

The Mendivil Family, Tucson, Arizona



“I barely get finished paying one bill when the next one comes in.”

For most of their 27 years of marriage, neither Carmen nor Francisco Mendivil of Tucson, Arizona, has had health insurance. Only during the last months of Carmen’s fourth pregnancy, when she developed diabetes, did she receive coverage through Arizona’s Medicaid program, AHCCCS.

With their household income patched together from a variety of small businesses, and hence unpredictable, the Mendivils have never felt they could afford to pay regular premiums for health insurance, which, given Carmen’s health history, could easily cost \$600 a month for the family. Instead, they’ve paid for their medical care as they needed it. “If I had the money, I’d pay right

then and there, and if I didn't, I'd send in a payment when I could," Carmen reports.

But when Carmen was stricken with a mysterious illness six years ago, the Mendivils learned firsthand what it meant to be uninsured. The need for sophisticated diagnostic tests, including two liver biopsies and a bone marrow biopsy, resulted in thousands of dollars in medical bills. Even today, with Carmen's illness finally diagnosed and under control, her medical bills continue to mount because she requires expensive laboratory tests twice a year. Not a week goes by without a telephone call from a collection company. "When they call, they say, 'Do you know you have these bills?'" Carmen reports. "And I say, 'Yes, I know, and I can't do anything about it. I'm sending in as much as I can, at least \$100 a month.'"

The Mendivils' situation is not unusual among Americans who are self-employed. With no employer to provide insurance coverage, and their income too high for them to qualify for government-provided coverage, they believe they have no option but to forgo health insurance and try to pay out of pocket for medical care.

"Write your bill on ice"

The Mendivils are luckier than most families in similar circumstances. The physician who provides Carmen's primary care doesn't charge Carmen for his services, apparently as a favor to her sister, who has worked for him for 15 years. He's also persuaded two other specialists, an oncologist and an ophthalmologist, to treat her without charge. "I remember him telling the eye doctor in Spanish, 'This lady has a lot of problems, and she doesn't have a lot of money, so I want you to write your bill on ice,'" says Carmen, marveling at the physician's empathy for her situation.

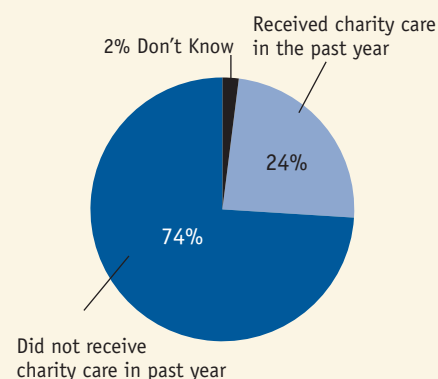
The Mendivils live in a comfortable three-bedroom cement-block house in a neighborhood near the Tucson city limits, with a view of the Tucson Mountains from their front yard. Carmen, 44, is a lifelong Tucson resident; Francisco, 47, immigrated to the United States from Sonora, Mexico, as a young adult. They share a sense of frugality and strong entrepreneurial instincts, which have combined to enable them to buy their own home as well as some rental property.

"Just after we got married, we bought ourselves two trailers on an acre in town," Carmen says. "We lived in one and rented out the other, using the rent we collected to pay off both loans. When the trailers were paid for, we rented them both out, which helped us make the payment on our house. Later on, we bought two more trailers, and the rent on one makes the payments for both, which means the other is good income for us."

The Mendivils make about \$10,000 a year from their rental trailers, their most predictable source of income. They also own two shrimp boats based in the Gulf of California, which, in a good year, can produce a \$20,000 profit,

Most Uninsured Families Do Not Receive Health Services for Free or at Reduced Charge

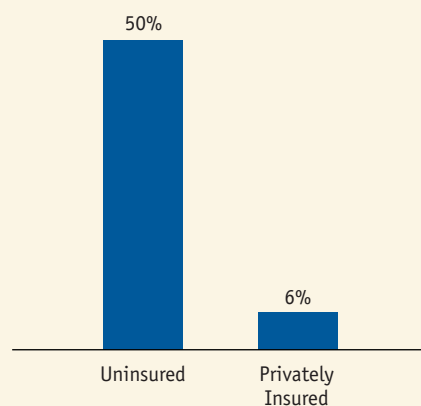
9.3 million families with at least one uninsured member



Source: Kaiser Survey of Family Health Experiences, Round 3, 1997-1998.

Even Among Those with Serious Health Problems, the Uninsured Are More Likely Not to Get Care as Often as Needed

Nonelderly with serious health problems
Percent not getting needed care*



*Serious health problems include reporting fair/poor physical or mental health, and/or having an activity limitation due to an impairment or health problem.

Source: Kaiser Survey of Family Health Experiences, Round 3, 1997–1998.

though they can't count on it. "With shrimp, you can have one good season where you make a lot, and then a couple of bad seasons where you don't make anything," Carmen says. "With El Niño, the water was so warm a couple of years ago that it killed the larvae and there just weren't any shrimp. It costs a lot of money to run a shrimp boat, and we lost a lot."

Until three years ago, Francisco also operated two other small businesses—a tire repair shop and a firewood service—and Carmen ran a booth at a flea market. But they quit those enterprises, which didn't produce much income anyway, to start a new venture—an ostrich ranch on land that Carmen's father owns about 30 miles west of Tucson, next to an Indian reservation. Right now, a fenced-in area there serves as home to about 100 ostriches, which the Mendivils hope eventually to sell for profit. "But that isn't producing any income yet," Carmen says. "That's still costing us money. The market's really depressed, and I don't know if the ostrich ranch will ever be profitable."

The Mendivils live modestly, but, even so, their fixed expenses consume much of their income: \$427 for the monthly payment on the family minivan; \$450 a month for a mortgage; \$300 for utilities; \$100 for Carmen's medications; and at least \$400 for food. Then there are the regular payments for car insurance, property taxes, insurance on their home and the rental properties, and old medical bills. There's just never seemed to be enough room in the budget to pay a monthly premium for health insurance, too. "You think that you're never going to get sick, so why put \$600 a month into health insurance?" Carmen explains.

Carmen first developed health problems in the second trimester of her fourth pregnancy, and lab tests showed she had gestational diabetes. She had to begin injecting herself with insulin once a day and see a high-risk pregnancy specialist. Because of diabetes-related complications and her baby's large size—13 pounds—the birth required a Cesarean section. Arizona's Medicaid program paid her hospital bills; she paid the obstetrician's fee.

After the delivery, Carmen's diabetes went away, which is common for pregnancy-induced diabetes. But about a year later, her blood sugar levels again rose alarmingly, and Carmen has been on daily injections of insulin, as well as oral medication, ever since.

About six years ago, Carmen started losing weight. Being overweight at the time, she was pleased at first. But she kept losing more and more, and ultimately she acknowledged to herself that it was because she was feeling too sick to eat. "I just wasn't feeling good, and I was sleeping a lot," Carmen says. At the urging of a sister, she had blood drawn for some tests.

"The results came back that my liver was not functioning, and my blood sugar was really low," Carmen recalls. Her doctor referred her to a liver specialist, who performed a biopsy, at an out-of-pocket cost to the Mendivils of \$3,500. The biopsy was inconclusive.

A few more months passed, during which Carmen continued to lose weight. (All told, she lost 100 of her 250 pounds.) She developed a dry cough and periodically spiked high fevers. “At 106 degrees, I would start shaking,” she recalls. “If I didn’t take the medicine to keep it down, I would wake in the middle of the night with cold sweats.”

The liver specialist performed another biopsy. (This time, he waived his fee, but the hospital charges came to \$1,800, which the Mendivils had to pay.) “Again, they could not find what was wrong with me,” Carmen says.

The liver specialist sent her to another specialist, this one an expert in infectious diseases. More expensive tests were ordered, and again the results were inconclusive.

Suspecting that Carmen might have been exposed to tuberculosis, the infectious disease specialist put her on some expensive drugs, which Carmen had trouble paying for. But instead of getting better, she got even sicker. “I was nauseous and dizzy all the time,” she recalls. “Then I started swelling. I was barely functioning by this point. I’d get up and cook meals for the family and then go right back to bed.”

“My God, you’re a sick lady”

Shortly after New Year’s 1995, Carmen went back to see her primary care physician, whom she hadn’t seen for months, since she was being bounced from one specialist to another. “He looked at me, and said, ‘My God, you’re a sick lady,’” she recalls. “He immediately went to work on me. He took me off the TB medication, and ordered a lot of tests—\$6,000 worth in one month. He did X-rays and CT scans. He was looking for everything in the world from malaria to cancer. Everything came back negative.”

By now, Carmen had given up trying to keep up with her medical bills. “I would pay as much as I could, but the bills came in faster than I could pay them,” she says. “The labs couldn’t understand why I couldn’t keep up, and they referred them to collections.”

At last, a diagnosis

Finally, Carmen’s doctor referred her to an oncologist so she could undergo a bone marrow biopsy to look for evidence of leukemia. Fortunately, the test was negative for leukemia. But at last, she had a diagnosis: sarcoidosis. Carmen had never heard of the disorder. “As he explained it to me, it’s a very, very rare disease, so rare that none of the other doctors had even really considered it,” she says.

Sarcoidosis is a disorder of the immune system, whose cause is unknown. It results in the development of granulomas (inflamed cells) around a victim’s



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organs that impair function, but rarely cause death. Carmen says her liver was completely encircled by a thick granuloma, and her spleen, lungs, and eyes were affected, too.

The doctor prescribed iron pills to combat Carmen's anemia and a high dose of prednisone to reduce the inflammation. "I was still weak and tired, but I started feeling better, and after a few weeks I started getting my strength back," Carmen says. "And finally, after about a month, I felt healthy for the first time in a long time."

For much of the next year, she saw her primary care physician every two weeks, at no charge (except for laboratory work.) He gradually reduced her dosage of prednisone, but five years after the onset of symptoms, she still has to take it every other day. In addition, every six months she has to have blood tests. Although the doctor continues to waive his fees, the blood tests cost about \$300 each time, which she pays in installments. "I barely get finished paying one bill when the next one comes in," Carmen says.

Help from government clinics and charities

Carmen's experience with a chronic illness has made her keenly aware of the importance of regular medical care—and the cost of it. Because she's still paying off old medical bills, she has had to seek out local sources of low-cost health care so that she can be sure that she and other family members get annual physicals and treatment when they become ill.

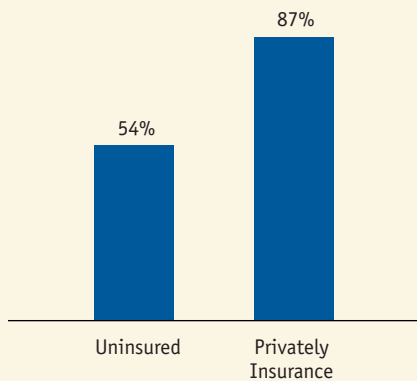
For instance, for her annual Pap smear and gynecological examination and periodic mammograms, Carmen now goes to the St. Elizabeth of Hungary health care clinic, which is supported by donations from United Way, the Archdiocese of Tucson, and other benefactors. (She's charged about \$25 a visit, based on a sliding scale, and \$50 for a mammogram.) Her youngest child, Franchesco, now 13, gets his dental care at St. Elizabeth's, at subsidized rates.

St. Elizabeth's clinic also covered some of the costs of surgery Franchesco needed a few years ago to remove a testicular hernia. (St. Elizabeth's paid for the anesthesiologist and the hospitals, and the Mendivils paid the \$1,000 surgeon's bill.) And for Franchesco's annual physical, required for him to play sports at school, Carmen takes him to a county-operated clinic for a free examination. If it turns out he needs a booster shot, she watches for the special "free shots" days and takes him then. "Thank God, my kids have all been pretty healthy," she says. (The couple's three oldest children are all grown up and living on their own.)

After years of ignoring his health, Carmen's husband, Francisco, finally agreed to have a complete physical two years ago. Carmen wasn't able to find a source of low-cost care for him, so the couple paid out of pocket for a visit to a private physician—about \$200, including laboratory tests. Francisco was found to have high blood pressure and is now taking medication for that.

Among Those with Serious Health Problems, the Uninsured Are Less Likely to Have a Usual Doctor Who Knows Them Well

Percent with a Doctor Who Knows Their Medical History Well



Source: Kaiser Survey of Family Health Experiences, Round 3, 1997–1998.

The lack of insurance makes the Mendivils feel very vulnerable about the future. Because diabetes is a chronic condition that carries with it the potential for major complications, Carmen knows she could face catastrophic costs in the future. “My doctor says I need to keep my blood sugar low or I’ll ruin my kidneys and my eyes,” she acknowledges. And she knows, too, that she and her husband are both approaching the age when medical problems often require hospitalization, whether for a hysterectomy, gall bladder removal, or heart problems.

How would the Mendivils pay for the costs of a major illness that required hospitalization or surgery?

Carmen thinks about the question for a minute. “I don’t know,” she says. “My husband and I talk about it a lot. We worry that if we had a big bill that we couldn’t pay, they might put a lien on our house. But we don’t know what we can do to avoid it.”

“We’d like to have insurance, if it was affordable, maybe a couple hundred a month. But I’ve never seen a policy that cheap. And there’s no way I could afford \$600 a month, not when we’re still paying a couple hundred a month on old medical bills.”



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