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*From the Los Angeles Times*

## Immigration debate hits home for liver transplant patients

The state funded the procedures for two young illegal migrants. But when they hit 21, coverage passed to L.A. County, which doesn't have the resources to implant the new organs they both needed again.

By Anna Gorman

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Ana Puente was an infant with a liver disorder when her aunt brought her illegally to the U.S. to seek medical care. She underwent two liver transplants at UCLA Medical Center as a child in 1989 and a third in 1998, each paid for by the state.



But when Puente turned 21 last June, she aged out of her state-funded health insurance and was unable to continue treatment at UCLA.

This year, her liver began failing again and she was hospitalized at County-USC Medical Center. In her Medi-Cal application, a USC

doctor wrote, "Her current clinical course is irreversible, progressive and will lead to death without another liver transplant." The application was denied.

The county gave her medication but does not have the resources to perform transplants.

Late last month Puente learned of another, little-known option for patients with certain healthcare needs. If she notified U.S. Citizenship and Immigration Services that she was in the country illegally, state health officials might grant her full Medi-Cal coverage. Puente did so, her benefits were restored and she is now awaiting a fourth transplant at UCLA.

Puente's case highlights two controversial issues: Should illegal immigrants receive liver transplants in the U.S. and should taxpayers pick up the cost?

The average cost of a liver transplant and first-year follow-up is nearly \$490,000, and anti-rejection medications can run more than \$30,000 annually, according to the United Network for Organ Sharing, which oversees transplantation nationwide.

Donor livers are also in scarce supply. In California, nearly 3,700 people are on a waiting list for livers, according to the network. Last year, 767 liver transplants were performed in the state. More than 90% of the organs were given to U.S. citizens.

Donor livers are generally allocated through a geographically based distribution system on the basis of how sick the patients are and how long they have been on the transplant waiting list.

Immigration status does not play a role in allocating organs.

But some say that it should and that illegal immigrants should return to their home countries for care rather than receive organs and costly transplants ahead of legal residents and U.S. citizens.

"All transplants are about rationing," said Roy Beck, executive director of NumbersUSA, which favors stricter controls on immigration. "I just don't think the public ought to be funding any kind of benefits for people who are breaking the law."

Larry Gonzalez, a U.S. citizen who has hepatitis C, has known for a decade that he needs a new liver but was just placed on the transplant waiting list last week.

"Why do we have to get in line behind immigrants, foreigners, when we have enough people here to fill the hospitals?" asked Gonzalez, 54, who lives in Ventura. "It just seems obvious to me that we shouldn't be taking a back seat."

But Dr. Michael Shapiro, vice chairman of the ethics committee for the organ network, said illegal immigrants have just as much right to organ transplants as U.S. citizens. He said it is likely that more illegal immigrants donate organs than receive them.

"People are people, and when you make an incision in an organ donor, you don't find little American flags planted on their organs," Shapiro said.

### **Holes in the safety net**

Illegal immigrant children with certain severe, chronic illnesses are eligible for funding under a state program called California Children's Services. But the coverage ends when they turn 21. After that, they can receive free or low-cost treatment through county services for the medically indigent and, in some cases, emergency Medi-Cal. But in Los Angeles County, doctors said neither program covers liver transplants.

State health officials said California law is designed so there is no gap in coverage, so children move seamlessly from state-funded treatment to county care. But that doesn't always happen. When they become adults, patients like Puente often have to switch doctors and hospitals and may lose

access to necessary care.

"Certainly it's not the ideal," said Stan Rosenstein, chief deputy director of healthcare programs at the California Department of Health Care Services. "We are strong believers in continuity of care, so it is concerning when you have a break in coverage."

That break can be life-threatening for people like Puente. "It doesn't matter if I'm undocumented," she said. "They should take care of me at UCLA for the rest of my life because I've been there since I was a baby."

Puente, who lives in Van Nuys, was transferred from County-USC back to UCLA this month after getting approved for Medi-Cal.

If illegal immigrants inform the state in writing that U.S. immigration services "is aware of their presence and does not plan to deport them," they could be eligible for full-scope Medi-Cal, said Norman Williams, spokesman for the state health department. Medical condition is one factor that would make immigrants eligible for coverage.

The immigrants send a form to Citizenship and Immigration Services, but the agency said it does not respond to patients or make any promises about their immigration status.

### **Looking to the future**

Dr. Sue V. McDiarmid, medical director of UCLA's pediatric liver transplant program, said that she regrets not being able to continue treatment for every patient but that it would not be "financially responsible" to waive all fees. She said the university does follow up with its patients once they are under county care.

"It is just not our philosophy to dump patients," McDiarmid said. "When things go wrong, it truly is a heartbreaker."

But she said liver transplantation is more than a surgical procedure; doctors have to consider whether the patient will have access to healthcare and medication in the long run.

"If we felt at any time that we were transplanting a liver into a person that the hope of any long-term outcome was very poor, we shouldn't be doing the transplant," she said.

McDiarmid said, however, that doctors do not ask about a patient's immigration status.

The larger problem, she said, is that the state healthcare system cuts off illegal immigrants who were covered as children. "We took care of those undocumented children because we thought, and the state thought, that it was the right thing to do," she said. "Why would we as a society then turn our backs on them?"

Puente is not the only young transplant patient who has shown up for county care recently. Dr. Andrew Stolz, who directs the liver consultation service at County-USC as well as the county's

outpatient Roybal Liver Clinic, said the facility is treating about 10 liver transplant patients who aged out of California Children's Services and no longer have insurance.

Though he does not know how many of these patients are immigrants, Stolz said those who are here legally could apply for full-scope Medi-Cal to cover a liver transplant.

Repeat transplants, which are not uncommon, can be necessary if the patients' bodies reject the livers at the time of the transplant or while they are on medication, or if the transplant livers develop hepatitis C, Stolz said.

Jose Lopez said he came to the U.S. with his mother illegally as a child. Soon after, he contracted hepatitis A and received his first liver transplant. Eight years later, he got cirrhosis and received another transplant.

Both were performed at UCLA and paid for by the state.

As his 21st birthday approached, his mother, Maria Elena Lopez, searched for clinics that might agree to treat her son. She applied for Medi-Cal for him but has not received a response.

Her son turned 21 on Aug. 7. He said the UCLA doctors gave him extra medications to hold him over.

About a month later, his mother found the Roybal clinic, which provided Lopez with medication and monitored his care. Though his drugs never lapsed, his liver is still in rejection.

"I'm just mad," he said from the Los Angeles apartment he shares with his parents. "You can't just leave a person to die. That's pretty much what they're telling me: 'You're illegally here. We're just gonna let you die.' "

He said he doesn't blame UCLA for not wanting to treat him free, but added, "I was hoping for some miracle."

Lopez just learned about the relief Puente received and said he may follow the same route. He hopes to return to UCLA for treatment.

### **A question of ethics**

Medical ethicists said doctors and hospitals have a duty to continue treatment for their transplant patients unless they can find them comparable care elsewhere.

"The worst ethical violation a physician can commit is abandonment," Arthur Caplan, chairman of the department of medical ethics at the University of Pennsylvania School of Medicine, wrote in an e-mail. "Physicians and institutions do have a duty to these patients once they transplanted them. . . . Insurance running out is no excuse for abandoning them."

Caplan said UCLA doctors were under no obligation to perform liver transplants on the illegal

immigrant children knowing that their insurance would run out at 21 and that their livers would probably need to be replaced.

Wesley Ford, director of children's medical services for Los Angeles County, said his office works with patients before their 21st birthdays to make sure they are covered. But that is more difficult for illegal immigrants.

"It's not that we want to deny care to these kids," he said. "It's required by state law that we discontinue care at age 21."

Los Angeles County picks up where the state left off, providing costly medications, performing lab work and conducting biopsies -- regardless of immigration status. But the key for patients who lose their insurance at 21, Stolz said, is to go immediately to the county before any lapse in medicine occurs and before their livers fail.

"We would hate for patients to lose a liver because they can't get medication," Stolz said. "A lot of people just are not aware that there is this safety net."

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Life in the Shadows is one in a series of occasional articles.

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