The issue of third-party reimbursement also came up. “We hope the guidelines will help with reimbursement with some of these therapies by becoming standard practice,” Denlinger said. “But we don’t yet know.”

Similarly, Philippe Spiess, M.D., genitourinary oncologist at H. Lee Moffitt Cancer Center in Tampa, Fla., and a member of NCCN’s bladder/penile cancer panel, said that uncertainty surrounds reimbursement for penile cancer as well, especially for new organ-preserving therapies, such as imiquimod or 5-fluorouracil cream, in the treatment of early disease.

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Bartering for Time: Realism Versus Hope

By Susan Jenks

In her new book, *The Cost of Hope: A Memoir*, Amanda Bennett says that the cost of her husband’s 7-year battle against a rare form of kidney cancer was $618,616—an expense incurred mostly during the last 2 years of his life.

But beneath those figures lies a far more personal story of navigating a complex health care system that tends to compartmentalize care (“We had a doctor for everything,” she says) and a disease that often defies certainty, even in diagnosis.

Bennett, a Pulitzer Prize-winning journalist and former editor of the *Philadelphia Inquirer*, delivered the keynote address at a roundtable discussion of the emotional and financial impact of cancer at the National Comprehensive Cancer Center Network’s 18th annual conference, March 13–17, in Hollywood, Fla. Today, she is an executive editor at *Bloomberg News*, directing special projects and investigations.

“The book isn’t even a story about the wicked insurance companies,” Bennett told the audience, noting that she and her husband had good insurance throughout their ordeal. “This is the story about the best of the system, where every person dying seems like a failure. Denial isn’t a strong enough word for what we went through.”

Bennett’s husband, Terence Foley—a “quirky and eccentric man” with a love of bow ties, Chinese history, and jazz, who earned a Ph.D. in his early sixties—learned he had kidney cancer in November 2000. Although doctors initially told him he had collecting-duct cancer, a rare and aggressive disease, he later received a surprisingly different diagnosis from a kidney cancer expert at the Cleveland Clinic: papillary cancer, also rare, but the most indolent form of the disease.

Ronald Bukowski, M.D., a former deputy director of the Taussig Cancer Center, who made that diagnosis and served on the National Comprehensive Cancer Center Network panel, advised Foley and Bennett to do nothing, which they did for more than 3 years, until the cancer’s final return.

The cost of “doing nothing” came to $36,000, Bennett said, after investigating the blizzard of envelopes from various insurers after Foley’s death at the age of 67. The charge came from eight clinic visits for computed tomography scans, which turned out to be a small fraction of the 76 scans Foley had at various institutions during his long illness, as the couple moved around the country for Bennett’s increasingly high-profile jobs. Whereas some providers charged $800, Bennett said, others charged as much as $2,400 for an identical scan.

“Were all of them useful and ordered for a good reason?” Bennett asked. “I’m positive of that. Were all of them necessary? I’m just as sure not.”

The panel evaluating these and other issues included several other physicians, besides Bukowski, who took part in Foley’s medical care. Veteran ABC journalist Sam Donaldson moderated.

Even now, the doctors said they remain uncertain over the type of kidney cancer that took Foley’s life.

“The tools to make a definitive diagnosis in this illness are still lacking,” Bukowski said. “I said, ‘Do nothing,’ because I felt it was a slow-moving cancer. Some patients may not need treatment even though they have metastatic disease So, you wait.”

Craig Turner, M.D., the Portland, Ore., urologist who removed Foley’s diseased kidney shortly after the diagnosis, agreed. “That’s the uncertainty,” Turner said, explaining the unclear pathology. “We try to speak to our patients with certainty. We’re uncomfortable with uncertainty.”

Keith Flaherty, M.D., director of developmental therapeutics at Massachusetts General Hospital’s Cancer Center and the last physician to treat Foley before his death, described the process as a “question of realism versus hope.” Each medical step
is guided by the belief that a patient can gain more time and, by participating in a clinical trial, Flaherty said, Foley gained 17 more months of life.

Where cost factors into this equation remains at the core of the heated national debate over health care, as the nation’s health care spending continues to rise, reaching $2.7 trillion in 2011, according to the most recent data. Employers are expected to continue passing more of that cost on to individuals, a trend that may ultimately reveal the unseen negotiations between payers and providers that Bennett likens to bargaining “like car salesmen or Chinese vendors” to get the best price.

“As a society we need to look at [costs],” said J. Cameron Muir, M.D., executive vice president of palliative-care organization Quality & Access Capital Caring and an assistant professor of oncology at Johns Hopkins Medical School. “At some point, something’s going to get us, whether it’s the bus on the street or the kidney tumor. Twenty-five percent of people in this country wind up in bankruptcy from medical costs.”

Muir suggested that Bennett’s book depicted hospice in too negative a light, with Foley receiving hospice care only for several days in the hospital, not in his home. “People mentioned hospice repeatedly, but I wouldn’t let them,” Bennett conceded, a tacit admission, perhaps, that to do so meant abandoning hope. But, although Bennett sometimes questioned her motives for pursuing the most aggressive medical care, she said, ultimately “he wanted it too,” and they both believed they got extra time with each decision. “Would I do it again? Absolutely.”

Not only were they able to take a trip to southern Spain with their daughter and move their son into his college dorm, the extra months allowed them to celebrate their 20th anniversary with a romantic carriage ride through Philadelphia’s cobbled streets. Such treasured memories were possible, Bennett said, despite frustration with a health care system that sometimes seemed “designed for the doctors, hospitals, laboratories and technicians, and not for Terence and me.”

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