Choosing Between Death and Deportation

What happens when an undocumented immigrant has a life-threatening diagnosis? Much depends on where the person lives.

June 20, 2018 By Dan Gorenstein

“Dear the most highly respected judge and court, I’m writing this because I love my mom. My mom is very important to me. I have no idea what to do without her. Even though my mom’s afraid, she’s not giving up.”

This is the beginning of a plea written by a 13-year-old girl to the Department of Homeland Security. The goal: to get her mother the insurance coverage she would need to enter a clinical trial.

Two years ago, the girl’s mother learned she had advanced stomach cancer. Undocumented and uninsured, the mother received free treatment at Bellevue Hospital in Manhattan through New York’s emergency Medicaid program, which undoubtedly prolonged her life.

Then, last fall, her doctor identified her as a good candidate for a medicine that has been remarkably effective for some lung cancers. Would it work for her disease? The researchers were eager for patients like J. to help them answer that question. (Kaiser Health News is identifying the patient by her first initial only, because of the threat of deportation.)

“You look at these clinical trials — there are some patients who just forget to die,” said Steve Lee, MD, J.’s oncologist. “She could be one of these long-term survivors.”

But it would not be a simple process for J. to enter a clinical trial. She emigrated from China 18 years ago on a visa that had long since expired. Her husband’s visa also expired years ago. The Queens couple have three children who are U.S. citizens, ages 13, 12 and 4.

To be accepted into the trial, J. needed the more complete coverage traditional Medicaid offers. And to get that meant declaring herself to Homeland Security and asking the agency not to act on its standing deportation order against her. That would call attention to herself and her status — and provide the agency with her address and the names of everyone she lived with.

“Before getting sick, legal status was clearly important,” J. said through a translator. “Now, both

legal immigration status and my ability to continue to live are intertwined, because I can only get good treatment if I obtain legal status."

The family faced this dilemma under President Donald Trump's growing threat of deportations. Federal figures show arrests of undocumented people living in the U.S. were up 40 percent in the first four months of 2017 compared with the same period in 2016. The administration also is considering a change that would penalize legal immigrants if they use public benefits like Medicaid.

Up to the point of the clinical trial, J. got care very similar to what anyone with private insurance might get. And that is a function of residence. Each state covers care for undocumented immigrants through its emergency Medicaid program differently, and New York has one of the most generous programs in the country.

"In some states, they say giving you dialysis is keeping you from dying. We are going to put you on emergency Medicaid," said Steven Wallace, a health professor at UCLA, who has studied immigrant health care in the U.S. "In other states — Georgia comes to mind — they will not put you on emergency Medicaid until you are in diabetic shock."

By the time J. learned of the drug trial, she'd had chemotherapy and separate surgeries to have her ovaries and part of her stomach removed. As comprehensive as New York's emergency Medicaid program is, it does not cover the costs associated with drug trials, even in dire situations.

For context, some estimates suggest that stomach cancer treatment for one year costs about $100,000. Costs vary by hospital, and Medicaid pays hospitals less.

Bellevue did not provide a tally of J.'s medical bills. The limited research available on care for very sick, undocumented immigrants shows that the treatment can vary even by county within a state. More often than not, Wallace said, when beset by a life-threatening illness such as stomach cancer, undocumented women and men miss out on the tests, procedures and drugs that could extend their lives.

By virtue of living in New York, J. did receive good care. But was the chance at the drug trial worth the risk of her or her husband being deported?

For most of an interview with a reporter, J. spoke Mandarin through a translator because of her limited English skills. But when asked whether she was more afraid to die or be deported, she answered directly, in English.

"Yeah, I [am] afraid to die, more than be deported," J. said. "Of course. Because my family need[s] me. My children need me."

Domna Antoniadis, a senior staff attorney at the New York Legal Assistance Group, works just across the hall from Lee at Bellevue. Her job is to help patients jump through bureaucratic hoops to get health coverage, and she said J. had a compelling case.

“She’s been here for almost 20 years. She has three young U.S. citizen children. She’s never been arrested; no criminal history. She’s worked. And right now, she has a very aggressive form of cancer,” Antoniadis said. “She’s saying, ‘Here I am. This is what’s going on with me, but please don’t remove me.’”

J.’s husband said his wife did everything she could to battle her disease, including changing her diet, walking up hills for exercise and following doctor’s orders. The decision on the drug trial was clear, he said.

“Life is more important than anything else. You have to face the cancer,” he said, speaking through a translator. “You have to face the pressures. You just have to do whatever it takes so that you can keep on living.”

J. submitted the application, and Antoniadis advised the family to be cautious. She told them if federal agents show up at the house, before opening the door the family should make sure the officials have a warrant. Her attorney gave J. a guide outlining her rights in Mandarin.

Over the fall, J.’s husband said the family felt vulnerable.

“We watch the news,” he said. “We see the things Donald Trump says, and we see that he’s been tough on immigration and has tried to make a lot of changes. So, for sure, we’re more worried.”

As they waited to hear from Homeland Security, a kind of balled-up fear settled over the family. J. talked less. Their 13-year-old daughter took over doing the dinner dishes. Their 12-year-old son set the table and played fewer video games, trying to make his mom happy. Their kid sister, age 4, asked why everything was different.

Before Homeland Security could respond, J. got word from New York’s traditional Medicaid program that she was accepted. The application to delay deportation was enough for the state to open the program to J. She had her first drug trial treatment last December. She tried to savor life.

“Now I’m not nearly as strict with my kids. I sort of just let them be kids. Before, I’d give them extra homework on top of what’s assigned at school. Now, I just want them to be happy,” she said. “Between my husband and me, we care a lot less about money. Before, we only go out to dinner once a month. Now we treasure every moment we have.”

Almost as soon as J. was in the drug trial, she was out. Her oncologist, Lee, said J. “had rapid growth of her cancer” and couldn’t remain in the trial. By early January, J. had started hospice. Her husband said it was a very difficult month for her, and on Feb. 6, J. died.

Asked if he thought the trial was worth all the risk and stress it caused the family, Lee said: “I think it’s easier to say that going on the drug trial was a waste of time, in retrospect. But the alternative for cancer like this is that she would invariably die. So I think that the opportunity to give her a shot at long-term survival was one worth putting a lot on the line for.”

Lee said what the trial really gave J., and her family — for a time at least — was hope.

Dan Gorenstein is the health care reporter for Marketplace. This story was produced in partnership with WHYY's The Pulse and Kaiser Health News.

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