

Sensationalizing a sad case cheats the public of sound debate

Posted by rattig November 29, 2008 19:30PM

In the crucial period leading up to Washington State's vote on an Oregon-style Death with Dignity law, this newspaper published a story featuring Barbara Wagner. A sensational story, an easy media "gotcha" on Oregon's Medicaid program, it completely missed the deeper questions crucial to public understanding of end-of-life care and our national healthcare debate.



*President of Choices
Compassion & Choices
Criticism Wagner's
"Choice"*

Barbara Coombs Lee

Readers will recall Wagner as a 64-year-old Springfield resident with end stage lung cancer, a life-long smoker enrolled in the Oregon Health Plan (OHP). Over several years the OHP had paid for extensive cancer treatment and it continued to pay for Wagner's healthcare until her death.

When it became clear that first and second-line therapies had failed and her prognosis was grim, Ms. Wagner's oncologist recommended a costly, third-line cancer drug called Tarceva. Research indicates that 8 percent of advanced lung cancers respond to Tarceva, with a chance to extend life from an average of 4 months to 6 months. The likelihood of no response to the drug is 92 percent, yet 19 percent of patients develop toxic side effects like diarrhea and rash. Based on the low indicators of effectiveness, Oregon Health Plan denied coverage.

The irresistible ingredients of sensationalism included a distraught patient, a doctor deeply opposed to Death with Dignity and an insensitive letter of payment denial. The media was called in and the rest is history.

As a publicly funded service, Oregon Health Plan aims to do the greatest good it can. It assigns a high priority to preventive care, health maintenance, and treatments that offer a near-certain cure. Elective, cosmetic or ineffective, "futile" care is not covered. Futile care is defined as any treatment without at least a 5 percent chance of 5 year survival. "We can't cover everything for everyone," said the medical director of OHP. "Taxpayer dollars are limited for publicly funded programs. We try to come up with policies that provide the most good for the most people."

The OHP letter denying one ineffective treatment did not close the door on all care. It included a long list of appropriate end-of-life care that OHP would pay for, including hospice, medical equipment, palliative services and state-of-the-art pain and symptom management. Yes, the list included medication prescribed under the Oregon Death with Dignity Act. The media juxtaposed denial of Tarceva with coverage for aid in dying in a sensational, emotional manner, suggesting the two were related. Many stories ensued about supposedly callous bureaucrats refusing to prolong life but agreeing to shorten it. It made for a catchy story ... but not truthful journalism.

Was it true that Ms. Wagner was harmed in any manner? Or that Tarceva was an efficacious option?

Ms. Wagner received Tarceva, anyway, when the drug's manufacturer, Genentech, responding to the media firestorm and provided it at no cost. News stories never mentioned that when Wagner bet on the remote chance to prolong life, she probably turned her back on hospice care, widely recognized as the gold standard for end-of-life care. Sadly, it turned out Tarceva didn't help Wagner and she lived only a short time after starting the drug.

While the media widely reported OHP's denial of this expensive experimental treatment, we worry the media missed the important issues inherent in the story.

What do patients like Wagner really understand about the "last hope" treatments their doctors offer? Do doctors inform patients of the true statistical chance these therapies will prolong life, or the chance of toxic side effects that diminish the quality of the short life that remains? Might Wagner have been better served, and perhaps even lived longer, if her doctors had referred her to hospice instead of recommending a drug so toxic and so unlikely to extend her life? How many times do patients lose out on the real hope and comfort hospice offers because they are encouraged to grasp for the small hope of largely ineffective chemotherapy? Do financial incentives play a role in whether physicians recommend long-shot chemotherapy instead of comprehensive comfort care?

While the OHP decision was closely scrutinized, there was no scrutiny of realistic options considered or not considered and the decision-making process. The burning health policy question is whether we inadvertently encourage patients to act against their own self interest, chase an unattainable dream of cure, and foreclose the path of acceptance that curative care has been exhausted and the time for comfort care is at hand. Such encouragement serves neither patients, families, nor the public.

Barbara Roberts, Oregon's wise and gentle former governor, tells in her first book the story of how she and her husband Frank reacted to the news that he had entered the terminal stage of prostate cancer. She describes how immediately after disclosing the grim prognosis, the doctor announced he was setting up an appointment for chemotherapy! Frank asked two crucial questions, "Will this treatment extend my life?" and "For how long." And when the answers, balanced against the likely toxic side effects, didn't add up to how Frank envisioned his last days on earth, he declined the doctor's recommended treatment.

Roberts writes that chemotherapy seemed, "a medical misjudgment encouraged by a culture in denial and a medical profession equally in denial and unwilling to treat death as normal." Frank said "no" to treatment. But he said "yes" to life and began the "hard work of acceptance" of what it means to be mortal.

In order for society to overcome its collective denial of mortality, we desperately need a public dialogue that shuns superficial sensationalism and leads us to, and through, the hard questions. We're Oregonians. We can handle it.

Coombs Lee is president of the group Compassion & Choices.

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LetDocDecide says...

My wife was diagnosed with Stage IIIB lung cancer (which really should have been stage IV) in April 2006. The diagnosing surgeon announced that there was no hope, and that my wife would only live a short time. In fact, the prognosis for my wife suggested she had a 1%-2% chance of surviving 2 years. Thankfully, we had an ambitious Oncologist that thought the surgeon's opinion was wrong.

While it is easy to armchair quarterback the appropriateness of health care treatments, You can be the one that tells my 8 and 10 year old sons that their mother should not receive Tarceva because it is an "experimental treatment". The efficacy of all chemotherapy treatments are ALL poor. The first line chemo treatment (carboplatin/Paclitaxel) that my wife received had only a 35% likelihood of a positive response. That was 2 years and 8 months ago and she is still kicking. Her response to Tarceva has been an exceptional one, resulting in a significant reduction of the size and number of tumors in her remaining right lung. After a 3rd tier chemo treatment failed 3 months ago, Tarceva is probably the only reason she is spending Christmas day with me and my boys. In fact, I expect that she will continue having a positive response to the Tarceva for at least a couple of months. Anyone with a loved one with a terminal disease would appreciate the added time.

On the topic of cost and side effects, the side-effects of Tarceva (rash and diahrea) are nothing compared to the side effects of the Taxane or platinum chemotherapy drugs (severe anemia, reduced white blood counts and platelet levels, severe nausea, body PAIN, etc..).

In addition to these benefits, the cost of Tarceva (about \$4000/month) is NOT HIGHER than the cost of chemotherapy (about \$8000 per treatment every 3 weeks). ~~It is expensive to treat cancer, period. It is unclear to me whether the author of this news story is appealing for the denial of all cancer treatments, or just Tarceva. If that is the case, they can tell the family of the next Stage IIb/IV lung cancer patient that treatment is not worth the cost. What the hell, perhaps we should just Euthanize all cancer patients at the time of dianosis to save a little money.~~

I believe that the spiralling costs of health care are not caused by the compassionate treatment of those with terminal diseases. The real culprits are 1) the fact that to many individuals that have no health insurance use emergency care at a huge cost premium over preventative care; 2) People have had no incentive to use healthy lifestyles as a preventative; 3) Many people with insurance are not smart shoppers when it comes to health care. This leads to people having expensive diagnostic procedures like MRI and CT scans inappropriately.

We need to wakeup, do a little research into the available treatments for our ailments, and determine if the increased public cost for not insuring everyone and using more preventative health care.

Respectfully
Bob

Posted on 12/25/08 at 12:16AM
Footer



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Barbara Coombs Lee is President of Compassion & Choices, a nonprofit organization dedicated to expanding and protecting the rights of the terminally ill. She practiced as a nurse and physician assistant for 25 years before beginning a career in law and health policy. Since then she has devoted her professional life to individual choice and empowerment in health care. As a private attorney, as counsel to the Oregon State Senate, as a managed care executive and finally as Chief Petitioner for Oregon's Death with Dignity Act, she has championed initiatives that enable individuals to consider a full range of choices and be full participants in their health care decisions.

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Posted September 27, 2010 | 11:33 AM (EST)

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