Rising Insurance Premiums, Piecemeal Coverage, and Government Repackaging Are Doubling HIVers' Efforts to Stay Healthy

Stephen Trivoli-Johnson is one of the lucky ones. The HIV-positive Garden Grove, California, resident is armored with not one, but four sources of health insurance. This includes a group plan HMO from Pacificare, a private Blue Cross preferred provider option (PPO), and Medicare A and B, not to mention dental coverage.

But anyone envious of Trivoli-Johnson's comprehensive insurance make-up should know that the vast majority of the retired forty-five-year-old's $900 in monthly Social Security income is funneled into paying for these health plans. He coughs up $340 each month for a Blue Cross premium, a figure which has jumped twenty-five percent in the last year; $198 goes to the HMO; then there's $45 for the dental; and copays ranging between $10 and $35 for his approximately twenty prescriptions. The total? About $700 a month.

"It basically makes me kind of a prisoner," he said of his restricted finances. He lives in government-subsidized housing and hasn't bought new clothing in years. Friends give him food.

Having so many health plans may seem counterproductive, considering Trivoli-Johnson's budget. However, the main reason he purchased the additional HMO was to cover the PPO's prescription deductibles, which run some $600 a month. Medicare alone is worthless because it doesn't cover prescriptions and is particularly stingy about paying for certain HIV/AIDS treatments.

Trivoli-Johnson is living proof of the fallacy that anyone fortunate enough to have medical insurance in this country can shuffle off the financial woes of the estimated 75 million (and rising) Americans who went without health insurance during at least part of the last two years. Consider that, of the 1.4 million Americans who lost their health insurance in 2001, about 800,000 of them made more than $75,000 a year, according to the Census Bureau. Analysts theorize that these figures represent not only people falling into unemployment, but buckling under the increasing cost of healthcare premiums—and bowing out of the game.

These disturbing trends jeopardize the lives of those who live with a chronic illness that comes with an astronomical price tag for survival. The average American rakes in $5,035 in yearly medical expenses, according to a recent report in the journal *Health Affairs*. But for people living with HIV/AIDS, costs for their HIV care alone range between $13,000 to $18,000—and can soar up to $30,000 for those with advanced HIV disease—according to a study from the University of Birmingham.

Someone has to pay these bills. These days, it's increasingly the patient who does.

[illegible] A decade-long calm in healthcare costs and insurance premiums has proven to be a precursor to the storm which now sits heavily over all Americans. The widespread switch from fee-for-service plans to managed care kept a steady rein on medical inflation during the 1990s. But that control is now spinning out of control. In the wake of a disenchanted public's move away from strictly managed care, the phalanx of mega-medications with mega-price tags, new high-tech procedures, and malpractice litigation have all contributed to a rapid increase in healthcare costs—and, subsequently, health insurance price tags.

The fallout is as ominous as it is unmistakable: According to the *Health Affairs* report, healthcare expenditures leapt 8.7 percent, to $1.4 trillion, in 2001—a figure which represents 14.1 percent of the total U.S. economy, the greatest proportion to date. Consequently, premiums for employer-sponsored health plans have seen their first double-digit increases since 1990: jumping eleven percent in 2001 and 12.7 percent in 2002, according to Kaiser Family Foundation. Few believe this momentum will slow during the coming years.

And in the face of a perennially dismal economy, cash-strapped employers are now beginning to pass along those costs to their workers and to reduce benefits, or even to strike health coverage altogether, particularly in smaller firms.

For people with HIV, this can mean having to find health coverage on their own. Unfortunately, the medical underwriting process practiced by private health insurers in most states will probably drive their premiums sky high, since the insurer will charge the consumer a rate based on how expensive he or she will be to the company. So, financially, practical alternatives for moderately-incomed people living with HIV/AIDS are limited at best.

A movement called "consumer driven care" has begun to gather steam as a possible way to temper the rising healthcare price tag. It centers around increased "cost sharing," in which insurers dump heavier deductibles and copays onto the consumer. The idea? That if patients have to pay cash for a portion of their medical bills, they will start to look for cheaper services and drive the market down in the same way that managed care used to.

"For some people [increased cost sharing] is not necessarily going to create a barrier, in fact it might be a good thing," said Alwyn Cassil, spokesperson for the Center for Studying Health System Change. "Because it will provide some incentives for them to economize and be more aware of the true costs of care. But for very low income people or people with a chronic

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condition, that increased cost sharing can become a barrier to needed care."

Translation: The extra fees can create a financial sinkhole for people living with HIV/AIDS, who, according to the American Academy of HIV Medicine, visit the doctor six to nine times more than those without HIV.

A "three-tiered" prescription copay system is one of the most apparent and widespread changes in the move toward cost sharing, and the most devastating to people who depend on multiple brand-name medications to keep them alive and healthy. In an attempt to dissuade patients from choosing the more expensive brand-name drugs over bargain basement generics, insurers match their copay rates with the drug's price. In 2002, the average copays were $9 for generic drugs, $17 for brand names on the insurers' preferred drug "formulary," and $26 for brand names not on the formulary (usually the priciest drugs). These average rates were up significantly from $8, $14, and $16, respectively, in 2000.

Nothing has illustrated the scope of the problem more unequivocally than a November 2002 report from The National Academy of Sciences, developed at the behest of Health and Human Services Secretary Tommy Thompson. It called the U.S. healthcare system "incapable of meeting the present, let alone the future, needs of the American public."

Recognizing this truth, George W. Bush and the now solidly Republican Congress are making waves about dealing with the problem of the uninsured and the high cost of healthcare for those who do have coverage. In his January 28th State of the Union address, the President said he would commit an additional $400 billion over ten years to "reform and strengthen Medicare"—most notably by providing drug coverage. However, Congressional critics on both sides of the aisle have lambasted the President's reform plan for encouraging Medicare recipients to move into private plans for their drug coverage, thus privatizing the system. Additionally, President Bush's intent to limit malpractice awards is moving its way through Congress, and he intends to give tax credits for those who purchase private health insurance.

The swelling group of Democratic Presidential hopefuls are pushing healthcare reform to the forefront of the 2004 election debate. But with haunting memories of their colleague Senator Hillary Clinton's failure to overhaul the industry in 1993-1994 when she was First Lady, they are fearfully uncertain about proposing changes on such a massive scale.

Even with the wheels turning for the first time in a decade, according to Pat Schoeni, director of public affairs at the National Coalition on Health Care, current proposed changes are simply Band-Aids to a gaping wound. "Incremental reform legislation is basically a patchwork. And those patches do not a full piece of fabric make," she said.

Rejection City As insurance companies scramble to remain profitable, they have become craftier—and stingier—with payouts, particularly for those who have high medical bills. According to the Center for Studying Health System Change, of those Americans who reported an unmet need or delayed care in 1997, 17.1 percent said it was because their health plan refused to pay; in 2001, this number leapt to 22.2 percent.

Dr. Tony Mills, an HIV specialist in West Hollywood, said that they are tightening their belts on coverage for treatments which insurers either claim to be experimental or for those which they think might have a cheaper alternative, even if the alternate choice is ineffective. The paperwork piles up and the patient goes untreated as insurers argue with Dr. Mills, for instance, over whether wasting really exists for people living with HIV/AIDS on HAART; or they might demand the patient see an additional specialist, and so on until one side of the battle cries uncle.

"Every prescription I write, [the insurer] questions every medication, every dose," said Dr. Paul Cimoch, of the Center for Special Immunology in Fountain Valley, California. "They insist on sending records and everything. It's just such a waste of time. Because ninety-five to ninety-nine percent of the time, they end up approving what you requested...There's this whole middle man tier of people trying to second guess you and basically practice medicine without a license."

Until there is a major upheaval in this country's insurance system, the financial woes of the chronically ill (and the healthy, for that matter) will only continue to worsen. Case-in-point is Tim Gillean, who owns his own interior decorating company in Tulsa, Oklahoma. He had just purchased a group health insurance policy for his company when he tested HIV-positive in 1991. The premium was $74 a month. Two years later, his company had no employees for a period of time and his plan reverted from a group to individual insurance, providing him less protection against premium hikes. In 1999, his bill was $277; a year later, it snuck up to $390. By December 2001, the cost was $634. And when he got the June 2002 notice that the new price was $868 a month, Gillean, who makes about $40,000 a year, desperately began searching for an alternative.

He could find no economical solutions other than closing his business and joining a large company to receive their benefits. Unwilling to do this, he switched to the Oklahoma High Risk Pool and lowered his premium to $500. But he missed one key detail before dropping his old insurance: The high risk pool has a lifetime cap of $500,000 in reimbursement.

High risk pools, available in twenty-nine states, serve as a dead last resort for those who cannot find insurance anywhere else. But a tidy safety net they are not: plagued with long waiting lists for admittance, high deductibles, and an average premium of over $3,000 a year. The sad reality is that for people like Tim—who are too poor to afford private insurance, and who are not poor enough for Medicaid, the AIDS Drug Assistance Program (ADAP), or other governmental assistance—there may be nowhere else to turn.

"My frustration really comes from the fact that there's nothing available," Gillean said. "There are no opportunities for us, people who are HIV-positive and healthy and trying to make a living and pay for our lives.

"If I ever get sick—quite frankly, if I ever got an opportunistic infection or anything, it could literally bankrupt me," he said.

Benjamin Ryan is a freelance journalist specializing in HIV/AIDS political coverage, and writes regularly for *POZ*, *HIV-Plus*, and *Numedx*, among other publications. A native of Seattle, Washington, he graduated cum laude from Columbia University. He lives in New York City.