Health: Everybody Means Everybody

Health care reform debate not over for people with AIDS.

October 1, 1994 By Mary Schnack

I sat down with my nurse practitioner for the required counseling before an HIV test. We spent more time talking about insurance than anything else. “I’m going to break this into two bills, the HIV test and the counseling,” she said. “I suggest you don’t turn the lab costs into insurance. You may raise a red flag and be dropped. For the counseling part, I’m going to give you brochures on genital warts, so I don’t have to put down HIV counseling, and you can get this part of the charge reimbursed.”

I did as I was told. I paid the $100 in cash and turned in the $45 consultation bill. I got my results back in two days. My other option was to wait several days or weeks to get an appointment at a county clinic.

Fortunately, I had the $100, because I can’t afford to lose my health insurance. So it’s better to pay the cash than to take the chance a red flag is put on my health insurance policy, possibly causing my coverage to be dropped.

If you’re wondering what all the talk and debate is about health reform, it’s time to stop wondering and pay attention. We all have a lot to gain and lose. People with HIV will be one of the major beneficiaries of health care reform if universal coverage is passed. No reform short of covering all Americans solves the nation’s health care problems. Without universal coverage, people with AIDS will remain second-class citizens. AIDS phobia can be disguised as “business decisions,” “pre-existing conditions” or “overtesting” when decisions are made to drop health insurance coverage of someone who is HIV positive.

AIDS care costs insurance companies a lot of money -- but so do premature babies, transplants and head injuries, and they don’t face the same discrimination. When the red flag of an HIV test, CD4 count or “viral infection” diagnosis hits a chart, coverage may be dropped. Forget getting new insurance. In most states, pre-existing condition clauses will allow your new insurance to cover your in-grown toenail but not anything that might have to do with HIV.

Universal coverage is not only important to those who have insurance and may lose it, but with the majority of people with AIDS not having health insurance and relying on the public health system, it becomes more critical. The patchwork of care between foundation grants, free clinics

and state- and county-funded hospitals becomes less and less reliable as budgets continue to get cut.

Unfortunately, universal coverage has become the political punching bag of the reform debate. Nobody's sure how it is going to be paid for, other than through employer mandates, and the business lobby isn't idly standing by and allowing that to pass easily. But the battle is still far from over when the universal coverage issue is decided. Whether or not we have universal coverage, there are more hurdles to be jumped. The next battle is against the mainstay of all the health-care reform plans, something called managed care. The alphabet soup of health care reforms we need to learn include HMOs (health maintenance organizations), IPA (physicians group) and PPO (preferred-physician organization). In these plans, a patient sees a family doctor and to be referred to a specialist must have authorization from a managed-care peer committee. This committee is usually made up of physicians who have a financial interest in how much is being spent or nurses who are on the company payroll.

The peer committees do not meet daily. Waiting one to two weeks for approval to see a dermatologist may not cause any alarm, and even waiting two weeks for authorization for knee surgery after a too hearty game of basketball may just prolong the pain. But when you don't have an intact immune system, waiting for approval could easily become a life-and-death matter.

As an example of how serious this issue is, Mullikin IPA, one of the largest in California, recently sent a memo to its member physicians suggesting how to handle communication with a patient when "referral authorization may not be expedient enough for you or the member." The memo instructed physicians to help patients "anticipate several possible treatment alternatives" and "rather than communicating to the patient that they need specific care, it may be best to let them know that you would like to discuss the case with a colleague to coordinate a treatment plan. We do not advocate lack of communication with our members, but rather a more thoughtful avenue of communication." To summarize, physicians are purposely being asked to deceive patients in order to control costs.

Besides fighting these "new communications skills," there are other issues with the managed-care groups. Most of these physician networks do not have HIV specialists. "Drug trials" and "new procedures" are rarely part of a peer review committee's vocabulary.

Since other forms of reform have little chance of succeeding because they do not encompass realistic cost controls, the managed-care model is probably not only here to stay, but will also be expanded throughout the country. Consequently, we must become our own advocates and learn how to jump through the hoops of the ridiculously complex bureaucracy that delivers health care. We need to insist that the physician groups have HIV specialists, both in family practice and in medical specialties. We must resist "thoughtful avenues of communication" and insist on honest and candid information. To this effect, an HMO in Los Angeles recently set up a regular meeting between AIDS patients and administration flunkies. The result is more caring, nurturing and responsive health care service. Work with your insurance plan to start the same type of collaboration.

The mandates of how care is delivered should not be decided on a one-way communication path. We need to not only get the traffic flowing in both directions, we need to make sure we’re doing some of the driving.

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