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Bleeding-Edge Benefits

A physician learns that many graduate students—including his niece—are just one serious illness away from considering medical bankruptcy.

by Jay Himmelstein

Hiking in the foothills of the Rockies in late summer 2004, I found it a challenge to keep up with my two fit and energetic twenty-four-year-old companions—my son Jesse and niece Emily—on a warm, cloudless Colorado afternoon. At one point, we stopped on a cliff top to rest, snack, and watch kayakers paddle the rapids below and rock climbers scale the canyon walls across from us.

"Uncle Jay, what do you think of this bump on my thigh?" Emily asked while we were sitting there. "The doctor at student health services thinks it’s probably just a fatty tumor, but she’s referred me to a surgeon to have it cut out—do I need to worry about this?" The doctor had also suggested that she get an MRI before the surgery. "But," Emily continued, "our student insurance only covers $1,000 in x-rays a year, so the MRI would cost me about $2,000 out-of-pocket. The surgery itself will cost me only $200 after insurance. Do I really need the MRI?"

When you're the doctor in the family, you get asked questions like this. I took a quick look at Emily’s leg as we finished our trail mix. Her skin looked normal, and the one-inch "bump" on Emily’s left inner thigh was soft and freely movable; it did, indeed, feel like a benign lipoma.

"I wouldn't worry too much about it," I said. "But you should follow up with the surgeon just to make sure."

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Emily smiled and seemed reassured, and I was pleased to help. After several more hours of hiking, we all went our separate ways, Emily to her graduate program at a state school in Colorado, Jesse to his graduate studies in France, and me to my work as a director of health policy at a medical school in Massachusetts.

A Few Weeks Later

On a Friday afternoon a few weeks later, I was interrupted during a meeting with a message that there was an urgent call from Emily. I went to my office to take the call, closing the door with trepidation. Emily was clearly upset. “The lipoma came out easily under local anesthesia,” she told me, “but then the surgeon felt something else. He called in another surgeon to consult, and eventually they pulled out a big bloody mass—it was the size of my fist!”

My mind was racing: “Oh, God…Emily could die from this…The second mass is probably some type of cancer.” I could sense that Emily was near tears, that the ground was unsteady beneath her feet. Slumping at my desk, I searched for the right words as I listened to Emily’s shaking voice. She said that the surgeon seemed concerned and had told her that he’d contact her when they’d identified the second mass. “They’re sending the tissue to the Mayo Clinic,” she added.

My thoughts raced on. Had I screwed up by examining her leg so casually? Maybe if I had spent more time with her, had been more thorough, I might have felt the second mass below the lipoma. Should I have insisted, despite the cost, that she have the MRI before the outpatient surgery? But more important—what about Emily? My focus narrowed in on her, and I straightened up in my chair. I heard myself talking, seemingly calm, comforting her.

“Everything is going to be OK,” I told Emily. “We’ll figure this out. But there is nothing we can do until we hear about the pathology.”

Finally, nearly three weeks after the surgery, the surgeon told her that the second mass they’d removed from her thigh was a synovial sarcoma, a rare, aggressive, malignant tumor. Emily’s Web search on “synovial sarcoma” found articles estimating only a 20–40 percent survival rate.

“I’m really scared, Uncle Jay,” she said in our next phone call. “And I’m not sure my insurance covers cancer treatments. What am I going to do?”

I offered to speak with the consulting oncologist in Colorado. In our phone conversation, she was blunt about Emily’s condition. “Emily should be treated at a major cancer center as soon as possible,” she told me. “The tissues margins from her outpatient surgery included cancer cells; she is going to need repeat surgery on her thigh to get clean margins and save the leg. She is also going to need radiation to reduce the likelihood of local recurrence.” I asked the oncologist about Emily’s likelihood of survival, but she wouldn’t commit herself until after the revision surgery. I also asked if the risk of local recurrence and distant metastases had been increased by having the initial surgery done in an outpatient setting without ben-
fit of a prior MRI. “Yeah, in retrospect,” she said. “But there is nothing you can do about that now.”

I felt awful. Although it had seemed sensible at the time, I worried that I had given Emily bad advice. As a physician with a large extended family, I’m often asked to advise family members about their health care. But this situation with one of my nieces was new and unsettling. Emily had a rare and potentially fatal cancer, limited financial resources, and a student health insurance plan with uncertain coverage. She was scared about her health and overwhelmed with concerns about where the money for her treatment was going to come from.

The oncologist referred Emily to a cancer center in the Boston area, which meant that she could move in with our family and live with us during her treatment. Within days, Emily underwent further evaluation in Boston. The physician team agreed that they needed to perform urgent revision surgery, to be followed with radiation. There now was a clear path for Emily’s treatment, but we were unable to get a timely answer from her insurance company about her benefits and payment for out-of-state consultations and treatment.

### Getting Treatment And Getting Billed

**Three weeks after her evaluation** at the cancer center, Emily underwent four-hour revision surgery while I and the rest of her family waited apprehensively. About an hour after Emily woke up in the intensive care unit, a surgical resident joined us at her bedside and gave us the first update: “We were able to save the leg, but we had to take a lot of muscle tissue. The tissue we removed appears to have clear margins on the frozen section, so that’s good news.”

When the final pathology report came back a few days later, the surgeon told Emily that he thought there was a less than 10 percent chance of recurrence. Radiation therapy, he said, might reduce the risk even further. She should be monitored for recurrence, including quarterly MRI scans and physician visits, for at least the next two years, then every six months after that. If the tumor recurred, it would most likely appear as a metastasis to the lungs. And it most likely would be fatal.

Out of the hospital and back in our home, after dinner one evening Emily spread her medical bills on the kitchen table for my wife and me to review. She seemed discouraged and confused. “What am I going to do with all of these?” she asked us. Her treatments were going smoothly, but her medical bills and notices were mounting fast and already filled several file folders. Now, about three months after her initial surgery in Colorado, Emily had received notices for more than $50,000 in medical bills, and it was still unclear what would—and what would not—be covered by her school insurance plan.

Emily detailed what she knew about the costs so far: “About $4,000 for the cancer consultants, $7,500 for the pre-op scans, and more than $35,000 for the surgery and five days in the hospital, and I haven’t even received any of the bills for post-
surgery follow-up or radiation yet.” We asked what she had learned from the insurance company. “The woman who answered the phone was nice enough,” Emily responded. “But she couldn’t tell me which of these bills would be paid for, let alone when. She said that’s because the larger bills—the ones that would bump me up into 100 percent coverage from my insurance—take time to be investigated. In the meantime, all of the smaller bills would be processed and rejected.”

Emily had purchased her university’s student health insurance when she entered graduate school because, she said, she knew it was the right thing to do. But now Emily was learning that her coverage had complicated limitations, and she was having trouble getting answers to key questions: Would her coverage pay for the out-of-state consultations and referrals to a cancer center? What would happen if her expenses exceeded the yearly $200,000 cap? Would her insurance cover the costs of further diagnostic tests and treatment? As a graduate student, Emily earned about $18,000 a year, before taxes. She’d counted on her student health insurance to cover any medical costs, but now she was unsure if it would.

Emily also was becoming frightened by the tone of the notices she was receiving from the Boston hospitals. “There is no way I can pay these bills! Should I consider bankruptcy?” she asked us. I encouraged her to hold off starting to pay any of the bills until she had a final determination from the insurance company. Given my familiarity with public insurance programs, I also suggested that Emily look into the possibility of applying for Medicaid and other state assistance programs to help with bills that wouldn’t be covered by her insurance. I was disturbed, too, that she thought her medical costs might drive her into bankruptcy.

**Having It Hit Home**

**From behind the lectern at the front of the classroom, I said,**

“OK, class—let’s get started. How would you characterize the approach to health insurance in the United States? On the basis of your experience or of someone in your family, can you tell me what parts of the system are working well and where we might have some room for improvement?” Posing this type of question to first-year medical and nursing students is, I’ve found, an effective way of involving them in an annual introductory lecture I give on U.S. health care policy. Generally, lots of hands go up, and then a number of students describe personal encounters that give life to the otherwise dry (and potentially mind-numbing) description of the peculiar state of health insurance coverage in the United States: More than forty-six million Americans have no health insurance, and about twice that number experience major gaps in their yearly coverage. Even those with insurance find that they have substantial copayments and deductibles, that specific conditions and treatments are excluded, and that payments on others are capped. Few people read the fine print of their insurance policies, and many find that they are not insured for the conditions they develop or the treatments they need.
This time I was giving the lecture barely three months after Emily’s diagnosis, however, and I found myself stumbling as I recited the same old familiar facts about the insurance crisis. Then I surprised myself by starting to tell the students Emily’s story: “My niece Emily is living with us now while she’s being treated for a synovial sarcoma. She’s currently receiving radiation therapy and is frightened about the treatments and whether she’ll survive the cancer. She has already received more than $50,000 in medical bills, and she is likely to be billed for more than $200,000 in the next year. Emily has health insurance through her school, but she can’t get an answer on how much of her medical expenses will be covered. Does it seem fair that she should have to worry about how she is going to pay for all of this in addition to worrying about surviving her cancer?”

I had to stop there. Suddenly I found myself choking up, and I was beginning to have difficulty forming my words. I stopped and took a sip of water. And then I found myself crying for the first time since Emily was diagnosed. I had to turn away to regain my composure; the class remained silent. After a few moments I was able to turn around and make it through the rest of the class. Talking about Emily’s experience with the insurance system had unexpectedly, and more dramatically than I could have imagined, given me a new perspective on the otherwise abstract and dry “insurance crisis.”

Insurance For Graduate Students

After completing her radiation treatments, Emily returned to school in Colorado for the 2005 spring semester, where she decided to become part of her graduate school’s student insurance committee. There she learned that she was one of several students who were “high-cost cases,” each of whom had had more than $100,000 in health expenses in the previous year. Because of this, the insurer would be raising the graduate student premium by 19 percent—an increase from $1,340 to $1,605 a year. Emily was both embarrassed and outraged that she was considered to be part of “the problem” that was causing the insurance company to raise rates for everyone.

The committee also was told that there was another reason the premium costs were going up: Few students were electing to purchase insurance. During the 2004–05 academic year, fewer than one in five students at the school had enrolled in the voluntary student health plan, and fewer still would be likely to enroll with the increased premiums. To keep the student insurance premiums relatively affordable, the carrier planned to continue the cap on annual coverage and to limit key benefits such as outpatient radiology, prescriptions, and consultations.

It turns out that these kinds of insurance plans aren’t unique; many college and graduate students are being faced with mounting costs and uncertain coverage. Although college students often are still covered as dependents on their parents’ plans, the number of students with coverage declines steeply after age twenty-
three—more than 35 percent of full-time students in this age group have no health insurance. Although most colleges and universities offer some form of student health benefit, an estimated three out of four public universities don’t require health insurance coverage. Some states, including my state of Massachusetts, have tried to address this problem by mandating health insurance coverage as a condition of enrollment as a full-time student, but the nature of the benefits and extent of coverage vary widely. Where insurance enrollment is voluntary and health costs are increasing, as is the case for Emily’s school, voluntary plans are subject to “adverse selection” (meaning that the plans attract those who expect to have significant health care costs), and plans attempt to control costs by limiting coverage for pre-existing conditions and by limiting benefits for specific services (lab, radiology, and prescriptions, for instance) or establishing yearly and lifetime benefits caps for specific conditions—such as cancer.

A Different View

Seven months after her original diagnosis, and two months after completing radiation therapy, Emily’s radiation burns had healed, and she’d completed an aggressive physical rehabilitation program. I’d been invited to New Zealand to speak on U.S. disability policy at a conference celebrating the thirtieth anniversary of New Zealand’s comprehensive accident and disability system. The timing was perfect to celebrate her recovery, so my son and I invited Emily to come with us.

Before the conference, we hiked a section of the Tongariro Crossing, one of New Zealand’s famed Great Walks through a stunning geothermal area. The four-hour uphill climb to the highest point of the crossing was challenging, but we took it easy. Nonetheless, Emily began moving slowly and eventually complained of leg pain, so we rested at the base of the mountain that had achieved fame as Mt. Doom in the film version of Lord of the Rings.

When I checked with Emily on how she was doing, she sighed. “OK, in general,” she said. “But I’m really frustrated; this hike would have been a piece of cake for me a year ago. The pain in my leg reminds me of the cancer treatments and the risk of the cancer coming back.” She was worried about her career and financial future, too. The bills from various health care providers were still coming in and now totaled more than $170,000. “I had hoped to do some international travel after finishing my master’s degree next year,” Emily told us. “But I can’t take the chance of losing my health insurance ever again. It pisses me off that I need to be making career choices on the basis of whether I can or can’t get insurance that covers me for my ‘pre-existing’ condition.”

It does seem crazy, I thought. There we were, on a mountaintop in a country on the other side of the world from the United States where Emily wouldn’t have this dilemma. As in nearly all modern, developed nations, New Zealand has a system of
universal health insurance for its citizens. When my New Zealand colleagues met Emily and heard her story, they were astounded. Medical bankruptcy is almost unheard of in New Zealand, and none of them could remember being concerned about whether their loved ones had adequate coverage. Nor did any of them seem to worry about what would happen to their children once they “aged out” of their family coverage—or about excluded conditions, or lifetime caps, or the need to make career decisions on the basis of health coverage. My son Jesse, who was still living in France, even as a foreign student, was covered in full by French national health insurance. Considering all the money we spend on health care in the United States, it just doesn’t make sense that graduate students—or anyone else—should have to fear bankruptcy while battling disease.

Living The Aftermath

It’s now two years since Emily was first diagnosed, and her scans and exams have been clear, with no sign of cancer. She is in good spirits and has resumed her active lifestyle, including martial arts and rock climbing. When the dust finally settled on the bills, the insurance company renegotiated the hospital billings and paid more than $200,000 of Emily’s medical expenses. Medical assistance programs in Colorado and Maine (where Emily’s parents live) paid roughly an additional $12,000. Emily paid off the remainder—about $3,500—in monthly installments.

Although Emily remained healthy during her second year post diagnosis, she incurred an additional $24,000 in expenses for her outpatient radiology and consultations. The now-revised benefits of her student health plan, however, covered only up to $1,250 for outpatient diagnostic radiology (and it doesn’t count toward her $2,000 deductible); this means that her school insurance paid less than $1,500 of her $24,000 in expenses. Because of her limited income, she qualified for the Colorado Indigent Care Program, which paid approximately $15,000 of her expenses and made her eligible for discounted fees. Nevertheless, Emily remains responsible for paying more than $6,000 this year alone for uncovered costs (which is more than 40 percent of her take-home income), and she is making monthly payments to the hospitals and doctors involved with her care. As I write this, Emily is completing her master’s thesis in wildlife biology, and she has spent much of her out-of-class time trying to figure out how to pay for her cancer care. She has joined with other students at the university in seeking to make changes in the student insurance plan, but so far to no avail.

Emily has received excellent medical care and now has a good prognosis, but she will need to be closely monitored with CT and MRI scans and physician consultations for the next twenty years. Emily has been able to claw her way out of financial quicksand—for the time being at least—with good planning, perseverance, and informed support from caring family and friends. Although she still lives...
with the threat of cancer recurring and worries about the new round of mounting bills, this first chapter has had a happy ending. But what if the cancer were to recur? It is highly likely that further treatments would easily exceed her plan’s $200,000 cap, and she would, once again, face potential bankruptcy. Her story isn’t over yet.

Are there any simple solutions to help Emily and others in similar situations? Mandating coverage with appropriately designed benefits for all students, considering health insurance costs in making financial aid decisions, and creating explicit catastrophic coverage from a public system would go a long way in addressing the confusion and inequities faced by college and graduate students. But students are, of course, only one of many identifiable groups that suffer the uncertainty, inequality, and inefficiencies of a highly fragmented voluntary insurance market. In some ways, Emily represents the bleeding edge of needed innovation in the U.S. health insurance market. Increasing numbers of Americans, like Emily, are one accident or one serious illness away from becoming a data point in the frightening statistics on health outcomes of the uninsured and the underinsured and on the growth in medical bankruptcies. Statistics tell us that insurance policies with restricted benefits aren’t only increasingly common among student populations, they’re seen by many as the answer to the affordability crisis in health care. Statistics suggest that more and more Americans are enrolled in high-deductible, limited-coverage policies and are encouraged to make poorly informed decisions about their medical care on the basis of financial incentives. And statistics confirm that the growing number of medical bankruptcies in this country are occurring among families with insurance policies that leave them liable for thousands and thousands of dollars in medical bills after a short hospital stay.

It has been said that “statistics are people with the tears washed off.” It’s true. Statistics on the uninsured and underinsured look very different to me now. When I think of Emily, I can see the people behind the numbers; I can see the tears and fears of sick people and their families fighting illness and a system that contributes to their pain. This is something we can’t wash away and shouldn’t turn away from. Our insurance system has to change.

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