# The Death Spiral

*By Rushika Fernandopulle, M.D.*

*Gina's story was taken from the recent book Dr. Fernandopulle coauthored with Susan Starr Sered,* Uninsured in America: Life and Death in the Land of Opportunity *(University of California Press: Berkeley; 2005). While Gina's story is real, her name and some details of her life have been changed to protect her privacy.*

By the time we met her, Gina had already entered this country's social underclass, a victim of the nation's healthcare death spiral. A plain and weary young woman with faded blond hair, Gina suffers from chronic stomach pains that have worsened over time. She had self-diagnosed the problem as a mixture of indigestion and the stress brought on by her financial situation. She works at FabuCuts, a national chain specializing in low-cost haircuts for walk-in customers. In an average month of working nine-hour days, she takes home about $900, barely enough to cover her rent, utilities, car insurance, food, and payments for the $15,000 she borrowed to attend hairdressing school. Although FabuCuts offers its employees health insurance, Gina cannot afford the monthly premium, deductibles, or copayments.

This lack of coverage has become a crisis. When her stomach troubles first started, Gina took over-the-counter antacids, but when the pains became unbearable, she went to the local emergency room. There a physician diagnosed a bladder infection, prescribed an antibiotic, and told her to see her regular doctor if she didn't improve. When she tried to see her previous physician, the office required cash up front because she was uninsured. Only then was she allowed to see a physician assistant, who diagnosed a kidney infection and gave her more antibiotics. The pain continued and a few weeks later she returned to the emergency room, where she received a diagnosis of gallbladder problems and a $5,000 bill. Another visit to her doctor led to another trip to the hospital, a $4,000 bill, and a recommendation to see a surgeon. Yet without insurance she must pay $200 before the surgeon's office will even schedule a consultation.

**This article appeared in the *Harvard Medical Alumni Bulletin* in the Autumn 2007 issue and is reprinted here with their permission and that of Dr. Fernandopulle.**

At this point, Gina's pain comes and goes; she knows stress makes it worse, but the condition itself causes considerable stress. She and her husband—who earns $6.25 an hour and does not qualify for health insurance—want to start a family, but can't even consider children in their current situation. Gina knows her gallbladder could rupture if left untreated, causing her to lose parts of her bowel, become infertile, or even die. She has learned to live with the pain, but

not with the fear. She knows that even if she could scrape together the $200 for the surgical consultation, she could never afford the surgery. What frustrates her most is that she and her husband work hard and yet find themselves falling only further behind.

Several years ago I found myself at a health care symposium sitting next to Susan Starr Sered, a medical anthropologist at Harvard Divinity School. One of the speakers shared survey results that seemed to deny Gina's experience. The survey, sponsored by the Kaiser Family Foundation in 2001, found that 55 percent of all American adults agreed with the statement that it doesn't really matter if you're uninsured because you can get all the care you need anyway at an emergency room or a free clinic.

Susan, knowing my background as a practicing internist who had long worked in the area of health care policy, leaned over to ask me whether this belief was true. I pointed out that the Institute of Medicine, a respected, nonpartisan federal advisory board, had recently issued a six-volume series summarizing hundreds of peer-reviewed studies showing that being insured does indeed matter. Compared to those with insurance, uninsured people get diagnosed later, suffer more pain, endure more complications, experience worse outcomes with virtually every major chronic condition, and die sooner.

The problem, Susan said, was that such data convinced no one. What persuades the American public, she added, are stories, not data—and perhaps that's what the national debate is lacking. We decided to leverage our disparate backgrounds and perspectives to get a better handle on the issue. We would travel across the country to ask consumers, providers, and advocates a few simple questions: What does it mean to be uninsured in America today? What is and is not possible for uninsured people, and how does being uninsured affect their lives?

We decided to focus on five areas of the country with different patterns of uninsurance: the Mississippi Delta, where residents live in stark poverty; the *colonias* of southern Texas, whose population has the highest rate of uninsurance in the nation; rural northern Idaho, where the collapse of the mining and logging industries has left many uninsured; urban areas in central Illinois from which large industry is fleeing; and eastern Massachusetts with its increasing population of the "middle-class uninsured."

One year and more than a hundred interviews later, we had gained a much sharper understanding of the issue. We were touched by the willingness of people like Gina to spend hours with us sharing deeply personal stories of how

their lack of insurance has undermined their health and lives. We also met doctors and other providers who have accepted huge cuts in pay, limited access to resources, and scanty backup to help underserved populations. The problem, we concluded, is structural, affecting not just the uninsured, but everyone in the nation.

We are all too familiar with the figure of 45 million Americans who chronically lack health insurance. But there are many others who find themselves cycling on-and-off coverage depending on their employment, their life situations, and changing eligibility criteria. The Commonwealth Fund estimates that 85 million people may be uninsured at some point in any given three-year period and that tens of millions more are significantly underinsured—meaning their coverage has major gaps, such as for mental health services, medications, or preexisting conditions.

Our interviews with uninsured people supported the Institute of Medicine data: Being uninsured absolutely matters when you are trying to obtain all the health care you need. While it is true that hospitals by law must diagnose and treat immediately life-threatening illnesses and injuries and respond to the imminent delivery of a baby, this mandate excludes many conditions. Over and over again we found the uninsured had difficulty getting preventive services; controlling chronic diseases, such as diabetes and asthma; or even managing serious but not emergent conditions, such as Gina's gallbladder disease.

We were particularly struck by the problems people faced getting dental care. Nearly everyone we interviewed had lost several teeth; some had even resorted to pulling them out themselves to stop the pain. Similarly, mental health treatment was an issue for almost everyone. Ironically, the system wouldn't provide even a few dollars for a doctor's visit or medications to manage hypertension or diabetes until those conditions reached a critical point, such as causing kidney failure or irreversible disability. Only at this end stage would people become eligible for Medicare benefits.

Even when people received care in an emergency room, they were often billed. Indeed, nearly everyone we met owed thousands or even tens of thousands of dollars to a hospital or doctor. Many fielded calls daily from collection agencies and had watched their medical debts ruin their credit ratings.

We weren't surprised to find these detrimental effects among the uninsured, but we found striking the effect uninsurance was having on society as a whole. A bedrock principle of the American Dream is the promise of a better life. If we work hard and play by the rules, we feel we have a chance to get ahead, regardless of who we are. We discovered that the issue of uninsurance was

seriously undermining this possibility of upward mobility and, indeed, was causing a growing number of Americans to become stuck at the bottom.

In our book *Uninsured in America: Life and Death in the Land of Opportunity,* we describe this phenomenon as a "death spiral," created because, almost alone among advanced countries, the United States structurally links health insurance to employment. As the Institute of Medicine data show, having health insurance carries a strong link to being healthy. But we also know that being healthy makes you more likely to have and keep a job, particularly one that provides health insurance. Thus we have created a circular dependency, which, if one part starts to fail, leads to a downward spiral.

We met several people, for example, who had lost a job—and thus health coverage—because of a layoff or a need to stay at home to care for a loved one. Without insurance, health problems—particularly chronic ones—worsened, making it harder to find employment and impossible to regain health insurance. We met many others whose descent into the spiral began with an illness that caused them to stop working, a particularly common occurrence among people with mental illnesses. Unemployment led them to lose their health coverage precisely when they needed it most, causing them to get sicker and become less able to regain their jobs and insurance.

For society, the result of this death spiral is what we call the "caste of the ill, infirm, and marginally employed." We use "caste" intentionally because, unlike "class," it connotes permanency. Several factors conspire to solidify this status. The first is the person's general health status—it's difficult to land a job if you're sick. The second is personal appearance. Being uninsured leaves physical marks over time: poor skin, limps, chronic coughs, and, most commonly, poor teeth.

Because of these physical difficulties, many people at the bottom of the spiral cannot get employment that involves face-to-face contact; instead, they are forced into jobs that typically do not provide health coverage. The third and final issue is debt burden. Medical debt locks people into this caste. With ruined credit ratings, they cannot acquire credit cards, buy houses or cars, or even rent new apartments.

Experts in this country have offered no shortage of proposals for tackling the issue of the uninsured. Nearly all major advocacy groups and national political candidates have put forward plans. The goal of our project was not to add another proposal to the mix, but to evaluate what was already on the table.

Most of the current debate in Washington and in state capitals revolves around incremental solutions, whether expanding existing public programs such as

Medicare or Medicaid or mandating that employers cover individuals. The problem is that none addresses the root cause of the death spiral: the link between employment and health insurance. This link may have made sense in an era when health coverage was inexpensive and people typically worked for the same company throughout their careers, but in an era of rising health care costs, transient patterns of employment, and the pressures of global competition, it has become obsolete.

Those on both ends of the political spectrum agree that we need to break the link between employment and insurance; what they argue about is how to do so. One way is to make health insurance a private matter, with individuals left to purchase coverage on their own—much as we now fund our retirements with 401(k) plans. The problem, of course, is that while this model would work for those who are educated and well off, it would leave those like Gina behind, unable to afford the premiums for private coverage.

An alternative would be to make health insurance the government's responsibility, and, like Canada, move to a single-payer system. Although this approach would dramatically reduce the bloated overhead in our current health care system—and be far more equitable—many fear such a plan would lead to long waiting lists for elective procedures, similar to what occurs in many other countries, and would hamper future health care innovation.

The solution likely lies somewhere in the middle. A possible analogy can be found in how we deal with primary and secondary education in this country. From before the Revolutionary War, we have believed that education is good not just for individuals, but also for society as a whole. Thus we make the provision of education to children a public rather than private responsibility.

We do not, however, make this the only way to obtain an education. Parents can choose to pay for their children to attend private schools, tutoring programs, and a host of other educational options. This system allows for the diversity and innovation that seem critical to U.S. culture.

Although one can certainly argue that grave disparities in quality exist among different kinds of schools, those gaps are considerably smaller than the gaps in health care coverage.

The current situation must be changed. My lasting response to all our interviews was one of shame—shame that such a rich nation can allow so many of its citizens to suffer because of an obviously broken system. The crisis of the uninsured is too often couched in the language of economics, and while this is certainly an important aspect, we must not forget that the issue is a deeply moral one as well.

We noticed that Gina, the stylist at FabuCuts, tried to keep her mouth closed even while speaking. When asked why, she explained that a cavity was rotting away one of her front teeth because she hadn't been able to afford dental care for three years. "You see," she said, "there's a hole there, and I've never had one there before." Gina was embarrassed; because of her teeth, she was beginning to look like a member of the caste of the ill, infirm, and marginally employed.

We must do better to create a system in which hard-working people like Gina can take care of their health issues—and have a shot at upward mobility. When we turned to leave and told Gina again that we couldn't see the gap in her teeth unless we practically stuck our heads into her mouth, she broke out in a grin that lit up the entire room. For a moment, her pain and stress receded, and she beamed a thousand watts of delight. Plain Gina turned into the beautiful young woman she is, and should be.

*Rushika Fernandopulle is an internist on staff at Massachusetts General Hospital. He was the first executive director of the Harvard Interfaculty Program for Health Systems Improvement and is cofounder of Renaissance Health, an innovative primary care practice in Arlington, Massachusetts. He can be reached at rf@renhealth.net.*