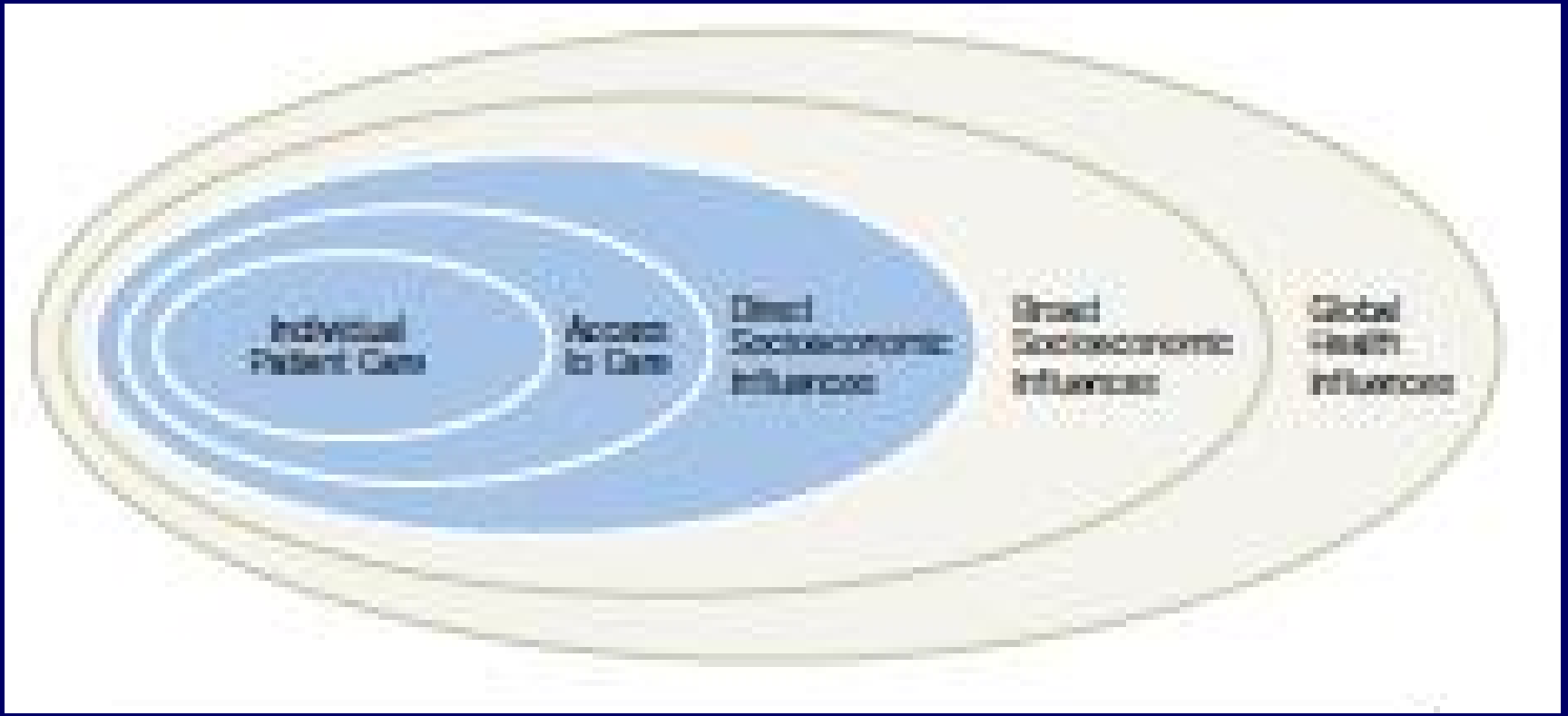
From:

Harrington SE, Smith TJ. The Role of Chemotherapy at the End of Life: "When Is Enough, Enough?" JAMA. 2008;299:2667-78

Case 3

- 72 year old woman presented with GI bleeding 6 years ago.
- Colon cancer diagnosed, met with oncologist and PCP, refused resection or chemotherapy. Continued relationship with these physicians.
- Presented with bowel obstruction, many metastases, sepsis.
- Oncologist and PCP arranged comfort care.
- Out of town family suddenly aware of patient's illness demanded rescue surgery. Patient incapable of decisions.
- Surgeon stepped forward to perform surgery → To the OR.

Physician's Professional Role in Society



-Gruen RL, Pearson SD, Brennan T A. Physician-Citizens—Public Roles and Professional Obligations. JAMA. 2004;291:94-8.

Physician's stewardship role at the Community Level

- Participate in decision making concerning appropriate use of cancer care resources
- Work with health care teams in deciding reasonable treatment options
  - Maintain continuity role in guiding care
- Participate in quality evaluation and improvement efforts
- Participate in setting limits

Case 1 - Epilogue

- Discussion with wife of patient one week after her husband's death:
  - "I needed to hear from *our* oncologist that the treatment should stop, that it would not help. Not that there was something that we could do or might do."
  - "Although I desperately wanted my husband to survive, he and I would even have elected not to have the brain surgery if it was unlikely to help. They needed to say: 'You're dying. This is what you should do.' My daughter never got to be with her daddy in the end."
  - "I still don't know what to say to her."

Summary: Physician's Role in Guiding Cancer Care

- Inform patients/proxies about course, risks and burdens of treatment in an iterative, ongoing fashion
  - Discuss prognosis if patient is willing
  - Continuity of *guidance*
- Work with care teams in deciding reasonable treatment options
- Participate in deciding what is appropriate use of cancer care resources on the policy level
  - Guide patients to receive care that best meets their goals within the constraints of policy level decisions
  - Discuss costs, disclose potential conflicts of interest

Oncology's Role in Guiding Cancer Care – What if:

- Oncology aimed to provide all the cancer care that Americans need by:
  - Fully participating in delineating what is a fair and appropriate cost for cancer care resources at the policy level?
  - Leading a social exploration of when resource-based rules might be suspended for rescue?
  - Demanding that the format of routine cancer care yield data that will continually improve treatment regimens, and explain why standardized approaches cannot be followed?

"Sorry I'm late, but they had me on a life-support system for two months."