Patients' Expectations about Effects of Chemotherapy for Advanced Cancer. Weeks, J et al. NEJM 367: 1616

Background
Chemotherapy for metastatic lung and colon cancer is not curative and is associated with substantial treatment related toxic effects.

To make informed decisions about chemotherapy, patients need a realistic understanding of its likely benefits.

Gap in previous literature: substantial prognostication literature (not the point of this article); less known about the understanding of the effectiveness of treatment for advanced cancer. Limited literature suggest that some patients with metastatic disease believe chemorx is curative but these studies used dichotomous outcomes, and the prevalence and determinants of this misunderstanding are poorly characterized.

Aims
1. Using data from the CanCORS (Cancer Care Outcomes Research and Surveillance) study, sought to characterized the reported expectations of patients with metastatic lung or colorectal cancer about the effectiveness of chemorx (likelihood of cure)
2. Identify clinical, sociodemographic and health system factors associated with the expectation that chemorx might be curative.

Methods
General design: national, prospective, observational cohort study. Phone interview survey of patients enrolled with newly diagnosed lung or colorectal cancer from 5 regions covering California, NC, Iowa, and Alabama, 5 large HMOs and 15 VA facilities. Data were obtained from a patient phone survey by professional interviewers in addition to a comprehensive review of medical records.

Eligibility and ineligibility criteria: age 20 or above, dx between 2003 and 2005, Stage IV cancer who opted for chemo rxand who were surveyed. N=1193

Important Measures:
Pt view of the effectiveness of chemo (page 1617); how likely did you think it was that chemotherapy would..help you live longer, cure your cancer, help with problems you were having because of your cancer. Responses- very likely, somewhat likely, a little likely, not at all likely, and don't kno.

Physician communication quality from CHAPS survey (doctors listen carefully, explain things, give as much information as wanted), encourage you to ask questions, treat you with respect and courtesy (sum of five items). Physician score summed and analyzed two ways (threshold score and perfect score).

Decision making role about chemotherapy assessed by patient controlled, shared control, physician or family control

Other: Gender, age, education level, race or ethnicity, marital status and household income, function (dichotomous measure)

Statistical Analysis
Examined association of the four level response about effectiveness with a non parametric test.

Then examined factors associated with responses about likelihood of cure were assessed in multiple logistic regression (not at all likely vs one of the other responses).
Sensitivity analysis (interaction of cancer type, disease progression, grouping do not know and no response with the accurate responses), and constructed a model in which only very likely to cure (sounds same as the primary model to me).

**Results**
Non response rate less than 1%. Some partial missing data (page 1618)
Table 1 for characteristics: shows per cents of cancer patients for each variable but not raw numbers (% of what).

Fig 1. Expectations data. 69% of lung cancer and 81% of colorectal cancer believed chemo curative. Overall 20-30% had accurate understanding.

Table 2. See odds ration in abstract or table. Factors associated inaccurate belief of cure were 1) type of cancer, 2) race or ethnicity. Patients more likely to have an accurate understanding if 1) in an integrated system or if they reported lower or 2) lower or worse communication score with their physician.

Education level, functional status, patients role in decision making were not associated with inaccurate beliefs.

**Authors' conclusions**
Patients may be compromised in their ability to make informed treatment decisions. This misunderstanding can represent an obstacle to end of life planning.

Patients perceive physicians as better communicators when given optimistic news (maybe. Did have an independent assessment).

Both patients and physicians contribute to the misunderstanding.

Cultural factors influence patient beliefs (actually measured pretty well). To measure better would consider questions about trust and distrust, spirituality.

All physicians need to learn to communicate “honestly...” Curious use of the word honestly near the end of paper vs “clearly” or some other term.

**Limitations and Critique**
From Authors. No audiotaping so do not know what physicians said. Some patients died before interview. Responses might have changed since dx. Potential interviewer response bias.

From reviewer.

Important, believable study. However this kind of quantitative data cannot tease out the combination of patient and physician factors involved in the misbelief. The study is an important reminder of the complexities of communication.

Do not know the raw numbers of ethnic minority and other characteristics in table 1.

VA vs HMO integrated care system isolated. HMO physicians have an economic incentive to reduce chemoRx and VA physicians do not.

No severity of illness measure but did measure functional status

Did not ask about trust, though mentioned in discussion.

Health literacy, concordant language may influence results

No data on beliefs about adverse effects as a predictor variable
Practice implications
Disclosure is not synonymous with understanding. Say it and say it again. Ask patients to reveal their understanding and beliefs.

Comments from geripal blog

- Denial is not just a river in Egypt. It's an incredibly powerful coping strategy, as articulated eloquently in the accompanying editorial by Tom Smith and Dan Longo.
- Tying physician reimbursement to patient satisfaction may create perverse incentives for physicians to give patients a false sense of optimism that treatment may be curable, so they'll receive higher ratings and more $$$.
- Palliative care clinicians can teach oncologists how to have honest conversations with patients about prognosis and the outcomes of treatment, in a way that enhances trust and esteem. And ideally, a patient should be referred to a palliative care clinician or hospice soon after diagnosis with these advanced cancers.

Addendum: I just talked to Tony Back about these results, and with his permission would like to paraphrase his thoughts about the physician communication rating.

Essentially, he said the satisfaction with communication questions were asking the wrong question at the wrong time. If your doctor tells you the bad news that your cancer can't be cured with chemotherapy, what do you expect if you ask them about satisfaction after the encounter?