

Measuring Hope: Patient Expectations of Chemotherapy for Advanced Cancer

“Chemotherapy can cause the cancer to shrink or even disappear.”

“Chemotherapy can put the cancer into remission.”

“I have treated lots of patients who have done well for years because of chemotherapy.”

“Chemotherapy can prevent the cancer from getting worse or causing symptoms.”

“Chemotherapy can help you live longer.”

“Chemotherapy has side effects, but most people tolerate it pretty well.”

“Some patients do really well with chemotherapy and go ages without problems.”

“Chemotherapy is the mainstay of treatment for your kind of cancer.”

“If this chemotherapy doesn’t work, we have many others that may.”

“On average, chemotherapy helps patients do better.”

There are dozens of accurate ways to describe the potential benefits of chemotherapy for treating cancer. When describing chemotherapy for metastatic cancer, the description becomes more complicated. Oncologists are all too aware that chemotherapy does not cure advanced cancers. They also know that although many patients get modest benefits from chemotherapy and a few see dramatic results, many show no benefit at all. And clinicians know that chemotherapy causes side effects that must be balanced against possible benefits. When we describe chemotherapy to patients with advanced cancer, we attempt to convey the *likely* outcomes in both managing the cancer and tolerating the treatment.

Although cognizant of these limitations, oncologists recommend chemotherapy for advanced cancer all the time. Chemotherapy for metastatic disease is arguably the signature treatment of our specialty. A quick perusal of NCCN Guidelines for the major malignancies (lung, colorectal, breast, prostate, pancreatic, gastric, esophageal, ovarian, and head and neck cancers) shows that treatment for advanced stages of all includes palliative chemotherapy.

What we don’t know, or know very little about, is how well oncologists communicate the *likely* benefits of chemotherapy for patients with advanced cancer. And we know even less about what patients really expect from chemotherapy.

Recently, my colleagues at Dana-Farber, Dr. Jane Weeks and Dr. Deborah Schrag, published an important survey of patient expectations of chemotherapy for advanced cancer.¹ Their study included a large population of adults receiving first-line treatment for metastatic lung or colon cancer; they asked these patients how likely treatment was to extend their life, improve their symptoms, or cure their cancer. In many domains, patient expectations were fairly realistic. The large percentage of patients correctly believed that chemotherapy was likely to prolong their life. Most patients believed that chemotherapy might lessen symptoms—a difficult expectation to gauge, as many patients receiving first-line chemotherapy may be asymptomatic. However, the headline in this paper was that a large fraction of patients thought it likely that chemotherapy would “cure” their cancer. Interesting, patients who scored their physician as being good communicators were even more likely to believe that chemotherapy could cure their cancer. What do these findings imply about managing patient expectations and treatment decision making?

It is tempting to say that these data show how unrealistic patients may be and to extrapolate from that conclusion the suggestion that physicians do not explain well enough or that patients may make flawed decisions regarding their care because



Harold J. Burstein, MD, PhD

Harold J. Burstein, MD, PhD, editor-in-chief of *JNCCN*, is an Associate Professor of Medicine at Harvard Medical School and a medical oncologist at Dana-Farber Cancer Institute and Brigham & Women’s Hospital. He is a clinician and clinical investigator specializing in breast cancer.

Dr. Burstein attended Harvard College and earned his MD at Harvard Medical School, where he also earned a PhD in immunology. He trained in internal medicine at Massachusetts General Hospital and was a fellow in medical oncology at Dana-Farber before joining the staff.

Dr. Burstein’s clinical research interests include novel treatments for early- and advanced-stage breast cancer and studies of quality of life and health behavior among women with breast cancer. He has written widely on breast cancer in both traditional medical journals and on the web, including *New England Journal of Medicine* and *Journal of Clinical Oncology*. International committees focusing on cancer treatments that he has or continues to participate in include the NCCN Clinical Practice Guidelines Breast Cancer Panel, St. Gallen Breast Cancer Panel, CALGB Breast Cancer Committee, ASCO Health Services Research and Clinical Research Committees, the National Quality Forum Breast Cancer Technical Panel, and other ASCO expert panels.

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December 2012

they lack insight into the natural history of their illness. Before going too far down the path of faulting doctors for not being candid or patients for being too optimistic, however, I think some caution is warranted, for several reasons.

The survey question these patients were asked was “how likely do you think it was that chemotherapy would ... help you live longer, cure your cancer, or help you with problems you were having because of your cancer.” Patient could answer “very likely,” “somewhat likely,” “a little likely, or “not at all likely.”¹ Phrasing questions that way, and juxtaposing “live longer” and “cure,” may have confounded these 2 treatment objectives in the minds of the respondents. In addition, the patients in this study—with metastatic lung or colon cancers receiving first-line chemotherapy—were in clinical situations in which guidelines strongly recommend palliative chemotherapy. Indeed, to have not offered these patients chemotherapy would have been to deny them the standard of care. This is not the same as asking patients with refractory disease whether additional chemotherapy is worthwhile. Patients with refractory disease may have both a more realistic sense of the trade-offs associated with chemotherapy—they’ve been through the experience—and a more guarded sense of possible outcomes.

Finally, any conclusion that doctors fail to communicate with patients is too simple. As noted in the study, doctors were deemed better communicators because they “listened carefully to you, explain things in a way you could understand, give you as much information as you wanted about your cancer treatments (including potential benefits and side effects), encourage you to ask all the cancer-related questions you had, and treat you with courtesy and respect.”¹ That suggests that the doctors who are paragons of virtue in this domain were more likely to have patients say that they thought they were getting curative therapy.¹

So if blaming one side or the other is too simple, what *are* the lessons from this interesting survey? These results point to the substantial gap between what clinicians think they tell patients, and what patients hear. It is easy to imagine errors and oversights on both ends. Doctors must be clearer about what chemotherapy goals are realistic. This is particularly true in situations where the possible benefits of chemotherapy are modest and substantial trade-offs exist between those gains and toxicities associated with the therapy. In advanced cancer, this most clearly describes patients with treatment-refractory disease, but also includes patients considering first-line therapy for many tumor types. If we expect patients to make rational decisions about chemotherapy, factoring in quality of life, improvements in symptom control, and survival gains (and maybe even cost or convenience), they must have a better understanding of what is at stake. This means not simply getting the facts but *getting* the facts.

At the same time, these data strike me as a quantification of hope. Few cancer patients make choices based solely on single-dimension factors. Even patients who know the odds are inclined to hope that their experience will be better than advertised. They may know that “cure” is a lottery-like long-shot, but patients can always hope that they are the ones who will beat the odds. Patients who consider chemotherapy curative for metastatic cancer, are probably misunderstanding the science, but they are probably also expressing the fundamental hopefulness that is an essential part of the human experience. Oncologists need to be careful to describe chemotherapy with fairness and accuracy, and they need to be careful not to take away hope.

Reference

1. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med* 2012;367:1616–1625.