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## Learning From Amy Berman: Barriers To Palliative Care And How We Might Overcome Them

Posted By [Diane Meier](#) On April 30, 2012 @ 4:02 pm In [All Categories](#), [Consumers](#), [End-of-Life Care](#), [Hospitals](#), [Personal Experience](#), [Physicians](#), [Quality](#) | [No Comments](#)

Editor's note: You can hear [Amy Berman](#) <sup>[1]</sup> discuss her April Health Affairs [Narrative Matters essay](#) <sup>[2]</sup> at the recent [release event for the April issue](#) <sup>[3]</sup>. You can also [join Amy tomorrow \(May 1\) at noon for live online chat](#) <sup>[4]</sup> hosted by the Washington Post, which will also be publishing an abridged version of her essay. In addition, Amy appeared with Diane Meier, the author of this blog post, on [a recent edition of the Diane Rehm show](#) <sup>[5]</sup>.

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Amy Berman's story in [Narrative Matters](#) <sup>[2]</sup> describes the experience of a perfectly healthy professional faced with a new diagnosis of inflammatory breast cancer. [Inflammatory breast cancer](#) <sup>[6]</sup> is a rare subtype, and, as a result, there are few studies to guide treatment. Amy has Stage 4 inflammatory breast cancer that has spread to her bones — a feared diagnosis with no great treatment options.

Because Amy is a medical professional she knows the consequences of toxic chemotherapy, surgery, and radiation, and she knows that there is a good probability that none of these therapies will make much difference to her long-term survival outcomes. They will, however, make her quite sick and miserable. So she made a logical and common-sense decision to preserve her quality of life, while at the same time pursuing disease-modifying options (hormone therapy and bisphosphonates to protect her skeleton) with tolerable side-effect profiles.

Eighteen months after diagnosis, Amy looks great, feels great, and is working full time. Her tumor markers are normal, and flat. There is nothing wrong with this picture. The oddest thing about Amy Berman's story is that it is unusual. So why is Amy's decision so rare?

Perhaps in part because Amy is an executive at the John A Hartford Foundation (full disclosure, the Hartford Foundation is a long-term funder of the organization I lead, the [Center to Advance Palliative Care](#) <sup>[7]</sup>), she knows a lot more than most people about palliative care. She knows that it is a form of health care focused on maximizing a patient's quality of life during serious illness, that it is delivered at the same time as all other beneficial treatments, and that in several studies patients who received it not only lived better but tended to live longer than controls receiving only usual cancer care.

### The Public, Patients, And Their Families Are Receptive To Palliative Care

Public opinion research conducted by CAPC and the American Cancer Society in the summer of 2011, found that, like Amy, over 90 percent of those polled endorsed palliative care (see note 1) as treatment they would want for themselves or a loved one during a serious illness. This strikingly high level of endorsement did not vary by political affiliation, geographic location, sex, age, or prior caregiving experience of the respondents.

To the public, and to patients and their families, the benefit of this added layer of support from a team focused on quality of life and clear and accurate information in support of shared patient and family decisions, is obvious. The likelihood that a better quality of life helps people live longer is also unsurprising to public audiences; it is physicians that seem to have trouble with the concept of attending to quality of life and control *at the same time* as life-prolonging treatments. My colleagues struggle with the explanation: How, exactly, could a better quality of life result in a longer life?

The mechanism of action of a longer life in association with palliative care is unknown, but may have to do with avoiding toxic and risky treatments, avoiding hospitalization with its

attendant risks of infection and other adverse events, and experiencing better mood, quality of life, symptom burden, and feeling in control. We know, for example, that depression is an independent predictor of mortality in every disease in which it has been studied, from cancer to heart failure, to stroke and dementia, and that palliative care significantly reduces risk and severity of depression.

A [2010 randomized trial published in the \*New England Journal of Medicine\*](#) <sup>[8]</sup> found that newly diagnosed stage 3 and 4 lung cancer patients randomized to usual cancer care at the same time as concurrent palliative care (compared to usual cancer care alone) had fewer symptoms, less depression, less end-of-life chemotherapy and hospitalization, and lived 2.7 months longer than controls. [A 2010 study published in \*Cell\*](#) <sup>[9]</sup> found that cancerous mice placed in enriched environments were more likely to sustain remission and experience reduced tumor cell growth, described by the authors as "*mens sana associated with a corpore sana.*"

Despite the growing body of evidence in favor of concurrent palliative care along with disease-specific treatment, the inflammatory breast cancer expert did not recommend it to Amy; did not ask her what her goals were for her treatment and her remaining time; and despite lack of evidence, assumed that surgery, radiation, and chemotherapy were both the rational, and the only, option for her. It is the unusual patient who has the courage to question such a confident expert pronouncement, especially when facing a fatal diagnosis, and feeling confused, afraid, and vulnerable.

### **Physicians' Mistaken Understanding Of Palliative Care**

Why this persistent failure to recommend palliative care to newly diagnosed cancer patients? Unlike the public, more than 75 percent of whom have no idea what palliative care is and are, therefore not biased against it, physicians hold onto an incorrect and outdated understanding, often conflating palliative care with hospice. While hospice is an important form of palliative care at the end of life, under statute, hospice is restricted to patients with a 2-physician certified prognosis of under 6 months who are willing to forgo life-prolonging treatments. As a consequence of these restrictions on access, the median length of stay in hospice in the U.S. is about 3 weeks, and 30 percent of hospice patients receive it for less than a week before death.

Palliative care, as in Amy's case, has no such restrictions. Amy is pursuing well-tolerated disease-modifying and life-prolonging treatments, has already lived 18 months without evidence of disease progression, and enjoys an excellent, completely independent, and functional quality of life. Physician failure to refer is not attributable to lack of access to palliative care. Palliative care teams are available at 85 percent of large (more than 300 bed) hospitals in this country where the majority of seriously ill patients receive their care, including the hospital and cancer center where Amy sought oncology care.

In addition to hospitals, palliative care teams working in out-patient, cancer center, telemedicine, and home care settings have been shown to improve quality of life for patients and families, reduce avoidable hospitalization and ICU stays and — in an increasing body of evidence — prolong life. Based on the accumulating data, the [American Society of Clinical Oncology \(ASCO\) recently recommended](#) <sup>[10]</sup> palliative care from the time of diagnosis of cancer. Withholding this beneficial and evidence-based approach from seriously ill patients because of physician's outmoded and incorrect understanding of palliative care and its benefits is no longer acceptable.

How can we overcome these physician barriers to palliative care during serious illness? There are three options.

**Educating the public about palliative care.** First, we can make sure the public knows what palliative care is and encourage them to ask their doctors for it under appropriate circumstances. Media coverage of studies demonstrating gain in both quality and quantity of life in association with palliative care have begun to change patient and family behavior in precisely this direction, as our hospital consultation service receives a growing number of requests that were initiated not by the doctor, but by the patient or family member.

**Making palliative care a key measure of quality.** Second, we can frame palliative care as a core component of quality care and require that health care settings serving the seriously ill — hospitals, nursing homes, assisted living facilities, home care agencies — routinely screen their patients for palliative care needs, such as poorly controlled pain, depression or other symptoms, lack of clarity about medically achievable goals for care, what to expect in the future and how to plan for it, and family caregiver exhaustion and stress; we can require that identification of these needs trigger care protocols designed to address gaps in care. NY State recently passed the [Palliative Care Access Act](#) <sup>[11]</sup> (PHL Section 2997-d) requiring just such a process. Similar to checklists popularized by Atul Gawande and others in the critical care and surgical setting, universal assessment and identification of common palliative care issues may lead to consistent and higher quality care for the most seriously ill and most vulnerable.

**Retraining physicians and revamping medical training.** Lastly, and perhaps the most difficult of these options, we can retrain practicing physicians and change the educational requirements for medical students and residents in an effort to depart from outdated practices of waiting to request support from palliative care teams only when the patient is within hours or days of death.

Amy chose a path of simultaneous cancer treatment and palliative care because she prioritized her quality of life over surgery, radiation and intensive high dose chemotherapy that offered little or no benefit and high and serious risk of harm. Her story is a good example of the amount of avoidable and very costly (both to the patient and the healthcare system) medical tests and treatments that are routinely offered and provided in the U.S. The recently launched [Choosing Wisely campaign](#) <sup>[12]</sup> of multiple medical specialty groups [calls for physician attention](#) <sup>[13]</sup> to these sources of waste of common resources and real harm to patients.

Reasons for this therapeutic optimism bias among physicians are unknown but are often attributed to fear of blame for missing something or failing to do something that outweighs the fear of doing harm. Unnecessary diagnostic procedures and treatments are frequently justified by appeals to physician fear of lawsuits when, ironically, physicians are more likely to be sued for an adverse outcome of an unnecessary test or procedure than for a [thoughtful process of shared decision-making](#) <sup>[14]</sup> under the irreducible conditions of uncertainty that characterize both the practice of medicine and the human condition.

We seem to have forgotten our medical school graduation oath: [Primum Non Nocere](#) <sup>[15]</sup>, or do no harm. Patients should not have to be health professionals as smart, connected, and well trained as Amy to get care built around their own goals and values.

**Note 1.** Palliative care was defined in the survey as

specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

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URLs in this post:

[1] Amy Berman: <http://www.jhartfound.org/blog/author/amy-berman/>

[2] Narrative Matters essay: <http://content.healthaffairs.org/content/31/4/871.full>

[3] release event for the April issue:

[http://www.healthaffairs.org/events/2012\\_04\\_12\\_value\\_in\\_cancer\\_care/](http://www.healthaffairs.org/events/2012_04_12_value_in_cancer_care/)

[4] join Amy tomorrow (May 1) at noon for live online chat:

<http://live.washingtonpost.com/cancer-choosing-quality-of-life-over-aggressive-treatment.html>

[5] a recent edition of the Diane Rehm show: <http://thedianerehmshow.org/shows/2012-04-16/facing-death-choosing-quality-life-over-aggressive-treatment>

[6] Inflammatory breast cancer: <http://www.cancer.gov/cancertopics/factsheet/Sites-Types/IBC>

[7] Center to Advance Palliative Care: <http://www.capc.org/>

[8] 2010 randomized trial published in the *New England Journal of Medicine*:

<http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

[9] A 2010 study published in : [http://ac.els-cdn.com/S0092867410005659/1-s2.0-S0092867410005659-main.pdf?](http://ac.els-cdn.com/S0092867410005659/1-s2.0-S0092867410005659-main.pdf?_tid=347ae9cf7cfffedc54d12307c35309f&acdnat=1335797331_3e8faf860249b9316ad6abf)

[\\_tid=347ae9cf7cfffedc54d12307c35309f&acdnat=1335797331\\_3e8faf860249b9316ad6abf:](http://ac.els-cdn.com/S0092867410005659/1-s2.0-S0092867410005659-main.pdf?_tid=347ae9cf7cfffedc54d12307c35309f&acdnat=1335797331_3e8faf860249b9316ad6abf)

[10] American Society of Clinical Oncology (ASCO) recently recommended:

<http://jco.ascopubs.org/content/30/8/880.long>

[11] Palliative Care Access Act:

[http://www.health.ny.gov/professionals/patients/patient\\_rights/palliative\\_care/phi\\_2997\\_](http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/phi_2997_)

[12] *Choosing Wisely* campaign: <http://choosingwisely.org/>

[13] calls for physician attention: <http://jama.ama-assn.org/content/early/2012/03/30/jama.2012.476.full>

[14] thoughtful process of shared decision-making: <http://informedmedicaldecisions.org/>

[15] *Primum Non Nocere*: [http://en.wikipedia.org/wiki/Primum\\_non\\_nocere](http://en.wikipedia.org/wiki/Primum_non_nocere)