

Discussing Prognosis with Patients and Caregivers (516)

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(All speakers for this session have disclosed no relevant financial relationships.)

Objectives

1. Determine appropriate timing, quantity, and format for presenting prognostic information.
2. Discuss building skills in exploring and presenting prognostic information to patients and caregivers.
3. Learn to respond to patients' and caregivers' emotions and uncertainties when discussing prognosis.

Most patients and families dealing with severe illness want information about prognosis. However, discussions about prognosis frequently do not occur, and when they do, communication is often problematic. Consequently, patients often have inflated prognostic estimates and make decisions that are not in their best interests. Several factors complicate communication about prognosis. Patients' desires for information about prognosis are variable, change over time, and are not easily predicted by physicians. Seriously ill patients may want less information, while their caregivers want more. Many patients and clinicians do not understand statistics well enough to interpret them. Many patients and caregivers get information from the Internet which they do not discuss with their physicians. Many clinicians feel uncomfortable dealing with the emotional issues around discussions of prognosis.

Clinicians caring for seriously ill patients must be able to assess patients' and caregivers' expectations, ask what they wish to know, explain prognoses in general and statistical terms, use graphics and numbers where appropriate, know when to defer or reinstate discussions, and check understanding.

Session format. About 25 minutes will be data-driven, didactic presentations about patients' expectations for information and emotional support, preferred methods and formats (eg, general terms, numbers, graphical, etc.) for delivering prognostic information, and methods for checking understanding.

About 20 minutes will be skill-building exercises using a case of a real patient whose prognosis changed as the disease progressed. Participants will role-play discussions of prognosis with patients and caregivers.

About 15 minutes will be for discussion.

Domains

Structure and Processes of Care; Social Aspects of Care; Psychological and Psychiatric Aspects of Care; Cultural Aspects of Care

***Discussing prognosis with patients
and caregivers***

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Objectives

Overview of barriers and pitfalls in estimating and discussing prognosis in cancer patients

Review the state of the art and science of discussing prognosis

Develop criteria for timing, quantity and format for presenting prognostic information

Build skills in exploring and presenting prognostic information to patients and caregivers

To apply the process of estimating and discussing prognosis in challenging clinical situations

Sources

Systematic clinical reviews

NCI sponsored review of "Patient-Centered Communication in Cancer Care"

Selected quantitative and qualitative studies

Guidelines and expert opinion

Misunderstanding, Barriers, and Current Practice Patterns

Misunderstandings

1/3 of pts with metastatic disease believed it was localized

1/3 of patients receiving palliative treatment believed it was curative in intent

Most patients overestimate prognosis

They choose more aggressive treatment with no effect on survival or QOL

McKillop 1998, Gattelari 1999

Talking about prognosis in advanced cancer

What is said

- >80% of patients told disease is incurable
- 39-58% told prognosis
- QOL addressed 35% of the time
- Only 27-40% given full range of options (e.g., alternatives to palliative chemo, watchful waiting)

Information does not increase anxiety

Silviera 2000, Gattelari 2003, Koedoot 2004, Ford 1996, Foley 2001

How Well Do Physicians Predict Survival in Advanced Cancer?

(BMJ 2003;327:195-201)

“Correlated but not calibrated”

Overestimate by 30%

“Horizon Effect”

Relationship duration effect

What Patients Want

Information about prognosis and options

Realism with compassion

Hope

Lessening of uncertainty

But Patients May Be Ambivalent and Inconsistent...

Only 55% of patients referred for palliative care in US wanted information about dire prognosis

- Depressed patients wanted more information
- Anxious patients wanted less

Information needs change as death seems more imminent

- Want less information, **want** physicians to overestimate prognosis
- May not want to know that they are dying

Individual and cultural variation

- Older, less well-educated patients want less information
- Cultural beliefs in divine knowledge and intervention

Patients get divergent information from multiple sources

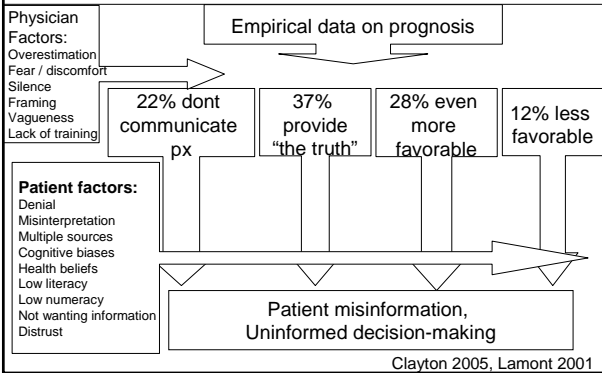
- Internet, relatives, other HCPs, media, etc.

False assumptions: SUPPORT study

- Patients are able to imagine the future– NOT?
- Self-ratings of QOL remain elevated even in advanced disease
 - Previously unacceptable options are reconsidered
- Patients recognize that there are choices – NOT?
- Decisions not "real" until the situation presents itself
 - "Choiceless choice" (M Little)
- Patients want autonomy – NOT?
- Aversion to thinking about unpleasant future events
 - "Responsibility compels us to make hard choices" (Fyodor D.)
 - Want to avoid regret
- Patients consider utilities and probabilities – NOT?
- Impressionistic, heuristic
 - Rule-following - don't want to "rock the boat"

Social influences on patient understanding and choices

- | | |
|---------------------------------------|---|
| Access to information | Trust associated with passivity |
| Patient education, literacy, numeracy | The clinical context |
| "Common-sense" and cultural beliefs | Misarticulated choices
- "Do you want "everything done?" |
| Framing effects | Direct to consumer ads |
| Gizmo-idolatry and technophilia | Social networks |



Should Family Members Be Present?

Most want family members present

Most want control over

- Who is present
- What is discussed

Frequent problems when family is told first

- Reluctant to share with patient
- Cultural variation

Outcomes Associated with Discussion

Open discussion of prognosis

- Increased satisfaction
- Decreased depression and anxiety
- Mixed effect on hope as prognosis worsens

Deceit or withholding of prognostic information

- Decreased satisfaction
- Increased anxiety, depression and distrust
- Choose overly aggressive treatment

Estimating Prognosis

Main Anchor

Specific diagnosis and extent of spread

NCI's Survival, Epidemiologic and End Results (SEER)
statistical software

Stage Specific Survival Curves

- Manuals, textbooks, public data
- Natural history studies
- Randomized controlled studies (if they have a best supportive care arm)

Other Influencing Factors

Vigano A et al. Quality of Life and Survival Prediction in
Terminal Cancer Patients. *Cancer*. 2004;101:1090-8.

Performance Status

- Karnofsky Performance Scale
- Palliative Care Performance Scale

Patient signs and symptoms

- Dyspnea
- Dysphagia
- Xerostomia
- Anorexia
- Cognitive impairment

Other Influencing Factors

Morita T et al. The Palliative Care Prognostic Index.
Supportive Care Cancer. 1999;7:128-133.

Physician Clinical Predictions

- Tend to overestimate survival
- But do correlate

Integrated Models

- Palliative Care Prognostic Index
 - Performance status plus specific signs and symptoms
 - 3 week survival prediction: sensitivity 83%: specificity 85%
 - 6 week survival prediction: sensitivity 79%: specificity 79%
 - Developed and validated on a very sick palliative care population
 - Uncertain generalizability

Discussing Prognosis

Some Potential Triggers

- New diagnosis of serious illness
- Major medical decision with uncertain outcome
- Patient/family ask about prognosis
- Patient family request treatment not consistent with good clinical judgment
- Would you be surprised if the patient died in 6-12 months?
- Patient actively dying

Preparation

- Ensure the facts are correct
 - Review clinical data; literature
 - Talk to consultants
- Estimate average survival and ballpark range
 - How will prognosis change with treatment
 - Seek consensus among key providers
- Invite key people
 - Family wanted by patient
 - Key clinicians; both expertise and relationship
- Protect time; attend to privacy
- Think through what you will say in advance

Ask – Tell - Ask

Ask

- If they want to talk about prognosis
- What they already know, and sources of information

Tell

- Give information in small amounts
- Build on what they already know
- Use simple straight-forward language

Ask

- Repeat understanding of what has been said
- If they would like to hear more
- Repeat as needed

Articulate if Possible

"Ballpark" estimates

- Average survival
- Median survival
- Inter-Quartile Range (IRO) 25% - 75%
- "Vast majority" 10% - 90%
 - Days to weeks, weeks to a few months, 3-9 months,...
- How do these estimates vary with and without treatment?

Acknowledge exceptions in both directions

- A relatively small percent will live longer
- A relatively small percent will live shorter

Ballpark with Exceptions

Caveat:

- *It is impossible to predict for any individual with certainty, but...*

Ballpark:

- *The average person with your illness will live (few weeks to a few months) (3-6 months)...*
- *Treatment, if it works, might extend that time (a month or two)...*

Exceptions:

- *It could be longer, and we will do everything in our power...*
- *Unfortunately, it could also be shorter, so we better get prepared just in case..*

Framing Effects

Odds of dying versus odds of surviving

50% survival data

- *The median survival is 6 months*
- *Half of patients with your illness will die in 6 months*

Ranges

- *75% will be alive for 3 months, 25% will live for 9 months*
- *25% will die in the first 3 months, 75% will die in 9 months*

Patients will make different decisions depending on whether odds are presented in terms of survival or death

- Understanding both dimensions probably best

Tversky: Kahneman. The framing of decisions and the psychology of choice. Science 1982: 211:453-8

Patient and Family Response

Inability to predict for any individual

Ask if it was expected

Respond to emotions (fear, anxiety, shock, anger, numbness)

- Acknowledge /Legitimate /Explore /Empathize /Support

Give everyone a chance to respond, ask questions

Make a Plan

Summarize what has been discussed

What are the next steps?

Make concrete short-term plans

Who will be providing follow-up?

Case Presentation

Initial Presentation

25 year old white male
– Uncle with melanoma
– Father of two young children

Mole on his lower back; observed for a long time

Biopsy – malignant melanoma
– Margins of biopsy negative
– (+) sentinel lymph node biopsy
– 1/20 lymph nodes (+) right axilla
– 0/20 lymph nodes (+) left axilla

Stage III

Other Prognostic Factors

Clark's levels:
– II: invades the papillary dermis
– III: invades to the papillary-reticular dermal interface
– **IV: invades the reticular dermis**
– V: invades subcutaneous tissue.

Absence (A) or **presence (B)** of ulceration

Metastases
– M1a – Skin, subcutaneous tissue, other LN
– M1b – Lung with no other visceral sites
– M1c – Other visceral sites (bone, liver, brain)

Staging
– IIIB
– T4B N2 M0

Other Potential Negative Prognostic Factors

Satellite lesions – discrete lesions clearly separated from the original lesion

Local recurrence: same negative prognostic significance as satellite

Serum LDH elevation

Increasing age

Head, neck, trunk primary worse than extremities

Serum S Protein – marker for worse prognosis

What does the literature say?

Balch et al. J Clin Oncol 2001;19:3628.

What does the literature say?

Balch et al. J Clin Oncol 2001;19:3636

What does the literature say?

Gimotty et al. J Clin Oncol 2005;23:8065

Stage IIIB, 2 positive LN

- 1 year survival – 91-94%
 - (1 year death rate – 6-9%)
- 5 year survival – 50-65%
 - (5 year death rate – 35-50%)
- 10 year survival – 33-43%
 - (10 year death rate – 57-67%)

Does treatment with high-dose INFa help?

Kirkwood et al. Clin Cancer Res 2004;10:1670

Pooled analysis of ECOG and intergroup trials

Effect on relapse free survival (RFS)

- 9 month median prolongation
- 11% absolute increase at 5 years (37 vs 26%)

Effect on survival

- 1 year prolongation in median survival (3.8 vs 2.8 years)
- 9% absolute increase in 5 year survival (46 vs 37%)

Treatment benefit largely in those with Stage III

What does this mean in terms of my future?

What we might tell our patient...

Average survival – about 5 years

75% chance he will live for at least 2 years

25% chance he will live for over 10 years

These odds can be improved modestly with treatment

There can be exceptions in either direction

Return to the Case

One year of treatment with INFa

Additional six months free of disease off treatment

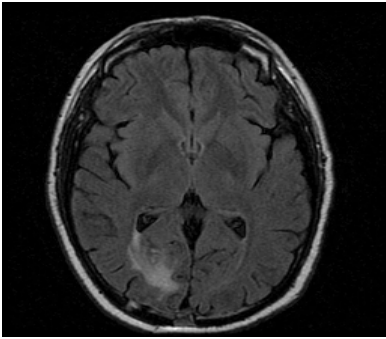
February 2005 local recurrence

- No adenopathy on clinical exam
- No evidence of distant metastases
- Treated with a large local incision

Buzaid et al. *J Clin Oncol* 1997; 15:1039

Return to the Case

- Spring of 2006 presented with R frontal headache
- MRI shows R occipital enhancing mass
- Presented to multidisciplinary brain tumor conference
 - Treatment options and recommendations
 - Information about prognosis
- Family meeting set up to develop a plan



Barth et al. *J Am Coll Surg.* 1995

Prognosis after Palliative Rx of Brain Metastases

Gaspar et al. *Int J Radiat Oncol Biol Phys.* 1997; 37:745

<u>Class</u>	<u>Prognostic Factor</u>	<u>Median Survival (months)</u>
I	KPS \geq 70% Age < 65 years Controlled primary site No extracranial metastases	7.1
III	KPS < 70%	2.3
II	All others	4.2

Karnofsky Performance Scale

<u>Rating</u>	<u>Definition</u>
100%	No evidence of disease
90%	Normal activity with minor signs of disease
80%	Normal activity with effort; signs of disease
70%	Cannot do normal activity but cares for self
60%	Requires occasional assistance
50%	Requires considerable assistance; frequent medical care
40%	Disabled, requires special care
30%	Severely disabled; hospitalization may be indicated
20%	Very sick; hospitalization needed for supportive care
10%	Moribund
0%	Death

What is his prognosis?

- Literature
- Median survival 7.1 months
 - 75% survive 4 months
 - 25% survive 10 months
- Positive prognostic factors
- Single brain metastasis
 - No other visceral or systematic involvement
 - Good performance status
 - Aggressive treatment associated with improved outcome

What does this now mean in terms of my future...

What we might now tell our patient...

*Median survival 12 months
75% will be alive at 6 months
25% will be alive at 18 months*

*Could be longer...
Could also be shorter...*

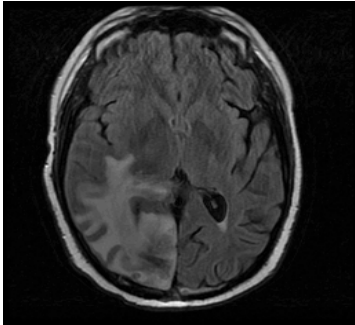
Return to the case

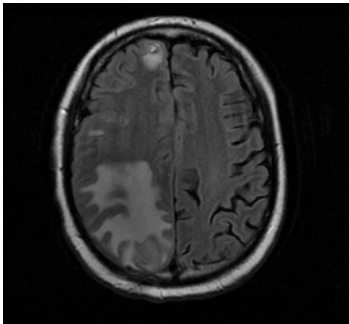
Treated initially with stereotactic radiosurgery followed by whole brain radiation

- Good response in terms of symptoms
- Dose of steroids able to be reduced

Return of headaches after a few months

- Repeat treatments with stereotactic surgery
- Trial of adjuvant temodar





Continue Case

Eventually reached a point where there were no other options available to treat brain

- 4 years after initial diagnosis
- 15 months after diagnosis of brain metastasis

Transitioned to hospice care

- **Prognosis < 6 months**
- Still wanting any treatments that might help
- Aggressive pain and symptom management
- DNR/DNI

Continue Case

Symptoms fairly well controlled

- Methadone
- Steroids
- Gabapentin
- Ativan

Severe new back pain

- 10/10 pain despite major doses of opioids
- Diagnostic evaluation on hospice?
- What treatment options are available / appropriate?

RCT (non-blinded) comparing surgery + XRT vs. XRT alone.
(Patchell Lancet.2005;366:643-8)

101 patients with isolated spinal mets were randomized

- Not highly radiosensitive tumors (germ cell, lymphoma, myeloma)
- Not cauda equina; not brain mets
- Not expected to die within 3 months

XRT was 10 3Gy fractions plus decadron for all patients

Primary endpoint was ability to walk

- 84% surgery+XRT vs 57% XRT alone (p=0.001)
- Median duration 122 days surgery vs 13 days XRT

Need for opioids and steroids decreased in surgical group

Surgery plus XRT had substantially better outcomes than XRT alone in selected patients with isolated spinal mets

What is his prognosis?

Clinical information

- Untreatable brain metastases
- Additional metastases to his back
- KPS about 30%

Prognostic information

- Median survival 4 weeks
- Usual range between 2 weeks and 2 months
- Could be longer and could be shorter...

What are his treatment options?

Surgery not recommended

Short course, high-dose radiation might help

- Similar short-term outcomes
- Long-term outcomes not as good

Need to relieve his pain before discussing prognosis

- Epidural or intrathecal infusion
- Resulted in dramatic relief of his symptoms

How long to you think he has?

What we might now tell his family...

It is hard to predict for any given patient, but...

the average person with his illness will live several days to a few weeks...

it could be longer if we are lucky, but...

it could also be shorter, so we better be prepared...

Return to the Case

Over the next 2 weeks in the hospital

- He had excellent pain relief
- He was unable to move his legs
- His mental status waxed and waned
- He had meaningful alert times with his family

He died peacefully with his wife at his side

- Four years after initial diagnosis
- Eighteen months after diagnosis of brain metastases
- Two weeks after his last hospitalization

Summary

Prognostication requires an analysis of studies, individual factors, and expert opinion

Physicians tend to be overly optimistic about prognosis as it worsens

The approach to telling patients and families about prognosis should be individualized

Summary

A practical approach to talking about prognosis includes

- Using an "ask, tell, ask" strategy
- Be guided by the patient's preference for information (or not)

If the patient does want to know prognosis

- Give a ballpark estimate that includes the majority of similarly situated patients
- Be sure to include outliers in both direction
- Respond to subsequent questions and emotions
- Make a clear short term plan

Common difficulties

When prognostic information is treated with skepticism...

– *The doctors told my aunt she had 2 months to live and she lived for 5 years.*

Patient / family believes in divine intervention

– *How can you say that? Only the Lord knows these things.*

Patient and family have divergent belief systems

– *Don't tell her – it will take away her hope.*

The hallway conversation

– *So, doc, tell me what the real story is...*

Common difficulties

Multiple clinician opinions

– *My [nurse/naturopath/doctor/...] told me that there are better treatments now.*

The patient who does not seem to understand the idea of probability, even in graphic formats.

– Tendency to see situations as “high risk, low gain” or “low risk, high gain” but not “high risk, high gain”.

– Endowment effects – wanting to do what is “normal” or “usual” and avoid what are perceived as extremes

A patient with whom you discussed prognosis, who now does not want to talk about it.

– *Just tell my family or, just turns away when asked*

Patients/families who consult the Internet (the majority, now).
