The Smith Family, Paterson, New Jersey

"I need some kind of help."

Each time a fever struck one of her daughters during the two anxious years when they didn't have health insurance, Yolanda Smith would ask herself a series of questions: How high was the temperature? What could she do to bring it down? Was it serious enough to require a doctor's attention?

First, she would try a home remedy—a child-size dose of acetaminophen—and hope for the best. If that didn't work, she would put the girls into her car and head over to her mother's. Because she's a registered nurse, her mother could often reassure her that there was nothing to worry about, that it was just something that was going around.

If the fever persisted, Yolanda might wait it out one more day. If it still hadn't come down, she would reluctantly borrow $40 from her mother to pay the fee that the doctor's office required up front. If her mother didn't have the money, Yolanda would play her last card and take her daughter to the emergency room, knowing that the bill for that visit, though huge, would drift in later.

This was the high-wire balancing act that Yolanda found herself performing every time one of her girls got sick. With every illness, she was forced to weigh the obvious benefits of seeking medical care against the risk of being left without enough money to satisfy the other demands on her biweekly paycheck or, put another way, the risk of not seeking medical care against the benefit of not piling up further debt.

Ominously, each time the girls received treatment for the sore throats or ear infections that were causing their fevers, doctors would shake their heads about the size of their tonsils and warn Yolanda that they needed to be taken out. But without health insurance to help cover the cost of the surgery, how would that ever be possible?

Making do without insurance

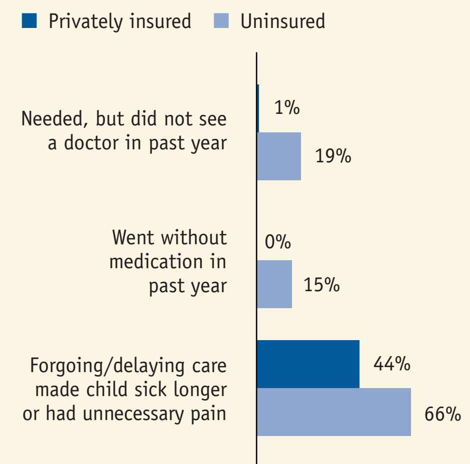
Yolanda tells the story of her families' health-care experience as she snuggles with her daughters, Dominique, 8, and Destiny, 6, on the couch in the living room of the duplex she rents from an aunt in Paterson, New Jersey. Her family's story is all too common among uninsured families in America. Struggling to make do without health insurance coverage, these families often delay medical care, which sometimes makes health problems worse and almost always results in piles of medical bills for emergency treatment.

Like the majority of uninsured Americans, Yolanda, 29, works full-time, in her case as a customer service representative for a cigar-distribution company. She is raising the girls by herself, with a lot of help from family members. The girls' father lives in another town and sends child support payments "once in a blue moon," Yolanda says. He owes thousands of dollars in back support, which she doesn't expect ever to collect.

Yolanda has been employed since she was pregnant with Dominique and working part-time at a hospital day-care center in Paterson. Though she only worked 20 hours a week, the hospital provided her health insurance for just $7 a pay period, and she was able to get good prenatal care for a $10 co-payment per visit. The insurance paid for Dominique's birth, but because Yolanda couldn't afford the higher premium for family coverage, she had to apply for Medicaid coverage for her daughter's medical care after birth. Medicaid also covered Destiny after her birth in September 1993.

For a time, Yolanda was covered by Medicaid, too. But that safety net disappeared in 1994 when Yolanda took the full-time job with the cigar-distribution company and began earning too much money to qualify.

Adequate Access to Care is a Problem for Uninsured Children



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

Too much money is a relative term. After nearly six years with the company, Yolanda earns $12.50 an hour, or about $26,000 a year. That puts her squarely in the hardscrabble territory of low-income America, defined as those who earn less than 200% of the federal poverty level, or $28,300 for a family of three in 2000. It is these workers and their families, living just a few handholds above poverty, that run the second highest risk, after the poor, of being uninsured.

Part of the appeal of Yolanda's new job was that it offered health insurance. But Yolanda suffered sticker shock when she found out what her share of the cost would be. To cover herself alone, she had to pay $85 every two weeks. Coverage that would include her daughters would have cost $150 every two weeks, an amount she simply could not figure out a way to pay. The total cost for a family policy would have amounted to nearly $4,000 a year, or nearly 15% of her annual household budget. And there would still have been annual deductibles of $200 for each family member, plus co-pays for each visit.

"Sometimes I have to hold off paying a bill to keep the gas and electricity on."

Finally, with household bills mounting, Yolanda even stopped buying insurance for herself. "I dealt with it for awhile, but when things got tough I had to drop my insurance," she says.

During the two years after the girls' Medicaid coverage ended and they had no insurance coverage—from the end of 1996 to the end of 1998—Yolanda could do little more than make sure they had the basic immunizations required for school enrollment. When they got sick, she relied mostly on emergency room care—leaving her with more than $1,000 in unpaid medical bills that have piled up in a drawer in her apartment.

Choosing which bills to pay

On her living room table, Yolanda spreads out the bills, some of them sent by collection agencies. There is one for $316 from the time Dominique fell and hurt her finger, and Yolanda took her to the emergency room because her mother thought it might be broken. There are others from the throat and ear infections and bronchitis attacks that both girls have suffered since they were young. And there are some for treatment of the bronchitis and migraines that she herself suffers.

The bills remind Yolanda of the constant risks she had to take before the girls were insured. When their bronchitis flared, Yolanda used to ask her mother to bring her saline solution, which she would substitute in her daughters' nebulizers for the prescription Albuterol that she couldn't afford. It wasn't what they needed, but it was the best she could do, and it seemed to help.

A look at the difficult choices Yolanda faces every month to make her household budget work helps to explain the kinds of trade-offs that constantly confront low-income working families like hers. After taxes and a modest $29.91 contribution to her 401(k) retirement savings plan, her biweekly net income is $737, or a little under $1,600 a month. Her monthly rent is $580, and her second biggest fixed expense is the $315 payment on her compact car, a necessity because of her daily 80-minute commute to and from work.

Then there's the $284 she pays for car insurance every other month, plus the weekly gasoline bills of about $25. Electric and gas bills for the house average $144 a month, leaving her about $300 for groceries and any other expenses that arise during the month. (For instance, the uniforms required by the girls' public school run about $40 for the complete outfit, and each needs at least two. And after-school care at the local Boys and Girls Club costs $60 a week for both.) Even though her mother helps with the cost of the after-school care and the girls' clothes, Yolanda's budget is in the red most months.

Yolanda's precarious finances are complicated by unpaid bills. Besides the more than $1,000 she owes for emergency care, she owes $800 to Sears—$600 for a kitchen appliance and $200 for interest. She used her income tax refund this year to pay off her Goodyear credit card bill of $900, including $200 in interest payments.

There have been times when she couldn't afford a telephone, and even now she uses an off-brand service that doesn't check her credit rating, but limits her calls to within a small radius, which forces her to have to borrow a neighbor's phone for other calls.

"Sometimes I have to hold off paying a bill to keep the gas and electricity on," she says. "My most important priorities are getting the girls fed and paying for the car so I can get to work, so health care falls low on the list. I wish it didn't have to be that way, but that's the way it is."

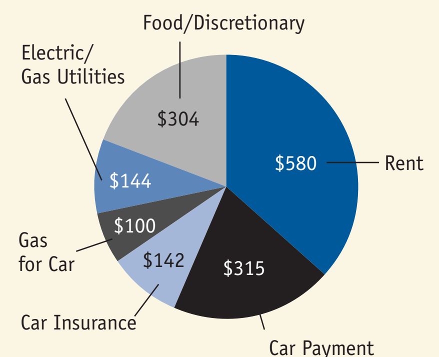
Finally, an end to sore throats

About three years ago, Yolanda heard about NJ KidCare, the new health insurance program created to help New Jersey's uninsured children get affordable health coverage. "NJ KidCare is for the children of hard-working families who cannot afford to privately pay the cost of health insurance," the program's official web site declares. "It is not a welfare program." Learning that there was a new program that could help her children's health was like an unexpected gift, Yolanda recalls.

Yolanda painstakingly got together copies of three months' worth of wage statements, the girls' Social Security cards and birth certificates, and all the other documentation the program required. In January 1999, the prized black

Smith Family Budget Leaves Little Room for Insurance Premiums

Family Income of $1,585/month



*Ms. Smith's mother helps out with the cost of child care and the girls' clothing. Income is the amount after a $29.91 monthly retirement contribution.

and white laminated cards arrived, certifying that Dominique and Destiny Smith were now enrolled in NJ KidCare and entitled to an array of health care benefits.

The NJ KidCare program covers children in families making up to 350% of the federal poverty level (a family of three with annual income of $49,525 would qualify.) The program enrolls eligible children into one of six HMOs, with the family required to pay a portion of the insurance premium, based on a sliding scale.

The federally and state-funded program provides a rich package of health care services, including well child and other preventive care, hospitalization, physicians' fees, lab and X-ray services, prescription drugs, mental health services, and eye examinations, for modest co-pays.

For Yolanda's daughters, the coverage has allowed them to begin getting the kind of care that will help them learn and grow to their full potential. It took Yolanda about five calls to find a doctor who participated in the plan and had privileges at a local hospital where she knew she and the girls would be treated with respect. "After they got the coverage last year, I started taking them back to the doctor for regular checkups," Yolanda says.

At long last, Dominique and Destiny have had tonsillectomies, with the bill covered by NJ KidCare. And with their new insurance plan also covering dental treatment and requiring only a $5 co-pay per visit, the girls recently visited a dentist for the first time in their lives. After years of neglect, Destiny had six cavities, which, with the help of KidCare, can be repaired.

The price of this health insurance coverage that gives so much peace of mind? Fifteen dollars a month, a bill that Yolanda Smith is happy—and able—to pay. "I love the children's plan!" Yolanda says. "I want to feel like I can make it on my own, but I need some kind of help."

Learning there was a new program that could help her children was like an unexpected gift.

CHIP: No coverage for parents

To Yolanda's regret, NJ KidCare doesn't provide coverage for parents (nor do CHIP programs in most states.) Although the states' CHIP programs expanded health coverage to many of the nation's uninsured children, many of their low-wage working parents are still going without because they're ineligible for Medicaid, unable to afford premiums for employer-sponsored health insurance, or not even offered the opportunity to get health insurance through their jobs.

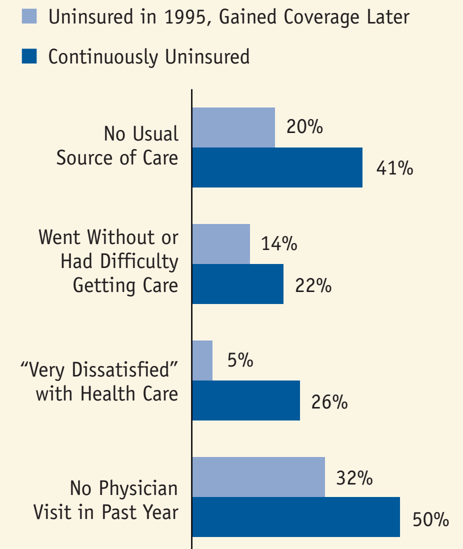
In Yolanda's case, not having insurance for herself has meant that she rarely gets proper treatment for recurring migraine headaches and periodic

bronchitis attacks. "I neglect myself," she says matter-of-factly, as the children play nearby. "When I get migraines, I borrow my mother's medicine or take as many Advil® as I can."

When her bronchitis flares up and she can cobble together $50, she goes to a doctor. The physician, knowing that she can't afford to pay for prescription drugs, will usually dip into her own supply cabinet and give her enough free samples of antibiotics to complete the recommended 10-day cycle. To get the only Pap smear she's had in recent years, Yolanda went to a local Planned Parenthood clinic and paid $50, based on a sliding scale linked to income. When the migraines are really horrendous, she goes to the emergency room—twice in the last few years.

Dental care is a luxury Yolanda can't afford either. Even though she has frequent toothaches, she hasn't seen a dentist since she got her braces off 17 years ago, while she was still in middle school.

Having Health Insurance Makes a Difference in Access to Care



Note: Coverage (either Medicaid or private) may have been gained in either 1996 or 1997. For those who did not gain coverage, the second measure was either in 1996 or 1997.

Source: Kasper, J., et al. 1999, using Kaiser Survey of Family Health Experiences