

# **When is it time to stop chemotherapy? (If ever)**

Tom Smith MD FACP  
Massey Endowed Professor of Palliative Care Research  
and Medicine  
Massey Cancer Center  
Virginia Commonwealth University Health System  
Richmond, Virginia USA  
tsmith5@mcvh-vcu.edu



# Objectives

1. Know what most oncology patients want to know about their prognosis, outcomes, choices.
2. Know what they are told.
3. Be able to use decision aids about transition points.
4. Why we do and do not do this.

# What patients want to know about their disease

- Patients say they want to know the truth....
  - Of 126 terminally ill patients, 98% said they wanted their oncologists to be realistic (Hagerty 2005)
  - Honesty associated with compassion and caring.
  - Patients want oncologists to be compassionate, stay the course, and be truthful. (Kirk 2004)
- About 5-10% will not want to know.

Reviewed in Matsuyama R, Reddy S, Smith T. JCO 2006; Harrington & Smith JAMA 2008

# What patients know about their disease, and choose

Matsuyama R, Reddy S, Smith T. JCO 2006

- 35 small cell lung cancer patients learned more about their prognosis from other patients than their doctors (The et al, WJM 2001)
  - Doctors did not want to give a death sentence
  - Patients did not want to hear it

# What patients know about their disease, and choose

Matsuyama R, Reddy S, Smith T. JCO 2006

- Patients given high dose chemotherapy & BMT (Lee S, 2001)
  - Overestimated prognosis greatly
  - Underestimated toxicity
  - Doctors overestimated prognosis MOST for those with the worst prognosis
  - Unable to appropriately balance risks and benefits
  - And the over-optimistic ones do not live any longer.  
Lee S, et al. 2003 Biol Blood Marrow Transplant. 2003;9:389-96.

# What patients know about their disease, and choose

- *Two months before death, half of all NSCLC patients had not discussed hospice with their doctors. Huskamp, H. A. et al. Arch Intern Med 2009;169:954-962.*
- *CANCORS; 1512 patients; "After your cancer was diagnosed, did any doctor or other health care provider discuss hospice care with you?" or medical record notation.*
- Only half of patients who died within 2 months after the interview had discussed hospice before the interview.
- Those who expected to live less than 2 years were much more likely to have discussed hospice, 45% vs 11%,  $p < 0.001$
- Almost three-quarters (70%) of patients who had a discussion before the interview used hospice within a year of diagnosis compared with just more than a quarter (26%) of those who did not ( $P < .001$ ).

# What patients know about their disease, and choose

- *Huskamp, H. A. et al. Arch Intern Med 2009;169:954-962.*
- Physicians face a number of barriers - patients and their families
- difficult and time consuming
- not be adequately compensated.
- some prefer to delay the timing of these discussions or not discuss these topics at all—a finding confirmed in our results
- However, among patients who discussed end-of-life care with a physician, many did not have a comprehensive discussion of end-of-life issues. For example, only a third of patients who reported discussing DNR preferences had also discussed hospice, representing a missed opportunity for health care providers and patients.

# What patients know about their disease, and choose

Perspective of those facing death...

Matsuyama R, Reddy S, Smith T. JCO 2006

- We routinely overestimate prognosis to patients with serious illness
  - Meta- analysis: 30-40% overestimate of time left (Glare 2003)
  - Best study of hospice: doctors overestimated to patients by 5.1: 1 (Christakis and Lamont)
  - We don't like to give bad news (Lamont 2002)

# What patients know about their disease, and choose

Perspective of those facing death...

Matsuyama R, Reddy S, Smith T. JCO 2006

- Solid tumor patients who are over-optimistic don't live any longer (Weeks et al, JAMA 1998; Smith & Swisher JAMA 1998)
- But are more likely to
  - Die in ER
  - Die in ICU
  - Die on vent
  - Be readmitted with complications

# What patients know about their disease, and choose

Perspective of those facing death...

Matsuyama R, Reddy S, Smith T. JCO 2006

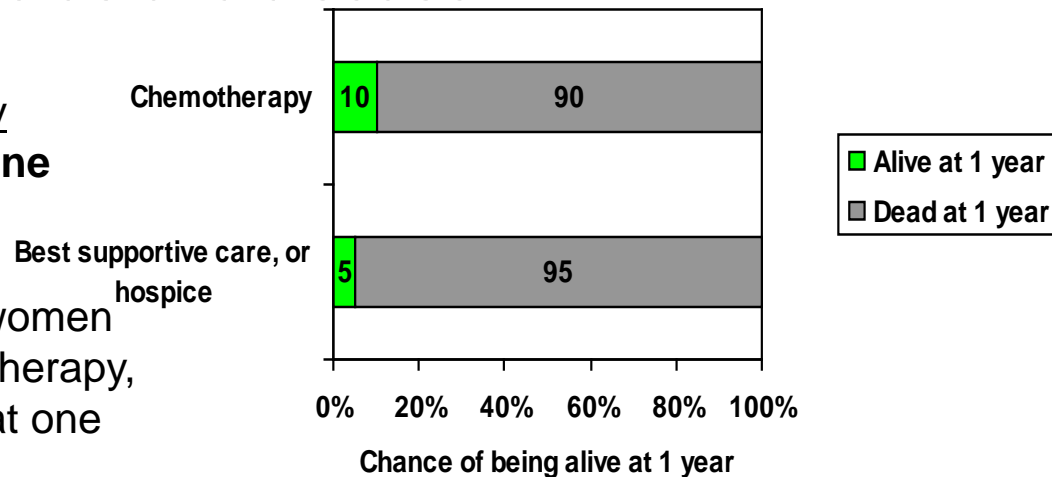
- Some patients may not believe the evidence presented to them, or choose to ignore it.
  - 1988 one third of metastatic lung cancer patients thought they are receiving therapy with curative intent (Mackillop 1988).
  - 1999, 35% of patients believed their palliative radiation was being done for cure (Chow 2001).
  - And that appears to be the same today. (Smith et al, in press)

# We have tested PIFs for metastatic disease

Breast Cancer, fourth line chemotherapy

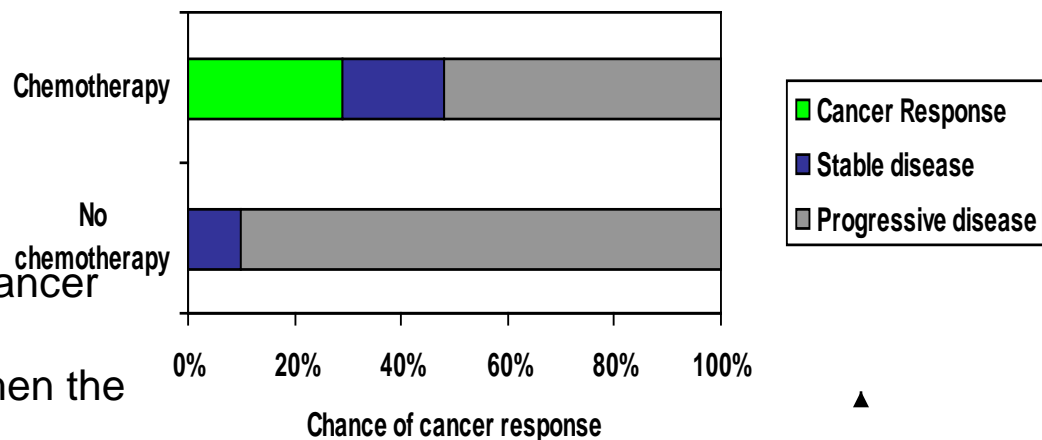
**What is my chance of being alive at one year** if I take chemotherapy, or do best supportive care such as hospice?

Without chemotherapy, about 5 of 100 women would be alive at one year. With chemotherapy, about 10 of 100 women would be alive at one year. (These are estimates.)



***What is the chance of my cancer responding to chemotherapy?***

About 30 of 100 people will have their cancer shrink by half, a “partial response”. This response lasts 2 months, on average, then the cancer grows again.



From  
NLM GO8 LM009525  
Smith T (PI)

# We have tested PIFs for metastatic disease

## Lung Cancer, Third Line Chemotherapy

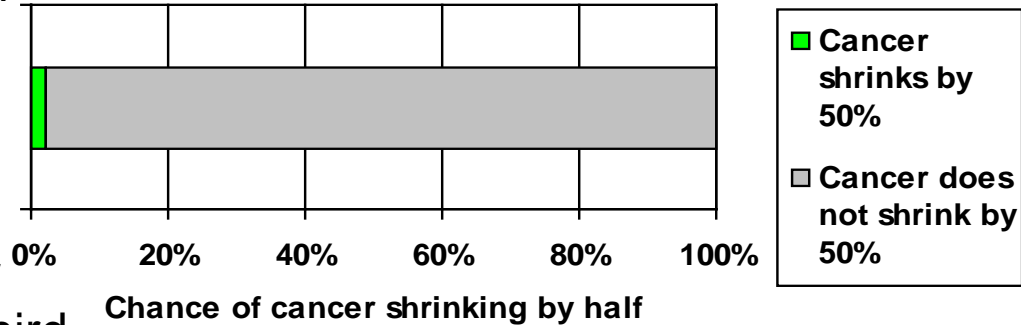
**What is my chance of being alive at one year ....**

Chemotherapy is not likely to improve the chance of being alive at one year.

The average time to live was about 4 months.

**What is the chance of my cancer shrinking by half?**

About 2 of 100 people will have their cancer shrink by half, if this is your third treatment.



**What is my chance of cure?**

There is no chance of cure.

From  
NLM GO8 LM009525  
Smith T (PI)

We have tested PIFs for metastatic disease

**Are there other issues that I should address at this time?**

Many people use this time to address a life review-- what they have learned during life that they want to share with their families, and planning for events in the future like birthdays or weddings).

Some people address spiritual issues.

Some people address financial issues like a will.

Some people address Advance Directives (Living Wills).

For instance, if you could not speak for yourself, who would you want to make decisions about your care? ▲

We have tested PIFs for metastatic disease

**Are there other issues that I should address at this time?**

If your heart stopped beating, or you stopped breathing, due to the cancer worsening, would you want to have resuscitation (CPR), or be allowed to die naturally without resuscitation?

Some people use this time to discuss with their loved ones how they would like to spend the rest of their life. For instance, how and where do you want to spend your last days?

Do you want to have hospice involved? ▲

These are all difficult issues, but important to discuss with your family and your health care professionals.

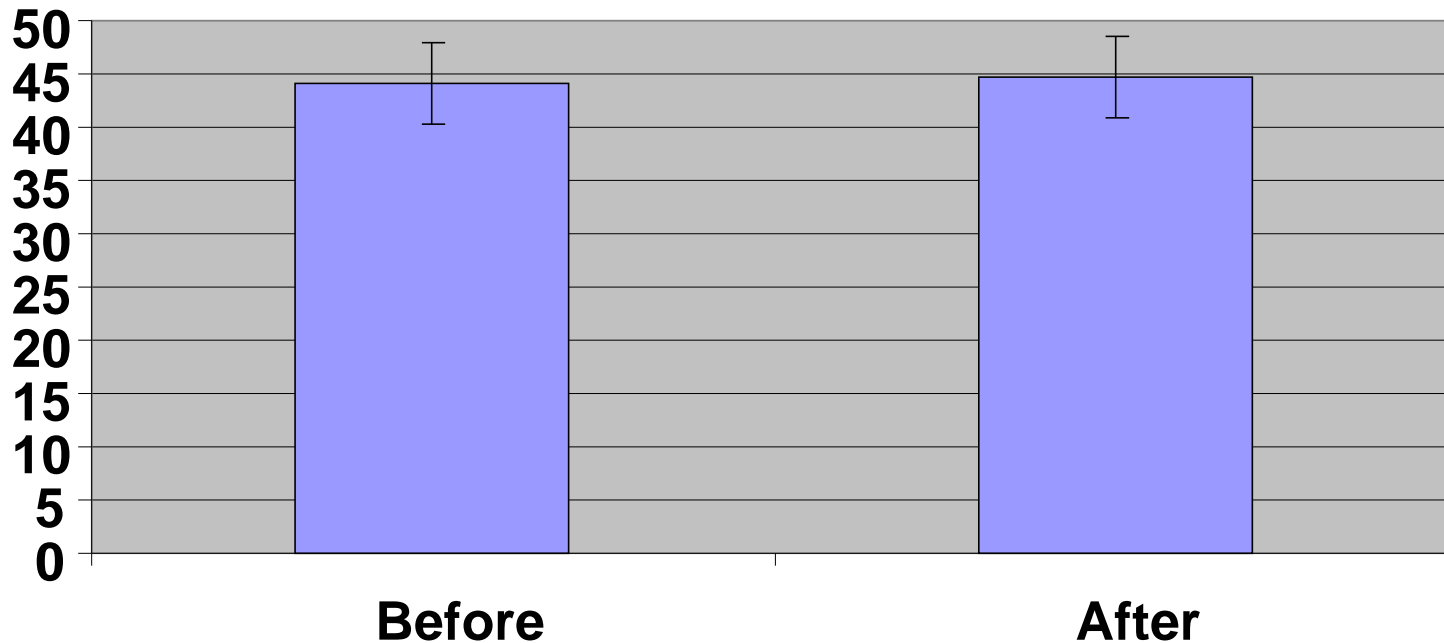
# We have tested PIFs for metastatic disease in 27 patients with metastatic disease

<b>Table 2: Patient knowledge about palliative chemotherapy before and after the PIF</b>				
	<b>Pre</b>	<b>Post</b>	<b>Change</b>	<b>Comment</b>
<b>Can this person with cancer in the bones and lymph nodes be cured by medical treatment?</b>	<b>Yes=14 No=11</b>	<b>Yes=8 No=19</b>	<b>52%→ 27%</b>	<b>Correct answer “no”</b>
<b>What is the chance of his _____ cancer being cured? In %</b>	<b>52.5%</b>	<b>47%</b>	<b>6% more accurate</b>	<b>All over-optimistic</b>
<b>What is the chance of his _____ cancer shrinking by half? In %</b>	<b>60±32</b>	<b>57.5±17.6</b>	<b>-4.2±28</b>	<b>All over-optimistic</b>
<b>What is the chance of _____ cancer symptoms being helped? In %</b>	<b>87±19</b>	<b>74.2±21</b>	<b>-6.7±27</b>	<b>All over-optimistic</b>
<b>How long does the average person live with advanced _____ cancer?</b>	<b>Slightly more realistic</b>			
<b>Herth Hope Index (score from 12 to 48, where 48 is the most hopeful)</b>	<b>44.2</b>	<b>44.8</b>	<b>0.63</b>	<b>Hope ↑</b>
<b>Distress observed by interviewer, nurse, or oncologist</b>	<b>No</b>	<b>No</b>		

Smith TJ, Dow L, Virago E, Khatcheressian J, Lyckholm L, submitted.

Hope is maintained even with truthful discussions that teach RR, PFS, OS, chance of cure, and transitions.  
Smith TJ, et al. Oncology, 2010.

**Herth Hope Index Values Before and After Educational Intervention**



# We have tested PIFs for metastatic disease in 27 patients with metastatic disease

Table 3: Intent to share the information	
Will you share it with anyone?	Yes=20 No=6 NA=1
If so, who? <input type="checkbox"/> My family <input type="checkbox"/> My oncologist <input type="checkbox"/> My oncology nurse <input type="checkbox"/> My primary care doctor <input type="checkbox"/> Other _____	All (family, ONC, PCP) = 14 PCP = 14 Oncologist = 12 Family only = 2
Was this Patient Information Sheet helpful to you?	Yes=25 No=1, "Bummer" NA=2

Smith TJ, Dow L, Virago E, Khatcheressian J, Lyckholm L, submitted.

It is becoming easier for patients to get honest information about metastatic disease.

	NCI Cancer.Gov	Up to Date© Pt Information
Cure	Nothing	Cure is possible, but it is very uncommon in women with metastatic breast cancer.
Prognosis-Survival	Nothing	The average length of survival ... is approximately 24 months
Goals of care	Nothing	...relief of symptoms, improved QOL, longer survival, and a longer progression-free or relapse-free survival
How to transition	Nothing	Nothing

# Paradoxes in why we do not bring up the "D" word

75 patients (most recurrent acute leukemia or lymphoma) admitted to VCH-Massey Oncology service

- 31/75 (41%) had an advance directive...that no one knew about.
- Only 5/75 had discussed advance directives with their oncologist
- Only 16/70 (23%) would *want* to discuss advance directive with their oncologist.
- 86% were willing to discuss advance directives with the admitting doctor ... 95% thought it was important!

Dow L, Kuhn L, Vramakrishnan V, Matsuyama R, Lamont E, Smith TJ. J Clin Oncol 2010

# Paradoxes in why we do not bring up the "D" word

- 75 patients (most recurrent acute leukemia or lymphoma) admitted to VCH-Massey Oncology service
- When given a choice of their doctors, 36/75 (48%) of patients would *prefer* to discuss advance directives with their oncologist, 36% with PCPs
  - But the oncologist had only brought it up in 2 of 75 cases....
  - We must educate patients on why ADs might be beneficial, and train all doctors, esp. oncologists, to *initiate* these difficult discussions.

Dow L, Kuhn L, Vramakrishnan V, Matsuyama R, Lamont E, Smith TJ. J Clin Oncol 2010

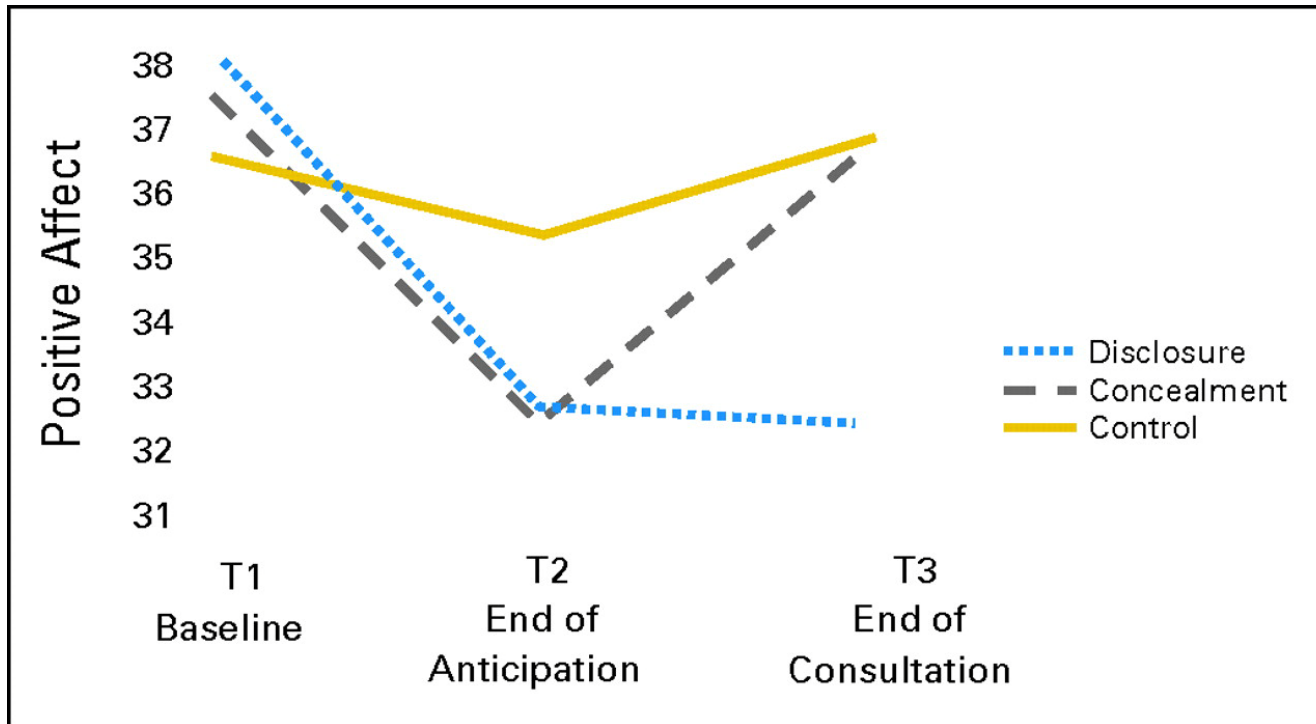
# Why we should bring up the "D" word.

- ADs have never been associated with worse survival in any study.
- *ADs associated with 2.2-fold OR better SURVIVAL in bone marrow transplant.* Ganti AK, et al. J Clin Oncol. 2007;25(35):5643-8. Chung HM, Lyckholm L, Smith TJ, BMT 2009.
- *Being over-optimistic about survival is associated with worse EOL care (ICU, vent, CPR, etc.) and NO better survival.* Harrington & Smith JAMA 2008)

# Why don't we bring up the "D" word? It hurts...*us*.

Task: Tell a 26 year old woman she has inoperable brain tumor, live less than 2 years. Randomized to 3 options:

1. Disclose complete information about diagnosis, prognosis, and treatment.
2. Conceal the true diagnosis, but still refer the patient for treatment.
3. Interview about dietary habits. (control)



Positive Affect goes down, Negative Affect goes up...if you are truthful. Easier to conceal. Panagopoulou, E. et al. J Clin Oncol; 26:1175-1177 2008

# Types of oncologists...and how we deal with death

<b>Themes</b>	<b>Biomedical</b>	<b>Biomed-Psychosocial</b>
<b>Care</b>	<b>Excellent biomedical care</b>	<b>Excellent biomedical care</b>
<b>Role</b>	<b>Curing, not caring</b>	<b>Help patients and families cope.</b>
<b>Relationships</b>	<b>Medical “professional rather than personal”</b>	<b>Interpersonal: Strong relationships</b>
<b>Satisfaction</b>	<b>“no death is satisfying”</b>	<b>“...ordeal...really satisfying”</b>
<b>Emotions</b>	<b>sadness and relief</b>	<b>sadness and relief</b>
<b>Communication</b>	<b>No clear method of transition Few recommendations</b>	<b>Responsibility to make recommendations Experimentation, reflection, role models</b>
<b>Role of PC</b>	<b>PC assumes care Being able to refer KEY skill</b>	<b>PC and ONC work together</b>

# Why bother to bring up the “D” word?

Wright A et al. JAMA 300: 1665-1673, 2008)

**People who have a discussion about dying...(and only 37% did)**

- **No difference in mental health or worry**
- **Less likely**
  - **to want heroic measures AOR 0.52**
  - **To undergo ventilation AOR 0.04**
  - **to be admitted to ICU AOR 0.27**
- **More likely**
  - **To admit being terminally ill AOR 2.77**
  - **Complete DNR AOR 3.46**
  - **To Use hospice AOR 1.99**
- **More family, spiritual, life review opportunities**
- **Better caregiver QOL after death.**
- **\$76 MILLION Difference in EOL care expenditures between individuals who had EOL discussions and those who did not. Saves 31% in last week. Zhang B Arch Int Med 2009**

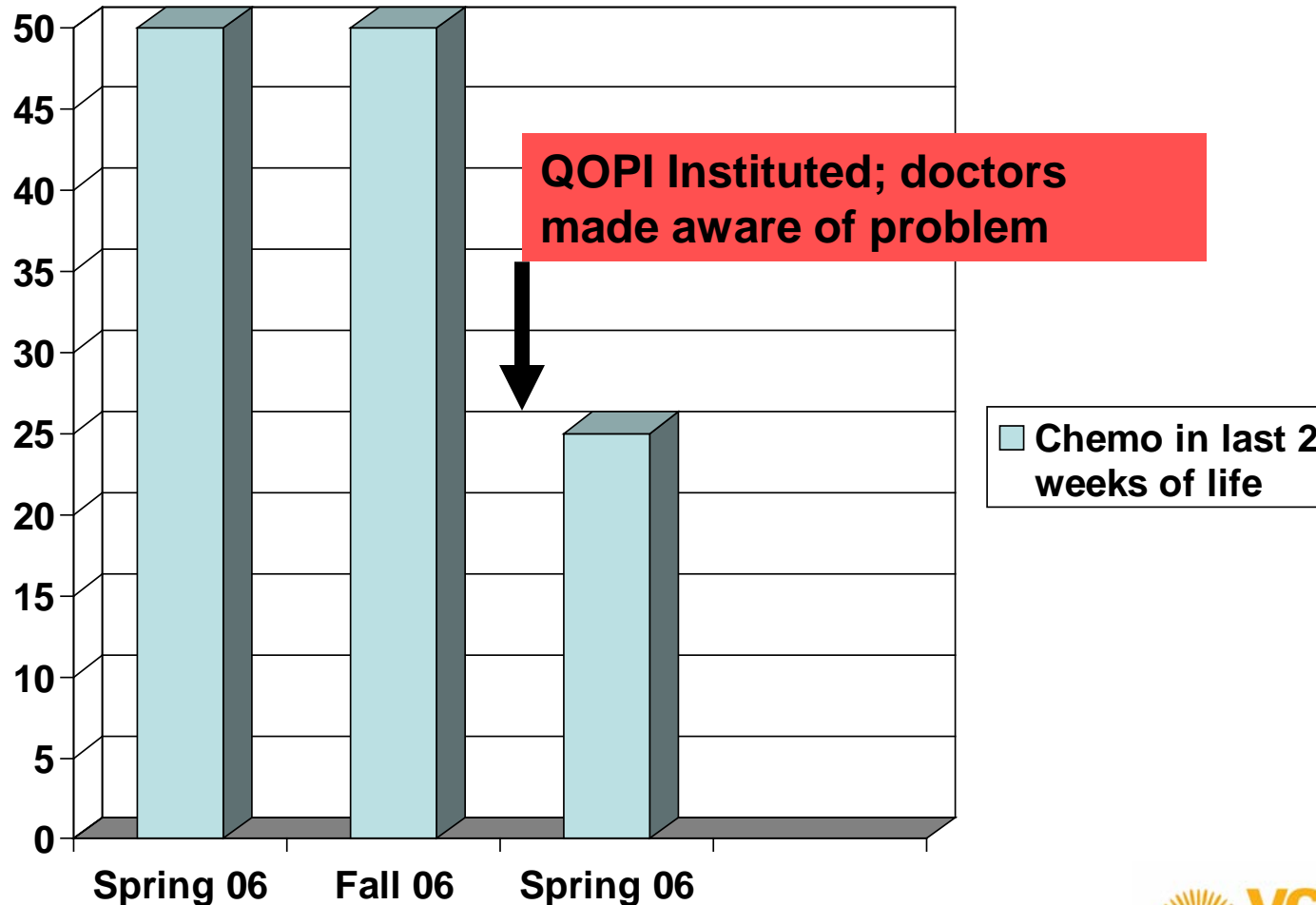
# Triggers for PC/hospice consult or transfer

- When to consult palliative care
  - Anytime a patient has an illness that could be life ending (metastatic BCA).
  - Better to bring it up early, “At some point, there may not be any treatment against your cancer. *There are still things we can do to help.* \* I will ask hospice to help.”
- Triggers
  - Pain > 9.
  - 2<sup>nd</sup> or 3<sup>rd</sup> line chemo?
  - PS ≥ 2?
  - Any malignant effusion, or hypercalcemia
- Do Palliative Performance Scale, and when the survival is short, call hospice *then*.

\*Please, NOT: "There is nothing more we can do."

# Oncologists who receive feedback give less chemo at the end of life.

Blayney D, et al. JCO 2009



# NCCN has useful guidelines

- No response to 3 sequential regimens (Breast)
- ...2 regimens (Lung)
- Or, PS  $\geq$  3 (in bed < 50% of the time)

[www.nccn.org/professionals/physician\\_gls/PDF/breast.pdf](http://www.nccn.org/professionals/physician_gls/PDF/breast.pdf)

# Ways to work with oncologists

- Let them know your expectations
- Give them real time data, ***compared to their peers***
  - Referrals to hospice
  - LOS in hospice
  - %-age referred to hospice with < 7 days LOS

Dear Dr. Smith: Thank you for your referrals. Your average LOS was 3 days (or 17 days). We can help you with referrals for \_\_\_\_\_.

Sincerely, Community Hospice

# Solutions: Better less costly care at the end of life.

Transitions to end of life care (See also Harrington SE & Smith TJ. JAMA 2008)

***When a patient is dying discuss what the future holds.***

**Wright A et al.  
JAMA 300:1665-1673, 2008**

***Only 37% had that discussion.***

- No difference in mental health or worry;
- 52% as likely to have heroic measures
- 4% ventilation
- 27% ICU
- 3.46 x DNR
- 2x hospice

**\$76-300 MILLION Difference in EOL care expenditures between individuals who had EOL discussions and those who did not.**

**Saves \$1000+ (-31%) in last week.**

**Zhang B Arch Int Med 2009**

# Solutions: Better less costly care at the end of life.

<b>Transitions to end of life care (See also Harrington SE &amp; Smith TJ. JAMA 2008)</b>		
<b>Use transition programs <i>alongside</i> usual oncology care. (Spettell CM, et al. J Palliat Med. 2009 Sep;12(9):827-32.</b>	<b>“Compassionate Care Program” - case management (CM) services .... ...computer found services that suggested a terminal illness. ... ...offered CCP (hospice) alongside.... ...few individuals declined these services.”</b>	<b><i>People lived just as long.</i>  Hospice use increased with CM - commercial members from 30.8% to 71.7% ( p&lt;0.0001); -hospice days increased 15.9 to 28.6 (p&lt;.0001)</b>

# Solutions: Better less costly care at the end of life.

Transitions to end of life care (See also Harrington SE & Smith TJ. JAMA 2008)

Use transition programs alongside usual oncology care. (Spettell CM, et al. J Palliat Med. 2009;12(9):827-32.

**IP days reduced**

**-1549 vs. 3986 days**

**-Medicare 2309 vs. 15,217 per thousand members**

**-saves \$32 million per 1000 members @ \$2500/day**

**-ICU days per thousand member**

**-Medicare CM Group; 1189 vs. 9840**

**-saves \$30 million per 1000 members, @ \$3500/day**

**-400,000 cancer hospice deaths**

**-400 (1000) x \$60 million = a lot of \$\$\$**

# Conclusions

- Communication
  - Patients generally want to know everything
  - We don't often tell them everything
  - We should, but we don't
  - But, they may not want to hear it from their oncologist. Then again, they might.
- Consultation - Insurance companies will be your friend!