MAMM SPECIAL REPORT

The New Have-Nots
ARE YOU ONE?

Millions of Americans have health insurance that won't cover the cost of cancer treatment.

Cary Vera-Garcia, 48, an attorney from Coral Springs, Florida, plotted a defense in case she, her husband or their daughter ever faced serious illness. When she resigned from a Palm Beach publishing company in 2001 to start her own newsletter business, she also left behind a corporate health insurance plan. To replace it, she and her husband bought a policy with an extra layer of protection. The new plan included what she thought was standard health insurance plus a separate cancer policy with a rider in case anyone ever needed chemotherapy. "We were willing to pay," she says, a total monthly cost of about $700—about average in her area, provided one accepted a high deductible and gave up certain extras, like maternity care.

Soft Policy, Hard Luck

A year later she felt "something hard" in her abdomen and noticed changes in her bowel movements. Surgery revealed that tumors had spread beyond her ovaries, from right to left hip and up to her rib cage. She had advanced ovarian cancer, stage 3C. "I lost most of my colon, parts of my ureters,

By Gurney Williams III and Pamela Weintraub

CORBIS

bladder and abdominal wall, and all the reproductive organs," she says.

On top of these catastrophic losses, she soon learned that her health insurance coverage was no shield against the onslaught of medical bills that she faced and that might thrust her family into financial ruin. While her oncologist had explained the cancer to her, it was his secretary who revealed the gaping hole in the insurance policy she thought would see her through: Her insurance allocated $1,000 a day for chemotherapy at her oncologist's office, but the charge was $6,000. That came to $30,000 out-of-pocket for the six sessions her doctor prescribed. What's more, since the office didn't take credit cards, she would have to come up with cash up front. "I got off the phone and started crying," Vera-Garcia says.

Cash Up Front, Please

If you have health insurance, you may be convinced you'll be covered should you ever fall ill. But think again. Today, many cancer patients with health insurance—even those with cancer policies—may lack sufficient coverage to pay for treatment of their disease. Mostly part of the middle class, these new "have-nots" often don't understand the danger of their situation until they fall sick. That's when they discover how quickly the high deductibles and copays add up, or run into restrictions that effectively limit the scope of their care. Depending on the patient, even the most solid policy may have gaps. The more complex the cancer, the more likely one is to run up against a policy's ceiling sooner or later, even if the policy is very good.

"A significant disconnect exists between what we've discovered in research and what we can deliver to all people," says Harold P. Freeman, M.D., president and medical director of the Ralph Lauren Center for Cancer Care and Prevention in Harlem and senior adviser on cancer disparities to the National Cancer Institute.

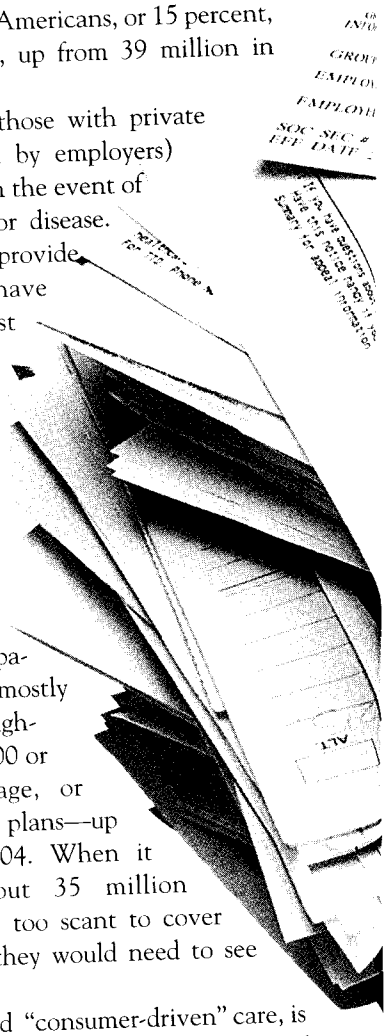
Tiered Health Care

As was always the case in America, health care delivery is tiered. Breast and gynecologic cancer patients generally fit into one of five tiers, each dispensing its own level of care.

The first tier includes the elderly and the very poor. Covered by Medicare or Medicaid, these patients comprise some 27 percent of all Americans. They are insured.

The second tier, the uninsured, includes those too young for Medicare or earning too much for Medicaid, but still too poor to afford insurance of their own. Some 45 million Americans, or 15 percent, now fall into this category, up from 39 million in 2000.

The third tier includes those with private insurance (mostly supplied by employers) inadequate to cover them in the event of a serious health problem or disease. While their employers still provide health insurance, they have shifted from more robust policies to ones with far higher deductibles and copays and innumerable restrictions, thus transferring the health care burden away from the employer or insurer and back to the patient. Twenty percent of companies with health plans (mostly larger firms) now offer a high-deductible option of $1,000 or more for single coverage, or $2,000 or more for family plans—up from 10 percent in 2004. When it comes to cancer, about 35 million Americans carry policies too scant to cover the standard treatment they would need to see them through.



The trend, often labeled "consumer-driven" care, is tied to a theory that patients forced to spend a lot of out-of-pocket money will likely seek less treatment, pushing the total cost of medicine down. But consumer advocates call the concept antipatient, and are up in arms about its newest incarnation, the health savings account. In

My Story

The cost of my cancer vastly exceeded what insurance allowed.
—Cary Vera-Garcia, Coral Springs, FL

GETTY IMAGES

this system, consumers agree to high deductibles and copays, but also get to save the unspent portion of the deductible in a personal, tax-free account. Health savings plans might make a lot of sense—for people who will never get seriously sick. But signing on for this plan means placing a bet that you won't get cancer or other long-term disease.

Whether "insurance lite" is served up through a health savings plan or another product, porous coverage defines the risky terrain inhabited by Vera-Garcia and other residents of tier three. Vera-Garcia's policy, purchased after she heard a commercial for it on the radio, was riddled with caps and deductibles. "Everything in the hospital had a cap," she says. "The anesthesiologist. The labs. Even the bed had a cap. They had a deductible of $3,000 for every time I walked through the door."

Tax Free & High Risk

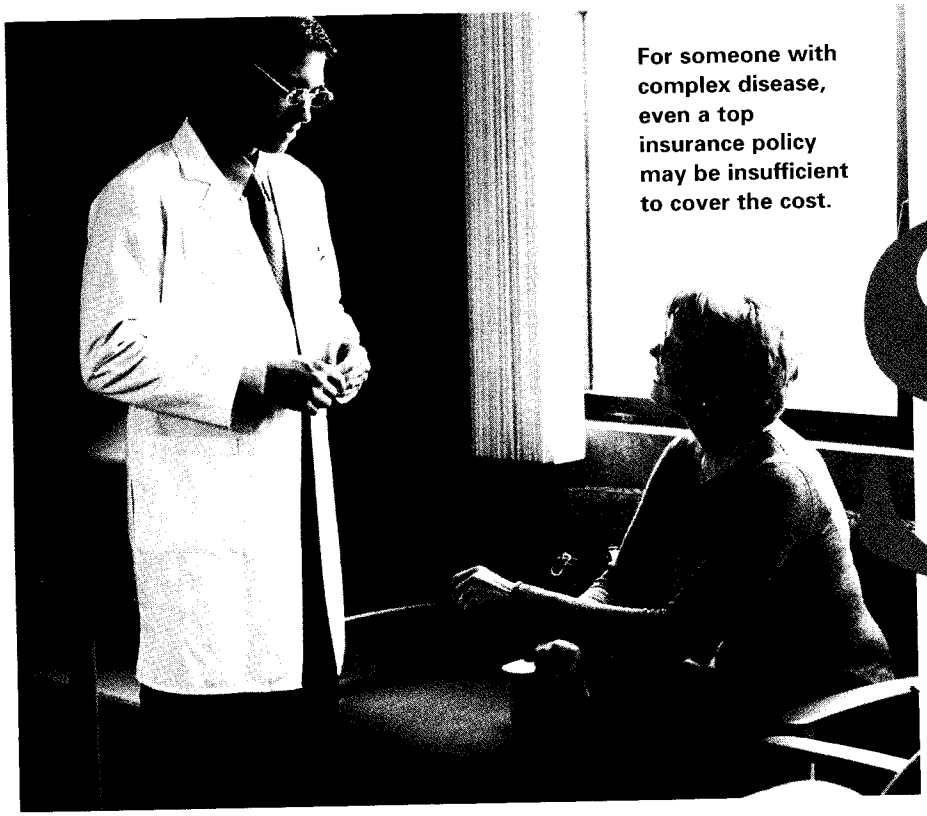
Then there is tier four, the comfort zone for some 115 million Americans with relatively generous private health insurance, usually employer-paid. These policies are robust enough to see them through recommended treatment for cancer much of the time. But these patients are hardly out of the woods: Their policies frequently have lifetime caps of $1 million to $5 million, with deductibles and copays that may add up over time when treatment is costly and long-term. For someone with a severe, aggressive or advanced form of cancer, even a tier-four policy may lead to bankruptcy at the end of the day.

Only the very rich or those with the best corporate insurance policies are adequately insured, Freeman explains. The richest Americans have so much money that they can pay for any care they want without relying on insurance at all. Protected by great insurance policies or great personal wealth, this relatively small percent inhabits the rarefied Olympus of tier five.

A Dose of Reality

What has often been swept under the rug in all this is that, while the wealthy pass through an orbit of privilege, the plights of the uninsured and the underinsured are remarkably alike. The message hit home after the Commonwealth Fund, a New York–based foundation, compared the financial problems of uninsured and underinsured people. Forty-six percent of the underinsured in the survey had been contacted by a collection agency about owing medical bills, compared to 44 percent for the uninsured. And 35 percent of the underinsured said that they had to change their way of life to pay medical bills, even higher than the 28 percent of the uninsured who did the same. "The underinsured were more likely than the adequately insured to forgo paying for basic necessities like food, heat or rent in order to pay medical bills," says Michelle Doty, the Commonwealth health policy analyst who produced the report. "They were also more likely to use up most or all of their savings, or take a large credit card debt or a loan against their homes."

Vera-Garcia, for instance, faced reality when her oncologist demanded a chunk of family savings for the first round of chemo,



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For someone with complex disease, even a top insurance policy may be insufficient to cover the cost.

FACT

46% of the underinsured are contacted by collection agencies over medical bills.

at his office. Unable to pay the $30,000 the doctor required out-of-pocket and also unable to charge it, she arranged for outpatient treatment at a hospital that would bill her later instead of demanding she pay in advance. This enabled her to receive treatment, but at a high price. The hospital charged $16,000 a day for the therapy—a far cry from the $1,000 her insurer allowed, and far more expensive than the $6,000 a day her oncologist had wanted up front. She quickly built up a huge tab.

"By May of 2005 we owed the hospital about a quarter of a million dollars," she says. Selling the family's three-bedroom home would have brought in about $275,000, barely enough to erase the debt and pay off the mortgage with nothing left over. "But if it had come down to losing my house, I would have stopped treatment," Vera-Garcia says. After all, she realized, she would face continual new rounds of chemo, and urgent new demands on the family's money, for the rest of her life. Bankruptcy was the only answer, allowing her to keep the house but forcing her into poverty and dependence on Medicare and Social Security disability checks.

Based on their balance sheets alone, "the underinsured are starting to look more and more like people who are actually uninsured," Doty concludes.

Rationing Cancer Care

Freeman agrees. Spearheading national hearings on cancer in 2000 and 2001, he found that "people who testified became bankrupt trying to pay for their cancer treatment, even if they were insured. For many, the deductibles and copays were so high, they were unpayable."

The people hit hardest in terms of insurance troubles were not the poorest, who generally were covered by Medicaid. In his groundbreaking report, "Voices of a Broken System," Freeman noted that the "uninsured and underinsured in the working and middle class hurt the most. As the problem slips up through the middle class, people are crying out."

In Vermont, Freeman heard from Karen Kitzmiller, an 11-year Vermont state legislator from Montpelier. At the time of her testimony, she'd been a five-year survivor of metastatic breast cancer—and a veteran of the insurance wars. Over the course of her treatment, she had to fight her HMO to obtain coverage for recommended treatment regimens and supportive

When insurance is not enough

The following organizations and resources may offer assistance when insurance runs out:

● CANCER CARE, a national nonprofit agency, offers free support, information, financial assistance and practical help to people with cancer. The Avon Cares Program for Medically Underserved Women, part of Cancer Care, provides financial assistance to low-income, under- and uninsured, underserved women throughout the country who need supportive services (transportation, child care and home care) related to the treatment of breast and cervical cancers.
Telephone: 800-813-HOPE (4673)
Web site: http://www.cancercare.org

● HILL-BURTON, a program through which hospitals receive construction funds from the federal government. The law requires that hospitals receiving these funds provide some services to people who cannot afford to pay for their hospitalization. Call to learn which hospitals are involved. Telephone: 800-638-0742
Web site: http://www.hrsa.gov/osp/dfcr/obtain/consfaq.htm

● THE PATIENT ADVOCATE FOUNDATION offers legal counseling to patients dealing with managed care, insurance, financial issues, job discrimination and debt.
Telephone: 800-532-5274
Web site: http://www.patientadvocate.org

● THE NATIONAL INSURANCE CONSUMER HELPLINE.
Hotline for help with insurance issues:
800-942-4242
Mon.-Fri., 8:00 A.M. to 8:00 P.M., EST.

● PHARMACEUTICAL REIMBURSEMENT ASSISTANCE.
Programs available through drug manufacturers. To sleuth these out, visit the nonprofit Web site Cancer Supportive Care:
http://www.cancersupportivecare.com/drug_assistance.html

● TRANSPORTATION AID. Airfare is often provided free or at reduced cost by nonprofit

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Middle-class Americans are especially vulnerable to insurance gaps.

FACT

An estimated 35 million Americans have policies inadequate to cover cancer treatment.

The Sick & the Broke

medications, including oral chemotherapy drugs. The HMO medical director, a general practitioner, opposed the chemotherapy regimen recommended by her oncologist and a protracted fight ensued. After her insurer finally agreed to pay for oral chemotherapy, she still had to pay up front (approximately $2,000 a month) and wait for reimbursement. She had to charge the treatment because she did not have the cash. Kitzmiller, a longtime breast cancer advocate, died not long after her testimony in 2001.

In Washington, DC, Lora M. Rhodes, a social worker and coordinator of the Advocacy and Survivorship Program at the Kimmel Cancer Center, Thomas Jefferson University in Philadelphia, recounted the case of a 45-year-old mother of three who had died the year before. She'd been diagnosed with and treated for breast cancer in 1990, then diagnosed with metastatic breast cancer in 1998. Unable to work, she applied for disability. Her employer stopped paying for her health insurance, and she had to pick up the tab herself. After paying for insurance on her own, she was left with just $950 a month to cover all of the household expenses for herself and her two dependent children. While she was undergoing treatment to try to save her life, she was faced several times with the threat of her gas and electricity being cut off. She had to give up her car and rely on family and friends for transportation, and she almost lost her home. Many factors caused her to discontinue treatment, but a major reason was fatigue from her financial strain, Rhodes said. Instead of fighting her cancer, she eventually decided to enter a hospice for end-of-life care.

Despite the coverage gaps revealed by these important hearings, insurance problems have only become more widespread. One woman we interviewed underwent a mastectomy in the early 1990s and suffered a recurrence of cancer a few years ago, when in her 50s. Under terms of a new company health policy, she picks up the first $3,000 of medical expenses, soon to rise to $4,000. Her take-home pay is about $30,000. So even before the higher deductible begins to take a larger bite of her income, she's already working more than one day every two weeks to cover medical bills that stretch far into her future. Looming somewhere in the years ahead, she knows, is a "lifetime cap" on benefits—a maximum that her insurance will pay amounting to $1.5 million. Treating recurring cancer can eat up every dollar, she says, "and then one is left with no insurance."

Ironically, her job involves counseling families "who have no idea where their next paycheck might be coming from when the breadwinner of the family dies," she writes in an e-mail. "This is a big reality for me because I face my own situation every time I have to refer a family for financial assistance." As afraid as she is of higher costs, she's almost as leery of angering her employer by complaining about the company cov-

IMAGE BANK

erage, which she knows to be second-rate. "Thanks for keeping my name out of the article," she concludes, "because it could cost me my job."

Another breast cancer survivor in her 40s yearns to tell her story and put us in touch with the doctor who performed reconstructive surgery on her six years ago. He's fed up with meager insurance reimbursements, she says. "There's a revolution going on," he's told her, among some doctors who are rebuffing even their insured patients unless they can pay the full fare themselves. She can't.

"My doctor would love to talk with you," she says. But she balks at making the connection, because she's in the middle of delicate negotiations with him to find some way he can repair a capsular contracture, a hardness in her left breast.

Freeman notes how easy it is for underinsurance to snowball. Those without sufficient coverage may put off mammograms, so their cancer is diagnosed later. Late diagnosis augers more complex and costly treatment that leaves patients with mounting deductibles and copays they cannot possibly hope to afford.

Navigating the Rapids

Gaps in cancer coverage have yet to elicit a coordinated national response. Instead, limited programs strive to help the disenfranchised, one by one. The most ambitious plan so far, pioneered by Freeman at Harlem Hospital, provides patients with expert "navigators" to facilitate timely treatment (along with other services) whether or not they are insured.

"There is a critical window to save lives with diagnosis and treatment right after the discovery of a suspicious finding," Freeman says, but the barriers, especially inability to pay, can be high. "There's usually a way to finance the treatment quickly if you know the ropes" (see "Resource Guide," page 33), he adds. "No person with cancer should go untreated. No person should be bankrupted by diagnosis of cancer. No person with cancer should be forced to spend more time fighting their way through the health care system than fighting their disease."

Today, thanks to the national Patient Navigator, Outreach and Chronic Disease Prevention Act of 2005, Freeman's prototype is going nationwide. Navigator programs throughout the country will be underwritten by $75 million in federal dollars as well as private benefactors and nonprofit groups.

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organizations for patients going to or from cancer treatment centers. Financial need is not always a requirement. Ground transportation services may be offered or mileage reimbursed through the local American Cancer Society or your state or local Department of Social Services. To find out about these programs, talk with a medical social worker or else contact the National Patient Air Transportation Helpline.
Telephone: 800-296-1217
Web site: http://www.patienttravel.org

● THE CANCER LEGAL RESOURCE CENTER provides, at no charge, telephone counseling on insurance coverage, employment issues and other potential legal problems. For more information, contact Barbara Ullman Schwerin, founding director and adjunct professor of law, Loyola Law School, Los Angeles.
Telephone: 866-843-2572

Federal Help Programs

● MEDICAID (medical assistance), a jointly funded, federal-state health insurance program for people who need financial assistance for medical expenses.
Telephone: 877-267-2323
Web site: http://www.cms.hhs.gov/home/medicaid.asp

● MEDICARE, a federal health insurance program for individuals 65 or older, people of any age with permanent kidney failure, and disabled people under age 65.
Telephone: 877-486-2048
Web site: http://www.medicare.gov

● SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME provides a monthly income for eligible elderly and disabled individuals or those who have certain income and resource levels, respectively.
Telephone: 800-772-1213
Web sites: http://www.ssa.gov/ http://www.ssa.gov/notices/supplemental-security-income/

● VETERANS BENEFITS. Eligible veterans and their dependents may receive cancer treatment at a Veterans Administration Medical Center.
Telephone: 877-222-VETS (8387)
Web site: http://www1.va.gov/Health_Benefits/

Self-Help

But the new programs will take time to launch, and will not reach everyone. In 2006 most patients must navigate themselves. The first goal, if possible, is recognizing the pitfalls and inoculating yourself against underinsurance right up front. If you want to make sure you are covered for cancer, this means finding the most comprehensive policy you can—one with a low deductible and small copays—and then making sure it is sturdy enough in other ways to carry you through cancer treatment without too many bumps. If you have the luxury of choosing a policy (as opposed to taking whatever your employer gives you), try to look for one that covers as much as possible. Some important guarantees include coverage of cancer-related drugs and therapies approved by the Food and Drug Administration and selected by a physician; procedures, drugs and technologies validated by the peer-review literature, even if not yet approved by the FDA; and any clinical trial approved by the FDA or any agency under the auspices of the National Institutes of Health. Coverage of the clinical trial should include diagnostic testing, hospital stays and physician office visits associated with it.

Lite Policy, Late Care

If the insurance you are given at work is lacking, you might want to shore up your existing policy by purchasing a cancer insurance supplement. But beware. Cancer insurance should only augment, not replace, a general health insurance policy. And as Vera-Garcia learned the hard way, not all supplements are the same—some cover only in-hospital care, for instance, and others kick in only after 90 days in the hospital (the average stay is only 13 days). Relying on a cancer supplement instead of a good general policy may not be wise.

Most people, of course, cannot pick and choose a wide variety of insurance policy options as if they were items on a Chinese-restaurant menu. Many others lack the funds to buy better insurance or riders to existing plans.

For many people, says Barbara Ullman Schwerin, founding director of the Cancer Legal Resource Center based in Los Angeles, "cancer becomes a financial spiral." But there are some steps to take: If you are denied by your health plan, appeal the decision immediately, she advises. While appeals ordinarily take time, one can often make sure the process is expedited by request. California, for instance, guarantees decisions in 72 hours for those who initiate appeals on an expedited track. Rejected appeals can then be taken up by a state insurance department or department of health. Many decisions upheld by insurance companies may be overturned on state level. Schwerin also advises that patients in financial trouble talk to doctors to request that the fee be waived or a long-term payment plan instituted instead.

Sometimes these precautions are insufficient and middle-class people who got by before they had cancer "start racking up bills, without a safety net in place," Schwerin has found. "As time goes on, basic expenses like rent, heat and electrical bills may go unpaid," she states.

Patients in this unhappy circumstance can often get help, even if piecemeal, as long as they know where to look. Nonprofit organizations may defray costs like mortgage and utilities so that most of the patient's income can go to treatment. Government and nonprofit programs may pick up the cost of treatment, as well.

Ultimately, there is Medicaid—although one must qualify, and that means family savings will have to be used first. "If expenses get too high, patients may need to divest themselves of everything, becoming impoverished to qualify for Medicaid," says Schwerin. Not only is the strategy financially devastating, it still leaves the patient uninsured for a period of time. The reason is that it can take up to a year to qualify, says Schwerin. In the period between divesting everything and waiting for approval, the patient who has lost a house and life savings may still be uninsured.

MAMM's advice to cancer patients? Call your insurer and ask what you're covered for immediately. Seek financial guidance as soon as possible after diagnosis—even if you don't think you'll have a problem—and consider how you will survive your cancer for the long haul.

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