Communicating About Prognosis: why it is important, and how to improve it

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1. I do not have any relevant commercial disclosures.

2. I have grant or research funding to Johns Hopkins University Sidney Kimmel Comprehensive Cancer Center from
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   - Lerner Foundation (fellowship in palliative medicine)
   - -ib for VEGF driven ascites trial, no financial support
   - Open Society Institute for work in developing countries
   - California Healthcare Foundation to establish web-based decision aids for solid tumors
Disclosure of ABIM Service: Thomas Smith, MD

- I am a current member of the Test-Writing Committee on Hospice and Palliative Medicine.

- To protect the integrity of certification, ABIM enforces strict confidentiality and ownership of exam content.

- As a current member of the Test-Writing Committee on Hospice and Palliative Medicine, I agree to keep exam information confidential.

- As is true for any ABIM candidate who has taken an exam for certification, I have signed the Pledge of Honesty in which I have agreed to keep ABIM exam content confidential.

- No exam questions will be disclosed in my presentation.
Objectives

1. Communication about prognosis is really important
2. We are not doing a good job of successfully communicating prognosis
3. There are some barriers to communication about prognosis, both patient/family and provider
4. There may be some better ways to communicate about prognosis
   A. Truthful information on the Internet
   B. Decision aids
   C. Question prompt lists for patients
   D. Prompts for health care providers
Definitions

1. Literacy
   - the ability to read and write
   - Simplified Measure of Gobbledygook (SMOG)

2. Health literacy
   - ACA: the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.
     - 98 million in 2003; Worse outcomes, more hospitalizations, lower compliance, higher mortality, less use of hospice
     - Older, Black vs. white, poor education, vision....

This is important to PC because 10 Randomized Clinical Trials (4 cancer, 2 MS, 2 mixed patients, dyspnea, CHF) now show...

✓ No harm in any trial
✓ Better satisfaction, and communication with providers
✓ Usually better Quality of Life
✓ Usually better symptom control
✓ LESS depression and anxiety, with more “prognostic awareness”
✓ 4 show better survival, none show worse
✓ No increased cost in any trial
✓ Increase in hospice referrals (lower cost and better survival)
✓ Usually markedly lower costs per day – at least $300/day
✓ Only if you access it.
Dr. Jennifer Temel’s trial got people’s attention

Clinical Director of Thoracic Oncology at Massachusetts General Hospital

Did a randomized trial of usual care vs. usual care + Pall Care for newly diagnosed NSCLC patients at MGH...one PC visit a month.


TAME
• Time
  ✓ 1 hour/month
• Assessment
  ✓ Symptoms (ESAS)
  ✓ Spiritual (FICA)
  ✓ Psychosocial (DT)
• Management
  ✓ protocols
• Education
  ✓ Prognosis
  ✓ Coping
  ✓ Advance Directives
  ✓ Hospice as best care
  ✓ Family coping
  ✓ legacy
Improvement in Prognostic Awareness, with LESS depression and anxiety and better mood

My cancer is curable: Yes or No (right answer is No)

Palliative care v Standard care
82.5% v 59.6%, p=0.02

Temel JS, et al. Longitudinal perceptions of prognosis and goals of therapy....
Palliative care in addition to usual oncology care allowed lung cancer patients to have much better quality of life (FACT), less anxiety and depression, and better MOOD.


Quality of life was Better

LESS depression
LESS anxiety
BETTER MOOD
End of Life Care was of Better Quality by documenting and honoring preferences

<table>
<thead>
<tr>
<th>Variable</th>
<th>Standard Care N (%) or Median</th>
<th>Early Palliative Care N (%) or Median</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documented Resuscitation Preference</td>
<td>11 (28)</td>
<td>18 (53)</td>
<td>0.05</td>
</tr>
<tr>
<td>Hospice Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice care &gt; 7 days before death (marker of good care)</td>
<td>21/63 (33)</td>
<td>36/60 (60)</td>
<td>0.004</td>
</tr>
<tr>
<td>Median days on hospice</td>
<td>9.5</td>
<td>24</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Final Chemotherapy at the EOL was reduced in the PC group

PC patients with accurate perception: IV chemo 9.4% v 50%; P = .02


Palliative care in addition to usual oncology care allowed lung cancer patients to live almost 3 months longer than those who got usual oncology care.

Palliative care in addition to usual oncology care allowed improved survival over most of the lifespan. Bakitas M, et al. Project ENABLE. JAMA 2009
We were not surprised that palliative care could change survival, because better pain management did.

ENABLE III: better survival for community common cancer patients receiving early palliative care compared to delayed palliative care

Marie A. Bakitas et al. JCO doi:10.1200/JCO.2014.58.6362

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**RCT**
- Early vs. Delayed Palliative Care
- High Power
- 4 APN visits by telemedicine

**TAME**
- Time
- Assessment
- Management
- Education

**Graph Details**
- **Overall Survival (proportion)**
- **Time (months)**
- **No. at risk**
  - Early: 104, 98, 83, 62, 48
  - Delayed: 103, 89, 73, 55, 39

Marie A. Bakitas et al. JCO doi:10.1200/JCO.2014.58.6362
Better survival for City of Hope NSCLC patient who received a PC Nursing Intervention + PC consult, compared to usual care

Ferrell B et al. JCO in press
Better survival for patients with dyspnea who received integrated palliative and respiratory care service compared to usual respiratory care at UK King’s College. Higginson I et al. Lancet Resp Diseases 2014

Figure 2: Kaplan-Meier estimates of survival according to study group

TAME
- Time
- Assessment
- Management
- Education
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   C. Question prompt lists for patients
   D. Prompts for health care providers
Current communication between oncologists and their patients is not satisfactory.

— Only 17% of incurable lung cancer patients could guess that their prognosis was less than 2 years. ¹

— Most (69%) of patients with metastatic lung cancer did not understand that chemotherapy was very unlikely to cure their cancer. ²

— 80% of patients want to know the full truth about their diagnosis, even though it may be uncomfortable or unpleasant.³


Most people with stage IV lung and colon cancer report that chemotherapy (and radiation therapy, and surgery) can cure them.

“...69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer.”
NONE of these were associated with ACCURATE or inaccurate response
- Race
- Education
- Functional status
- Patient’s role

Associated with MORE ACCURATE responses
- Care in an integrated network odds ratio, 0.70; 95% CI, 0.52 to 0.94; P=0.02
- Lower scores for physician communication, odds ratio, 1.90; 95% CI, 1.33 to 2.72; P=0.002
Chances of you having INACCURATE prognostic awareness (thinking you could be cured):

- White 1.0
- Hispanic 2.8
- Black 2.9
- Asian 4.32

Don’t know if that’s who you are, who is giving you (or not) the information, combination, or something else
“...oncologists usually tell patients when their disease is not curable.
...disclosure alone may not lead to sustained understanding among patients
....lack of trust in physicians, alternative belief systems, and use of ambiguous language by physicians.”

““Collusion” between patients with cancer and their physicians played a primary role, with a quick transition by both physician and patient from discussion of prognosis to discussion of treatment options and schedule, refocusing attention and leading to false optimism.”

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**Table 2. Odds Ratios for the Association between Various Factors and an Inaccurate Response to Questions about the Likelihood of Cure with Chemotherapy.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio (95% CI)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>Reference</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Colorectal</td>
<td>1.75 (1.29–2.37)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>0.06</td>
</tr>
<tr>
<td>21–54 yr</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>55–69 yr</td>
<td>1.10 (0.77–1.57)</td>
<td></td>
</tr>
<tr>
<td>70–79 yr</td>
<td>1.68 (1.10–2.57)</td>
<td></td>
</tr>
<tr>
<td>≥80 yr</td>
<td>1.47 (0.77–2.80)</td>
<td></td>
</tr>
<tr>
<td>Race or ethnic group</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>White</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>2.82 (1.51–5.27)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>2.93 (1.80–4.78)</td>
<td></td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>4.32 (2.19–8.49)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3.07 (1.50–6.27)</td>
<td></td>
</tr>
<tr>
<td>Integrated health care network</td>
<td></td>
<td>0.02</td>
</tr>
<tr>
<td>No</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0.70 (0.52–0.94)</td>
<td></td>
</tr>
<tr>
<td>Baseline interview type</td>
<td></td>
<td>0.06</td>
</tr>
<tr>
<td>Full</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>Brief</td>
<td>2.32 (1.03–5.26)</td>
<td></td>
</tr>
<tr>
<td>With surrogate for ill patient</td>
<td>0.80 (0.54–1.19)</td>
<td></td>
</tr>
<tr>
<td>Physician-communication score</td>
<td></td>
<td>0.002</td>
</tr>
<tr>
<td>0–79</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>80–99</td>
<td>1.37 (0.93–2.02)</td>
<td></td>
</tr>
<tr>
<td>100</td>
<td>1.90 (1.33–2.72)</td>
<td></td>
</tr>
</tbody>
</table>

* Odds ratios were calculated with the use of multivariable logistic regression. An odds ratio of more than 1 represents a greater likelihood of an inaccurate belief. Listed are variables with P<0.10 in the multivariable model. Full results for all variables that were included in the multivariable model are provided in Table S2 in the Supplementary Appendix.
Patients overestimate the likelihood of cure after surgical resection of lung and colorectal cancer

Kim et al, Pawlik T. Cancer. 19 JUN 2015 DOI: 10.1002/cncr.29530
Patients overestimate the likelihood of cure after surgical resection of lung and colorectal cancer

Chances of you having INACCURATE prognostic awareness (thinking you could be cured):

- White 1.0
- Female 0.79
- Unmarried 0.78
- African American 1.69
- Asian American 7.66
- Education NS
- Income NS

Don’t know if that’s who you are, who is giving you (or not) the information, combination, or something else

Kim et al, Pawlik T. Cancer. 19 JUN 2015 DOI: 10.1002/cncr.29530
It can be health literacy rather than race – after a video about CPR with almost no chance of success, MOST ALL people want comfort care rather than CPR.

Health literacy not race predicts end-of-life care preferences.
Race and experience does influence physician attitudes about EOL decision making, so it is not just education/literacy

1998 questionnaire to black and white physicians about treatments for themselves

- Is tube feeding in terminally ill patients “heroic”?  
  - Black physicians 28%  
  - White physicians 58%

- For Persistent Vegetative State:
  - Black physicians more likely than white physicians to want CPR, ETT/ventilator, artificial feeding 15.4% vs. 2.5%
  - White physicians more likely to want physician assisted suicide 29% vs. 12%

- Brain damage (severe) without imminently terminal illness
  - Black physicians more likely to want aggressive care (CPR, etc.) 23% vs. 5%

The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making.

Mebane EW, Oman RF, Kroonen LT, Goldstein MK.  
You can’t get good information from the Internet either....

We checked ACS, NCI’s Cancer.Gov, ASCO Cancer.Net, Up To Date, and at least one disease specific website

– Only 26/50 (52%), had some notation of 5 year survival.
– Only 4/50 (8%) gave any average or median survival for what the average person could expect.
– Only 13/50 (26%) noted that stage IV cancer was a serious and usually life-ending illness.
– Nearly all had some information about hospice and palliative care. None gave specific recommendations.

Chik I, Smith TJ. Getting Helpful Information from the Internet about Prognosis with Advanced Cancer. J Onc Practice, in press
And most hospice and palliative care information is not readable (literacy)

- End-of-life patient education material, from five nationally prominent palliative care organizations, written above recommended 6th US grade reading level
- About 1/3rd of materials required advanced literacy skills (university level) for full patient comprehension
- End-of-life patient education materials should be revised for average adult comprehension, to help informed decision making and to aid in closing the gap in health literacy


We CAN do better about prognosis, and it changes the process of care

<table>
<thead>
<tr>
<th>Study</th>
<th>Patients and Caregivers</th>
<th>Study Design</th>
<th>Outcome Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clayton et al, J Clin Oncol 25:715-723, 2007</td>
<td>Patients with advanced cancer, caregivers</td>
<td>RCT of <strong>Question Prompt List</strong> vs standard care</td>
<td>QPL - asked more questions - more prognostic issues - more EOL issues (30% v 10%; P = .001)</td>
</tr>
<tr>
<td>El-Jawahri et al, J Clin Oncol 28:305-310, 2010</td>
<td>Patients with malignant glioma</td>
<td>RCT of <strong>video decision aid</strong> on EOL care vs verbal description</td>
<td>Intervention (video) arm: 0% preferred life-prolonging care; 91.3% preferred comfort care Control (verbal) arm: 25.9% preferred life-prolonging care; 22.2% preferred comfort care (P &lt; .001)</td>
</tr>
<tr>
<td>Volandes et al, J Clin Oncol 31:380-386, 2013</td>
<td>Patients with advanced cancer</td>
<td>RCT of a <strong>video decision aid</strong> vs verbal narrative for CPR decision-making and preferences</td>
<td>Intervention (video) arm: - 20% wanted CPR; 79% wanted no CPR Control (verbal) arm: - 48% wanted CPR; 51% wanted no CPR (P &lt; .001)</td>
</tr>
<tr>
<td>Physician-targeted interventions Temel et al, J Clin Oncol 31:710-715, 2013</td>
<td>Oncology providers of patients with advanced lung cancer</td>
<td><strong>Electronic prompts on rate of code status discussion documentation</strong></td>
<td>1 year Code status documentation in EMR: 33.7% v 14.5% (P = .003) Mean time to code status documentation: 8.6 v 10.5 months (P = .004)</td>
</tr>
<tr>
<td>Stein et al, J Clin Oncol 31:3403-3410, 2013</td>
<td>Patients with advanced cancer, caregivers</td>
<td>RCT of <strong>written and discussion intervention</strong> vs standard care on rate and timing of DNR orders, and place of death</td>
<td>Intervention arm vs control arm: Rates of DNR orders equivalent <strong>Median time to DNR order:</strong> 27 v 12.5 days (P = .03) <strong>Hospital death:</strong> 19% v 50% (P = .01)</td>
</tr>
</tbody>
</table>

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.

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?

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.

Hope is maintained even with honest information about prognosis.

Giving honest information to patients with advanced cancer maintains hope.

PMID: 20568593
Decision Aid Upgrade: A Design Challenge

Thomas J Smith, MD, Johns Hopkins Hospital

Truthful Decision Aids for the 10 cancers that cause the most deaths in the US

Coming Late 2015
Change the office practice to recognize transition points and do Ask, Tell, Ask

The JH palliative care communication tattoo
See me for coupons to local tattoo parlors to make it permanent

1. What is your understanding of your situation?
2. How do you like to get medical information?
3. What is important to you?
4. What are you hoping for?
5. Have you thought about a time when you could be sicker...Living Will or advance directive?

What is your understanding of your illness? A communication tool to explore patients' perspectives of living with advanced illness.
The JH palliative care communication tattoo
See me for coupons to local tattoo parlors to make it permanent

1. What is your understanding of your situation?
   • Name the diagnosis,
   • natural history,
   • prognosis,
   • symptoms, and
   • what caused it?

What is your understanding of your illness? A communication tool to explore patients' perspectives of living with advanced illness.
Conclusions

1. Prognosis, and understanding of it (if desired, and 80+% desire), and acting on it makes a big difference.
2. Just as much helpful chemo. Depends on the situation.
3. Much less unhelpful chemo. Much more use of hospice, death at desired place, less distress and caregiver distress.
4. Possibly longer survival.
5. We need
   ✓ Some rewards for doing this tough work
   ✓ Better decision aids
   ✓ Prompts to remind us to do this
   ✓ Communication skills
   ✓ Some way to help ourselves do this.
   ✓ Or maybe having someone else (PC?) do this alongside ONC.
Thank you!

- The Harry J. Duffey Family for supporting the Harry J. Duffey Family Pain and Palliative Care Program
- Terry Langbaum – SKCCC – tireless advocate!
- Pioneers and Persistent Practitioners
  - Rita Moldovan
  - Sydney Dy, Stuart Grossman
  - Suzanne Nesbit
  - Donald List, Louise Knight
  - Coleen Apostol, Lynn Billing
- The JHH Palliative Care Committee
- SKCCC Development Office
- All those who have helped make this program grow
There is some evidence that prognostic awareness is not harmful and is actually beneficial


- Kim SY et al. Patients who were aware survived for a shorter period than did patients who were unaware median survival = 28 vs 35 days, respectively; p = 0.015. Psychooncology. 2013 Oct;22(10):2206-13.

- Ahn E. Psychooncology. 2013 Dec;22(12):2771-8. doi: 10.1002/pon.3346. National survey. Good Death Inventory score was significantly higher among patients who were aware of their terminal illnesses.
Questions for CME and boards

1. Palliative care alongside usual care gives which of the following benefits:
   a. Equal or better survival
   b. Higher patient satisfaction
   c. More prognostic awareness (knowing you have a terminal illness)
   d. Less depression and anxiety
   e. Less cost to patients, families, and society
   f. All of the above

Questions for CME and boards

1. Hospice care gives which of the following benefits:
   a. Higher patient satisfaction
   b. More dying at the place you’d choose
   c. More attention to spiritual care
   d. Less depression and anxiety
   e. MARKEDLY Less family distress
   f. Lower cost to payers and families: $8797 saved. 20% is $\$$.  
   g. Equal or better survival – even of the surviving spouse
   h. All of the above

Kelley AS, et al. **Hospice enrollment saves money for Medicare and improves care** ....
Questions for CME and boards

Oncologists do not discuss prognosis and imminent death with patients because: True or False

1. It will make them more depressed.
2. It will make them more anxious.
3. It is not culturally appropriate.
4. Most people don’t want to know or hear actual figures about survival.
5. No doctor can predict with certainty.
6. It will make them give up hope.
7. Hospice/PC worsen survival.

Mack JW, Smith TJ. Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. J Clin Oncol. 2012 Aug 1;30(22):2715-7


Questions for CME and boards

The best time to have the discussion about imminent death is ______________.

1. ...at least 2 months before you expect the person to die.
2. ...when there are no more chemo or radiation options left to use.
3. ...when it is time to send to hospice.


Questions for CME and boards

The best time to have the discussion about imminent death is at least a month before you expect the person to die. Aim for 3 months.

- More and longer use of hospice
- MUCH less chance of dying in the hospital
- And in the ICU
- And with depressed, distressed relatives (ICU death is the worst)