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Cancer Billing 'Operated by Satan,' Says Memoirist

Roxanne Nelson | Mar 18, 2013

HOLLYWOOD, Florida — What is the cost of hope? For Amanda Bennett, it was a bill that topped half a million dollars for care that eventually proved futile. Despite the best efforts, her husband, Terence Foley, eventually succumbed to kidney cancer. But in the aftermath of that journey, Bennett now believes that the system operates without rhyme or reason when it comes to cost, and that her husband received procedures and care that weren't necessary.

Bennett delivered the keynote address here at the National Comprehensive Cancer Network 18th Annual Conference. She is a Pulitzer Prize–winning journalist, an executive editor at *Bloomberg News*, and the author of *The Cost of Hope*, a memoir about her husband's 7-year battle with kidney cancer and her own investigation into healthcare costs.

Her story is not one of evil doctors with the patient as a victim. It is quite the opposite: She has the upmost respect for all of the physicians who cared for her husband. "We were all doing our best," she explained.

It isn't even about insurance. "I had the best insurance available, and nothing was denied." This is a story about the "very best of the system, but even the best left a lot to be desired," she noted.

It is also a story about the refusal to give up hope or accept the inevitable, no matter how irrational it was. "I thought I could keep him alive if I was strong enough and smart enough," she said.

Apparently, so did his healthcare providers. In the 4 days that preceded his move to hospice care, when he was clearly dying, their insurance was billed $43,711 for a cornucopia of physician fees, drugs, scans, and lab work.

An expert panel, including several physicians who were directly involved in Foley's care, joined Bennett to discuss her husband's treatment, especially the treatment choices made near the end of his life. The panel was moderated by Sam Donaldson, ABC News anchor, and included Ronald M. Bukowski, MD, from Bukowski Consulting in Cleveland, Ohio; Keith Flaherty, MD, from the Massachusetts General Hospital Cancer Center in Boston; Craig D. Turner, MD, from Urologic Consultants PC in Portland, Oregon; and J. Cameron Muir, MD, executive vice president of quality and access at Capital Caring and assistant professor of oncology at Johns Hopkins Medicine in Baltimore, Maryland.

Satan-Designed System

The bill for his 7 years of treatment totaled $618,616; almost two thirds of that was incurred in the final 24 months of life.

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"We designed a billing system that is operated by Satan," said Bennett.

As an example, one computed tomography (CT) scan cost $800, whereas another cost $2400. "It is a matter of which insurance company negotiated the cost," she said. "There is a lot of overtreatment going on in this Satan-designed system."

Her husband had 76 CT scans throughout the course of his illness. "Were they all necessary? Of course not. Could it have been cut in half? Probably," she said.

The journey through the healthcare system "turned us into general contractors," Bennett said. "We found a doctor for

everything, but there was no one who was just interested in him."

Long Journey Through Care

As is often the case with kidney cancer, Foley's tumor was discovered accidentally, when he was having a scan done for another problem. There was some disagreement over the type of cancer. It was first diagnosed as collecting duct cancer, and later on as papillary cancer.

He began treatment with interleukin (IL)-2 for the cancer, which had metastasized to his lungs. It was the only available therapy at the time, but made him violently ill, forcing him to discontinue treatment. Dr. Bukowski, who treated him at the Cleveland Clinic 2 years after his initial diagnosis, advised a watch and wait protocol because the disease appeared to be indolent and the tumors had shown no further growth. That was the course of treatment for 3 years, until a scan revealed that the lesions in his lungs had begun to grow.

"We wait, and then introduce treatment when the illness starts to progress," Dr. Bukowski explained during the session. Because there is no cure, there is no reason to subject a patient to possible adverse treatment effects, he explained.

When the lung tumors began to grow, Dr. Bukowski recommended entering a clinical trial and referred Foley to Dr. Flaherty, who put him into a trial of bevacizumab (*Avastin*) and sorafenib (*Nexavar*).

The treatments worked for a while, but the cancer eventually returned and worsened. He tried another drug, sunitinib (*Sutent*), only a few weeks before his death, but his condition continued to worsen. He entered hospice care 4 days before his battle with kidney cancer came to a end.

End of Life

"We have a noble path for curing disease, but there is no noble path for letting go," said Bennett. She laments that; because she didn't believe her husband would die, they never had a chance to say goodbye before he entered hospice care.

It is sometimes difficult to find the line between optimism and realism. "We always hope for the best and prepare for the worst," said Dr. Muir. "Certainty is such a hard-driving force. To be able to sit comfortably and discuss uncertainty is a skill that needs to be developed and honed."

Dr. Turner agrees that "we are uncomfortable with uncertainty." But at the end of the day, it was "Terence's cancer," and an individual is not a statistic, he said. "Your chances are 0% to 100%, but I can't tell you which it is." Dr. Turner removed Foley's kidney when the diagnosis was first made.

Dr. Flaherty explained that population data and statistics suggest what the prognosis is for any given disease. "It helps us in our decision making, but it is up to the individual patient to decide what data they want to hear," he said. "Hearing numbers can be comforting or discomforting. I have to ask them: Do you want the numbers or do you just want to know about the chances?"

The Cost of Dying

In retrospect, Bennett said she would have liked to have hospice and palliative therapy running alongside regular care. "That's what we needed," she said. "It was mentioned to me, but I didn't believe he was dying. This was the end of his life, and we weren't prepared."

Dr. Muir reiterated that the current cost of cancer care is unsustainable. There is also still the idea that patients see physicians as a gods of sorts, who can cure them. Look at "how many people enter bankruptcy in order to pay medical costs," he said. "There is a big conspiracy of silence about this."

Physicians need to develop skills in discussing these issues, he explained. "We need to know how to take the statistics and subscribe them to a person who has a full range of options."

Dr. Bukowski agrees that cost needs to be discussed. "Most [physicians] don't ask; we usually refer patients to someone who helps them with that," he said. "I think the issue of cost vs benefit is an important one."

National Comprehensive Cancer Network (NCCN) 18th Annual Conference.

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