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Another Cancer Battle: Costs

By LAURA LANDRO



Cancer patients can turn to support groups when dealing with the rigors of treatment. It's far more difficult to get help with the growing financial burdens of care.

The new health-care legislation contains some provisions that aim to help cancer patients and survivors in the future, including limits on out-of-pocket costs, insurers who impose caps on benefits and premiums for patients with pre-existing conditions. But some provisions won't fully kick in for four years.

In the meantime, patient advocacy groups are stepping up programs to help identify patients under duress from financial woes and steer them to help. The Patient Access Network and four other non-profit groups that help insured patients with all or part of co-payments for medications paid out a total of \$274.7 million last year, an increase of 52.7% over the previous year. Applications for aid rose more than 26% in the same period. The groups, which are funded by drug companies, foundations and private donations, provide grants of up to \$10,000 per year to qualified patients, according to Julie Reynes, president of the Patient Access Network.

The Cancer Support Community last year introduced a new guide, "Coping with the Cost of Care," and is piloting a program to screen cancer patients in hospitals and clinics around the country for emotional and financial problems in order to identify those who need referrals to mental-health counselors and financial-assistance resources.

"There are many resources to help, but this information isn't getting out to patients systematically through the health-care system," says Kim Thiboldeaux, president of the organization.

While an estimated 70% of cancer patients under 65 have private health insurance, according to the American Cancer Society, many have policies that cap benefits or have lifetime maximums that can leave even middle-class families vulnerable to high out-of-pocket costs. According to a study last year by the group "Spending to Survive," some patients amass medical bills of more than \$100,000, despite having insurance coverage throughout treatment. The society also found that the median out-of-pocket cost for privately insured breast-cancer patients was \$2,616.

Demand for its services, such as help locating financial aid, rose 20% in 2009, while requests for free lodging at the 29 Hope Lodge facilities the American Cancer Society maintains near cancer-treatment centers increased more than 23%. The society has developed an online database to help patients quickly locate national and community financial-aid resources.

"The financial stress of having cancer has always placed a burden on people," but the current economic crisis and high unemployment has worsened the situation for many, says American Cancer Society Chief Mission Delivery Officer Terry Music.

"We have people contacting us for problems which run the gamut, from 'I can't buy medications' to 'I can't pay my bills' to 'I can't keep my lights on.' "

Financial Stress

A new study by the non-profit Cancer Support Community—formed last year by the merger of two leading support organizations, The Wellness Community and Gilda's Club—found that the financial strain of cancer treatment can overwhelm patients and their caregivers, making them vulnerable to post-traumatic stress syndrome comparable to survivors of disasters like Hurricane Katrina. The distress in turn renders them less able to take advantage of free services and financial-assistance programs, and patients may delay or forego care as a result, says co-author Mitch Golant, senior vice president of the organization's research and training institute.

Of the 105 patients surveyed by the organization, 43% had household incomes of less than \$40,000 annually, but 91% had health insurance of some kind. Yet many of the respondents reported that they had to deplete savings and accept loans from family and friends to pay out-of-pocket costs.

About one-third used a co-pay assistance program or pharmaceutical-company assistance program, but almost half were not aware that the programs existed, feared they would not qualify or felt too overwhelmed to take action. The study was presented Friday at the annual meeting in Seattle of the Society of Behavioral Medicine.

Mike Davis, a 58-year-old Air Force veteran from Scranton, Pa., with lung cancer that has spread to his spine and lymph nodes, says he might never have learned about aid programs had he not been referred to four charitable assistance groups by the cancer center where he was initially treated. He was on disability from a previous injury but needed help covering the costs of chemotherapy, and he is now being treated in a residential program at a Veterans Administration facility. After joining a support group sponsored by the Wellness Community, he encouraged other patients to pursue the programs.

Screening for Need

St. Joseph's Hospital in Denver, one of the pilot sites, is testing a screening program that asks patients specific questions related to concerns such as depression or financial worries to determine their need for aid. The hospital enters responses into patients' medical records, so other hospital staff can follow up within 48 hours to offer help such as a psychology referral or financial-aid counseling.

"The bottom line is that cancer is not just a medical condition, it affects all aspects of a person's life," says Jeff Kendall, director of psychosocial oncology at the hospital. If the hospital doesn't have a program for patients in need, it will refer them to the Cancer Support Community for help in finding other state and national resources, Dr. Kendall says.

Some pharmaceutical companies are making it easier for patients to access their programs that provide free cancer medications based on financial need. Drug maker Genentech Inc., a unit of Roche Holdings AG, which provided funding for the Cancer Support Community study, says it will use the results to better help patients access its drugs. A spokesman says the company has updated its program to provide free medicine to patients who reached lifetime caps on payments from health insurers, and has improved enrollment forms "to make them easier to fill out and ensure they do not add more burden to an already stressful situation."

The American Cancer Society's 2009 report on cancer costs notes that even the high-risk pools in some states designed to help cancer patients and others who are uninsurable because of a pre-existing condition charge premiums that some find difficult to afford. Cancer survivors who have been in remission for years and have a good long-term prognosis have had trouble finding coverage or had to pay higher premiums, and patients with low incomes who aren't eligible for public programs such as Medicaid and are too ill to work have no affordable insurance options.

Nancy Boozer, a 57-year-old former paralegal who lives in a suburb of Atlanta and is in treatment for breast cancer that has spread to her bones, says she was able to get by on disability and Social Security payments, but forced herself to make dozens of phone calls looking for assistance with medical costs. She was able to find a state program that provided funds for low-income cancer patients and a co-payment assistance program that helps

cover \$334 monthly in medication costs. "You can't be timid, and you do have to be your own advocate," she says. "I wish I had known about some of these things earlier, because it would have saved me so much anguish."

Write to Laura Landro at laura.landro@wsj.com

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