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Being a Patient
Recourse Grows Slim for Immigrants Who Fall Ill

By NINA BERNSTEIN

When Ming Qiang Zhao felt ill last summer, he lay awake nights in the room he shared with other Chinese restaurant workers in Brooklyn. Though he had worked in New York for years, he had no doctor to call, no English to describe his growing uneasiness.

Mr. Zhao, 50, had been successfully treated for nasal cancer in 2000 at Bellevue Hospital in Manhattan, which has served the immigrant poor since its founding in 1736. But the rules there had changed, and knowing that he would be asked for payment and that security guards would demand an ID, he had concluded that he could not go back.

So Mr. Zhao went to an unlicensed healer in Manhattan's Chinatown and came away with three bags of unlabeled white pills.

A week later, his roommates, fellow illegal immigrants from Fujian Province in China, heard him running to and from the toilet all night. In the street the next day, July 6, he collapsed.

Immigrants have long been on the fringes of medical care. But in the last decade, and especially since the terrorist attacks of Sept. 11, 2001, steps to include them have faltered in a political climate increasingly hostile to those who face barriers of language, cost and fear of penalties like deportation, say immigrant health experts, providers and patients. More and more immigrants are delaying care or retreating into a parallel universe of bootleg remedies and unlicensed practitioners.

Last year, about 80 bills in 20 states sought to cut noncitizens' access to health care or other services, or to require benefit agencies to tell the authorities about applicants with immigration violations. Arizona voters approved such a requirement in 2004 with Proposition 200. Virginia has barred adults without proof of citizenship or lawful presence from state and local benefits. Maryland's governor excluded lawful immigrant children and pregnant women from a state medical program for which they had been eligible.

Most proposed measures were not adopted, but new versions are expected. Ballot initiatives modeled on Arizona's Proposition 200 are circulating in California and Colorado. And in December, the United States House of Representatives passed a sweeping bill that would make "unlawful presence" in this country a felony and redefine "criminal alien smuggling" to include helping any immigrant without legal status.

"We've seen a real rise in anti-immigration measures across the country," said Tanya Broder, a public benefits lawyer in Oakland, Calif., for the National Immigration Law Center, "and it's engendered confusion and fear that prevent immigrant families from getting the care they need."

Some who had been drawn into medical treatment by outreach efforts have retreated, like Mr.

Zhao, fearing the harder line toward immigrants, especially those without money or proper papers. Even legal immigrants and parents of children with legal status are more skittish about their health care, scared that medical bills and public medical insurance can hurt their chances for citizenship, bar relatives from coming to the United States or break up their families.

"I heard that if you go to the emergency room or go to the doctor, they were going to deport you," said Alejandra, a mother from Colombia living in Queens, referring to a rule proposed in 2004 by the Centers for Medicare and Medicaid Services that would have made hospitals report the immigration status of emergency-room patients in exchange for more federal money. "So then my four children are going to be without me because I don't have documents here."

The proposal did not pass, but like many of the proposed rules immigrants hear about on television or from neighbors, its chilling effects lasted.

Restrictive bills are part of what supporters describe as a movement to end tolerance for the country's estimated 11 million illegal residents.

"It's certainly an effort to make them go back," said Dan Stein, president of the Federation for American Immigration Reform, a group calling for fewer immigrants and stricter enforcement of immigration laws. "It will never be acceptable for people to break our laws and then expect taxpayers to provide health care."

Almost by definition, the most fearful immigrants are the least likely to talk. The Colombian mother in Queens, however, was among 75 immigrant parents, both legal and illegal, who were interviewed in depth by researchers from the New York Academy of Medicine for a study to be released later this year, with the guarantee that their real names would be withheld.

What emerges from the transcripts, and from dozens of other interviews conducted by The New York Times with patients, health-care providers and experts on immigration, is a picture not only of heightened anxiety but also of immigrants who are primed to flee rather than fight for help from a system that even the native-born often find baffling and rude.

For Nadege, pregnant and in pain when she sought treatment at Queens Hospital Center, a public hospital, the defining moment was a snub by a fellow Haitian who had been summoned to interpret. "She said to me, 'Don't come here saying that you have a bellyache: no one is going to stay with you the entire day,' " Nadege recalled.

"I cried," she said. "I picked up my belongings and left. Even if I was dying that day, I wouldn't go back."

Lard and Vodka, Not Doctors

No one is suggesting that hospitals and clinics are seeing a decline in immigrant patients. On the contrary, as a decade of record immigration continues at an estimated annual clip of 1.2 million newcomers, the number of patients who speak little or no English is growing everywhere. And

some hospitals and clinics are trying harder than ever to at least meet language needs.

But even in New York, a gateway of immigration, a national climate that makes immigrant patients more timid also emboldens some front-line workers to bar the way.

"If you have one renegade public-benefits worker who thinks they should be discouraging access because they believe it's a drain on taxes, the word on the street is it's too much of a hassle to apply," said Adam Gurvitch, director of health advocacy for the New York Immigration Coalition, an umbrella group for more than 150 immigrant organizations.

Problems getting insurance sometimes lead to risky decisions about children's health care. A legal immigrant from Russia, Oksana, confessed to academy researchers that she had delayed her daughter's vaccinations for months, keeping her out of school until she could borrow $300 to pay for them. Melosa, of Mexico, had so many problems with state-subsidized insurance that when her severely asthmatic son ran a high fever she resorted to rubs of pig lard and carbonate, instead of taking him to a doctor.

Vera, a Brooklyn mother from Belarus, used vodka rubs and borrowed medications when her daughter was delirious with fever from the flu. "We couldn't go to the doctor without medical insurance," she said.

In the end, immigrants often return to mainstream care in dire need, only to have their chaotic medical histories compounded by a beleaguered system whose costliest medical technology is no substitute for timely treatment. In Mr. Zhao's case, an ambulance took him, unconscious, to a bankrupt hospital system where his life hung in the balance for weeks, and where one of his roommates, a 19-year-old waiter with uneven English, served as the interpreter.

"No money, no ID, no good English," said the waiter, Hong Chung. "What you going to do? Nobody pay attention to us."

Mr. Zhao was in a coma when his brother, Ming Tong, 49, and Fujianese friends came to the hospital, clutching the unlabeled pills, which had been described as herb-based remedies for high blood sugar, high blood pressure and insomnia.

Mr. Chung remembers pleading, "If you find out the name of the ingredients, maybe he won't have to die." But he said doctors told him that the hospital was unable to do such an analysis. The hospital, St. Mary's in Brooklyn, was scheduled to close after more than a century serving the immigrant poor. St. John's in Queens, where Mr. Zhao was transferred for more tests 12 days later, was up for sale. Their parent organization, St. Vincent's Catholic Medical Centers, the largest Roman Catholic hospital system in New York State, had just filed for bankruptcy protection.

At struggling hospitals, interpretation can seem like a luxury, despite longstanding federal and state laws requiring equal language access and studies showing that it cuts cost by improving quality. Few hospitals have laboratories capable of analyzing underground remedies.

"With regular drugs, we know what the side effects and interactions are," said Dr. Sarvesh Parikh, a resident at St. John's, who wrote a note in Mr. Zhao's chart about his roommates' account of the pills. "About these kinds of pills, we don't know anything."

The larger mystery was why Mr. Zhao, a thin, quiet, frugal man, had gone without medical care instead of returning to Bellevue. In 2000, seven years after he and his brother arrived on American shores, jammed into the fetid hold of a smuggling ship, Bellevue doctors had diagnosed and eradicated his nasal cancer.

But even when treatment is a medical triumph, without sick pay or a safety net it can be personally devastating. In Mr. Zhao's case, the effects of surgery, radiation and chemotherapy left him unable to work. His wife and son in China had counted on his income, and without it, she divorced him to marry another man. Then staggering medical bills arrived at the apartment that he and his brother shared with six roommates.

Medicaid reimburses hospitals for emergency care of the poor, regardless of immigration status. Outside of emergency care, however, illegal immigrants like Mr. Zhao are ineligible for Medicaid; in two-thirds of states, so are most legal noncitizens, no matter how indigent.

James Saunders, a spokesman for Bellevue, like Debby Cohen, a spokeswoman for St. John's, said confidentiality laws barred discussion of Mr. Zhao's case. But Mr. Saunders emphasized that Bellevue has a mandate not to turn anyone away because of immigration status or lack of money, "and an obligation to the federal government to collect what we can."

After the Sept. 11 attacks, about the same time Bellevue security guards began demanding ID cards, clerks started collecting sliding-scale fees from the uninsured. Mr. Zhao was charged $20 per visit, then $150 for a CAT scan. Destitute, intimidated, unable to keep borrowing such sums, and unaware that the fees could be waived, his brother said, Mr. Zhao gave up on Bellevue in 2002.

"The doctor said that he was supposed to come back every two months, every three months, every six months, until the end of his life," Ming Tong Zhao recalled through an interpreter. "But he couldn't go back, because he couldn't pay."

By the time Mr. Zhao again ended up in a hospital, he was in a coma; just his intensive care bed, at St. Mary's and then at St. John's, cost Medicaid $5,400 a day. For more than a month, a parade of doctors did spinal taps, EKG's, CAT scans and an M.R.I.; infused him with antibiotics, anticonvulsants and blood thinners; and placed him on a ventilator. Tests showed diabetes and high blood pressure, though their role in his collapse was uncertain.

Ming Tong, visiting between his work renovating kitchens in Manhattan, could not get a clear answer about what was wrong with his brother and was afraid to press. "You understand," he said, "people in the United States without legal status don't want to cause too much trouble."

Afraid to Seek Help

Whether legal or illegal — and many immigrant families include members in both categories — noncitizens are fearful of asking for too much. Many echo Catalina, a Queens woman from Colombia who hesitated to sign her toddler up for the free speech therapy urged by his pediatrician because she and her husband had a pending application for a green card. "It scared us," the woman said, "because if you are asking for residency, you have to show you are capable of living here without any help."

Noncitizens are two to three times more likely to lack health insurance than citizens, studies show, and the gap has widened, even for children. Even legal immigrants qualified for government medical coverage often think twice about accepting it.

Special concerns arise among different ethnic groups. Korean parents in Staten Island mistakenly fear that their children will forfeit future chances for a college loan, said Jinny J. Park, a health specialist at Korean Community Services. And mothers at the Latin American Integration Center in Queens worry unnecessarily that free medical care will later mean their children's military conscription. As one, Melosa, put it, "Everything we receive from the government is like giving my children away little by little" to the Army.

The changing political climate makes it hard to separate myth from reality. Laws codify disapproval of government aid for noncitizens. An immigrant deemed "likely to become a public charge," for example, is to be denied a green card as undesirable. The 1996 welfare overhaul barred most legal immigrants who arrived after August of that year from receiving federal Medicaid until they become citizens, and the state-by-state patchwork of exceptions is confusing.

Even New York, which extends Medicaid to lawful immigrants and to low-income children regardless of status, reserves the right to sue their sponsoring relatives for reimbursement, though it is not doing so.

Those who do apply for public insurance discover a stark gap between the enthusiastic multilingual marketing of H.M.O.'s and the Kafkaesque task of getting and keeping an insurance card that works. They tell of learning only in the doctor's office that a sick child's card is not valid and then being turned away for lack of money.

The public health implications alarm James R. Tallon, president of the United Hospital Fund, a nonprofit policy group in New York. "Anything that keeps anyone away from the health system makes no sense at all," Mr. Tallon said, noting that early detection is crucial in case of Avian flu or bioterrorism. "It takes one epidemic to change everyone's attitudes about this."

In some cases, the change in attitude comes instead from immigrants who arrived with high expectations of American medicine and now yearn for the kind they left back home. Yelena Deykin, a legal refugee who came from Ukraine in 2000, said that if she had the money, she would take her son back there for treatment of his thyroid ailment. "Our doctor not like your doctor," she said. "Altruism — not business."

In Mr. Zhao's hospital room, visitors began to hope for his recovery. After three weeks, he

seemed responsive when they called his name. So it came as a shock when Mr. Chung, the waiter acting as a translator, relayed a new request from a doctor: Would they agree to let Mr. Zhao die?

Mr. Chung, who would soon return to work at an Asian restaurant in South Charleston, W.Va., translated the request for a "do not resuscitate" order as best he could, and drew his own conclusions. "Maybe some people don't like Chinese," he said.

Ming Tong refused to sign the order, then telephoned his brother's son, in China, and asked him to decide. The son wept. Now 23, he had been a child of 9 when he last saw his father. As they discussed it again on Aug. 9, Mr. Zhao grew agitated. He tried to pull free of his tubes and his oxygen mask, as though he wanted to speak. Instead, despite resuscitation efforts, he died without a word.

In the End, No Answers

"The one thing that he wanted the most in his life was to see his son again, and he didn't even get that chance," Ming Tong said. "Why did he die? I asked the doctors. They didn't know. They didn't answer me."

For immigrants, the divide of language and culture often deepens after death. In this case, doctors requested an autopsy. Ming Tong refused, in keeping with Chinese tradition. Doctors certified the death as natural, not mentioning the pills. The official cause of death was lobar pneumonia and sepsis, secondary to diabetes and hypertension — acute lung and blood infections, that can attack patients on ventilators, but whose origins in this case are unknown, and chronic conditions that weaken the system.

On Aug. 13, The World Journal, a Chinese-language newspaper circulating to 300,000 in North America, described Mr. Zhao's death as part of a pattern of fatal misdiagnoses and wrong medications given by unlicensed practitioners on East Broadway, the thoroughfare of Fujianese Chinatown.

But at the Medical Examiner's Office, where an inquiry could have been ordered, no one reads Chinese and no one was aware of questions about the case. Permission for cremation was granted the next day.

Most of Mr. Zhao's possessions fit into his coffin. The rest, including the pills, were discarded. But a woman going to his funeral called The New York Times and accused an unlicensed practitioner on East Broadway of mishandling Mr. Zhao's case.

A decade ago, the Chinese American Medical Society helped spur a short-lived state crackdown on a Chinatown subculture of fake doctors. But "there are more illegal doctors than ever now," said Dr. Peter Fong, an ophthalmologist and a former vice president of the society. They are not just offering herbal supplements, for which no license is required, he said, but practicing medicine without a license — a crime.

To John C. Liu, the first Asian-American elected to the New York City Council, the reason is obvious: "What empowers the quacks is lack of access to health care."

Chinese workers scattered in jobs throughout New York and across the country periodically return to East Broadway, the hub of Fujianese life in the United States, to find health care — of a sort.

No. 52, where Mr. Chung says he accompanied Mr. Zhao last summer and saw the dispensing of the pills, is stacked with self-styled clinics. One thrives at the back of a basement computer store; another features $30 pregnancy sonograms and a crookedly lettered sign for "precise dental art."

The establishment of Yu Yuan Zhang, 50, where Mr. Chung said he and Mr. Zhao went, has operated for 11 years. Near drawers of Chinese herbs hangs a New York State medical license — in someone else's name. Visibly nervous, Mr. Zhang denied that any pills he dispensed could cause harm. "They're made in China," he said, "available all over, in the street."

By then, the only evidence left of Mr. Zhao's 12 years in the United States were bills, ashes and a death certificate that his brother could not read. Pressed about the case, the practitioner did not hesitate.

"There is no such person," he said. "There is no Ming Qiang Zhao."