Underinsured Patients and the Financial Fallout of Cancer Care

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Each morning, as I walk across the lobby of our cancer center, I am conscious of how fortunate I am to be headed to my office instead of a chemoinfusion chair. Because I am aware of the challenges they face, I talk with our patients and their caregivers whenever possible, to ask some really important questions as they journey through their treatment under our care. Some of these questions are: “What are you hoping for? What should we be doing differently? What worries you the most?”

I am not surprised to hear that one of the issues worrying patients most is the financial impact cancer is having on their lives. This is well illustrated with the stories of 2 of our patients.

Real-World Examples

A Young Mother

ES is a 30-year-old nurse and mother with acute leukemia. Her children are 1 and 3 years old. She needs a bone marrow transplant—her only hope for cure. The transplant process is lengthy and dangerous, involving significant disruptions to her family and work lives. Her caregiver is her mother, who will also experience significant disruption of her work and family lives during this lengthy treatment period; while ES’s young husband is trying to hang on to his job (and their health insurance) and parent their children.

ES had already faced the anxiety of identifying an appropriate, willing bone marrow donor when she learned that the type of transplant she needs is not available in her hometown or within her insurance network. For treatment, she needs to manage the logistics of relocating for months, to fight for her life in a strange city, with limited support from family and friends, and without her husband and children. The insurance company denied her out-of-network access to this treatment, so the cruel reality is that she must also initiate an appeal.

The appeal process is lengthy and complicated, requiring a series of sequential steps that involve her husband’s employer, her insurance company, her insurance case manager, the medical director of the insurance plan, her local physicians, and the physicians, administrators, case managers, and financial coordinators here at Johns Hopkins, the institution that can provide her with this treatment. In addition, out-of-network benefits usually require significantly larger copays, adding to the financial burdens of travel and housing expenses for ES and her mother, and the loss of income for both of them during the treatment.

A Husband, Father, and Grandfather

GM was a 70-year-old husband, father, and grandfather on a fixed retirement income with a late-stage biliary tract malignancy that resulted in a catastrophic and terminal admission. His wife has been diagnosed with dementia. GM’s only health insurance was Medicare A. His son is now attempting to sort through his father’s estate and deal with medical bills and funeral expenses while caring for his mother. Medicare paid a $250,000 hospital bill, but because GM did not purchase Medicare Part B, his family
now faced with a $60,000 bill for physicians’ care during his lengthy and complex admission. GM’s son states there are limited funds from a small insurance policy that was left by his father, and he wants to make a settlement on the outstanding physicians’ bills. The family has no other funds with which to pay his father’s health care debt.

The Larger Picture

In this country, medical problems contributed to at least 62.1% of bankruptcies in a national 2007 sample. In one study, Himmelstein et al found that the share of bankruptcies from medical problems increased by 49.6% between 2001 and 2007. A 2013 study from the Fred Hutchinson Cancer Research Center in Seattle compared patients with cancer versus demographically matched controls without cancer between 1995 and 2009. The authors found that people with cancer were 2.5 times more likely to file for bankruptcy than those without cancer.

At my institution, we take patients’ financial concerns as seriously as their medical concerns, and we work diligently and creatively to help them find solutions. As health care costs have risen in the past 10 years—and a greater proportion of health care costs have been shifted to the patient—we can see an escalation in the anxiety our patients feel. I find it very sad that so many of our patients battling a life-threatening illness find themselves distracted by fear of a catastrophic outcome for their financial health as well.

Every day there is a new twist on the problem. For example, patients who cannot afford to pay for COBRA benefits when they can no longer work; or perhaps an insurance plan limits outpatient visits to 5 per year; or a patient’s previous cancer makes them uninsurable for their recurrence without exorbitant premiums that they cannot afford. Patients may have to relocate to get the appropriate care and can incur thousands of dollars in living expenses not covered by insurance. Or perhaps a patient has no outpatient pharmacy coverage and requires $30,000 worth of outpatient drugs at discharge from their bone marrow transplant.

Oncologists in private practice can seldom afford to treat patients who are uninsured or underinsured. As of this writing, the government sequester, necessitating a reduction in reimbursement for cancer drugs covered by Medicare, has caused some private oncologists to elect not to treat patients with Medicare. This moves this population toward hospital-based oncology treatment. Ironically, moving patients into hospital-based care costs the Medicare program much more than the 2% cut in drug reimbursement will save.

I believe that health care reform will take us in the right direction, because the number of uninsured individuals will diminish under the new law. However, many citizens purchasing insurance for the first time through the state exchanges will gravitate toward lower-cost plans, in which the patients bear more risk for their health care costs. When patients experience a lengthy, complex, or high-cost health problem, they will find that their copays, deductibles, and out-of-pocket maximums are extremely high. Some of these plans will also limit the number of visits and will provide access to only a limited network of providers. The distribution of underinsured patients may change, placing more financial risk on community- and hospital-based providers and, in a cruel irony, on patients.

As providers of care, we see the causes of the dramatic rise in health care costs in the United States compared with other developed countries. These include the extremely high burden of administrative costs associated with health care, lack of regard for the value of the health care dollars spent on care, fraud and abuse in our system, and failure to develop and follow evidence-based care pathways. Care at the end of life is one of the major drivers of health costs, but we refuse to face it head on, and we don’t
have enough trained palliative care providers to make significant progress. In a 2008 study by Morrison et al, patients who received a palliative care consultation during their admission and were eventually discharged from the hospital had an adjusted net savings of $1696 in direct cost per admission compared with matched controls. In the same study, patients who received a palliative care consultation during admission but who died in the hospital had an adjusted net savings of $4908 per admission. With an intervention as simple as a palliative care consultation prior to discharge, more patients will have better controlled symptoms and more patients will be admitted appropriately to hospice, improving quality of life and survival.

One of the most important aspects of my job is to ensure that patients with cancer can access appropriate and timely treatment. I do this by becoming a patient advocate, and by knowing and staying aware of the public and private resources available to patients through the federal government, through my state, through our hospital’s charitable status, through public and private agencies and foundations, and through local and national organizations that provide financial support to patients with cancer. As health care providers, we can also work with employers to educate them about appropriate cancer benefits to provide to their employees, and we can fully understand the new products and programs under health care reform, so that we can educate, advocate for, and support our patients during this time of change. All of this means staff time and effort, which is costly, and therefore adds to the cost of health care in the United States.

Still, in my world, we celebrate every new discovery and every “clean” follow-up scan. We also celebrated with our patient and our transplant financial coordinator when, after weeks of effort and scores of letters and e-mails, we were finally able to get coverage for ES, the young mother, for her bone marrow transplant.

References