



The North Carolina Cancer Control Program

Caring for Uninsured and Low-Income Patients with Cancer

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"You have cancer." Last year, nearly 36,000 North Carolinians heard their doctors say these life-changing words, and began the process of evaluating their treatment options.¹ North Carolina, which has three National Cancer Institute-designated comprehensive cancer centers, 10 Community Clinical Oncology Program (CCOP) sites and 27 American College of Surgeons (ACOS)-approved cancer programs, is highly regarded for its state-of-the-art cancer treatment. But despite the apparent abundance of availability, some North Carolinians, especially those with no insurance or a third party payor, find that access to the most effective therapies is limited by their inability to pay for care.

The Unknown Burden of Uninsured Persons with Cancer

Other than simple estimates of the number of affected persons, we know almost nothing about the burden of cancer among uninsured persons in North Carolina or the nation. The Institute of Medicine estimates that 7% of US cancer patients have no insurance;² data from the NC Central Cancer Registry suggest the percentage in North Carolina is 3.4% (NC State Center for Health Statistics, unpublished data). Since cancer affects predominantly older persons, who are likely to have Medicare, the proportion of uninsured cancer patients is less than that for the general population. Nevertheless, there are still 86,000 persons in the US with a cancer diagnosis and no health insurance.²

Lack of insurance is associated with worse cancer outcomes. Several studies have reported that, even after adjust-

ment for other sociodemographic variables, patients without insurance are diagnosed at later stages and have higher mortality.^{3,4,5} Lack of insurance may increase cancer mortality in several ways. A number of national surveys, such as the Behavioral Risk Factor and Surveillance Survey, note that uninsured persons are less likely to be screened for cancer.^{6,7} Quality of care often suffers when patients lack insurance. High out-of-pocket costs may inhibit patients' ability to return for follow-up of abnormal results, or to comply with treatment recommendations. An awareness of costs also may affect doctors' recommendations in staging or therapy. Finally, lack of insurance is more prevalent in lower-income and minority populations, who may have transportation, literacy, and language/cultural barriers to quality care.

The Cancer Control Program

North Carolina has been at the forefront in addressing the cancer-related needs of its indigent residents. In 1945, under the Cancer Control Act (General Statutes 130A-205), and at the urging of the Women's Field Army (now the American Cancer Society) and the North Carolina Medical Society, the NC General Assembly established a Cancer Control Program (CCP). The statute included a provision that the Cancer Committee of the North Carolina Medical Society serve as an advisory council to the Department of Health and Human Services. The legislative purpose was "to establish and administer a program for the prevention and detection of cancer and for the care and treatment of persons with cancer." This was the first such program in the nation. The Program

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was initially funded by a grant from the American Cancer Society, but in 1947 the legislature took over funding. The amount budgeted has gradually increased over the years from an initial appropriation of \$36,700 to \$3,934,972 for fiscal year 2001.

For 56 years, the Cancer Control Program, administered through the Department of Health and Human Services' Division of Public Health, has served indigent cancer patients by covering medical care for eligible individuals who need inpatient or outpatient diagnostic and treatment services. The Program uses several mechanisms to further its goal of improving cancer detection and treatment: direct payments to doctors and hospitals through the Purchase of Medical Care Services (POMCS); contracts with outpatient cancer centers; and cancer prevention and screening programs through local health departments.

Direct payments to doctors and hospitals through POMCS account for 64% of the Program's funds. In FY 2000, 460 fee-for-service providers delivered CCP-sponsored diagnostic services to 1,507 North Carolina residents at an average cost of \$573; 93% of recipients were female; 34% were minority; and 73% had no third party coverage. In that same year, 299 providers delivered CCP-sponsored treatment services to 549 North Carolina residents; 88% were female; 42% were aged 21-34; 34% were minority; and 66% had some type of third party coverage.

The average cost of Program-sponsored treatment was \$2,063/patient. The breakdown by cancer diagnosis was as follows: 19% breast, 59% cervical (including pre-cancerous conditions), 3% colon, 1% lung, 2% prostate, 2% skin, and 14% other. It is important to note that the Program succeeds in serving primarily those with little or no resources for diagnostic and treatment services. To be eligible for the Program, recipients must have gross incomes at or below 115% of the poverty level (that is, at or below \$19,608 for a family of 4). In actuality, more than half of those served during FY 2000 had incomes that were less than 85% of the federal poverty level.

The Program covers up to eight days of diagnostic services and 30 days for treatment services per state fiscal year. Two follow-up visits can be included in those limits. Providers are encouraged to schedule several services on a single day to ensure maximum benefit for their patients. Requests for inpatient diagnostic services are approved only if justified by medical necessity. The Program covers both hospital and professional services. Reimbursement is set at the NC Medicaid rate (except for hospital inpatient care, which is paid at 80% of their cost rate). Beginning in fiscal year 2000, the Program limits each claim payment to 1% or less of the

annual POMCS fee-for-service providers' budget (approximately \$25,000 for FY 2001).

Palliative care, drugs for use outside the treatment facility, and reimbursement for travel are not covered. Reconstructive surgery may be covered, but only when the Cancer Control Program paid for a treatment related to the same diagnosis. Meals and overnight stays can be covered only in conjunction with treatment services covered by the Program, and only if the treatment facility is over 50 miles from the patient's home.

Eligibility and Enrollment of Patients

To qualify for diagnostic and treatment services through the Cancer Control Program, patients must satisfy the following requirements:

- ◆ *Residency.* Patients must live in North Carolina and intend to make North Carolina their permanent home, or qualify as migrant farmworkers or dependents of one. Illegal aliens must have applied through Immigration and Naturalization Service for resident alien status and document intent to be permanent residents of the state. Foreigners with temporary visas are not considered permanent residents.

- ◆ *Financial.* The income scale, which is updated each July 1, is based on 115% of the federal poverty level. The Program calculates eligibility using the patient's or family's gross income from the 12-month period prior to the requested date of service or the application date, whichever is earlier. Medical expenses cannot be deducted from gross income. Once patients are approved, there

is a 12-month period during which providers must initiate authorization requests for necessary diagnostic and treatment services.

- ◆ *Medical.* The patient must have a condition that strongly suggests cancer and requires confirmation of the preliminary diagnosis, or the patient must have a known cancer and a $\geq 25\%$ chance of surviving for five years (based on the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) data, which are available online at http://seer.cancer.gov/Publications/CSR_1973_1997/).

Over the past two decades, the Program has instituted several policy changes affecting eligibility and benefits. In FY 92, medical eligibility was limited to the current 25% chance of five-year survival. In FY 95, the number of diagnostic and treatment service days was expanded from 2 to 8, and from 8 to 30, respectively. The financial criterion (percentage of federal poverty level) has varied over time, from 100% (net

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1996 - 2000 North Carolina Cancer Control Program Average Annual Number of Participants Served, Treatment Services



Source: North Carolina Department of Health and Human Services, Office of the Controller

North Carolina Center for Health Information & Statistics

income) to 200% (gross income). The latter limit only pertained for the period of July 1995 through March 1997.

A major concern is that the current financial eligibility requirement (gross income $\leq 115\%$ of the federal poverty level), instituted in response to the FY 97 budget shortfall, too severely limits access for many cancer patients, particularly the working poor without insurance coverage. Essentially, they "fall through the cracks." With the shift from net to gross income, a minimum-wage earner cannot qualify. The present financial eligibility requirement, which considers gross income during the twelve months prior to the treatment request or application, and which does not allow deductions, essentially excludes previously working patients who had no insurance or lost it when they could not work during their treatment. For some, not qualifying for the CCP may mean delaying or forgoing treatment services.

Providers have up to one year from the date of service to submit to the Program an application for coverage. Usually the provider works with the local health department, hospital social worker or financial counselor to complete the required two-part application (financial eligibility form and service authorization request). Efforts are under way to have the forms and Program information available on the North Carolina Advisory Committee on Cancer Coordination and Control website (www.nccancer.org).

Cancer Prevention and Early Detection

For more than 50 years, the Cancer Control Program has supported education and services related to the prevention and early detection of cancer. Breast and cervical cancers have been a focus for the Program, which since 1994 has funded breast cancer and cervical dysplasia clinics by contracting with outpatient cancer centers. For several years, the Program has supported a statewide public awareness campaign about the risk of skin cancer from ultraviolet radiation exposure, as well as skin cancer prevention and screening programs at local health departments.

Evaluation and Future Directions

Even though many patients are already being helped, the Cancer Control Program is currently comparing utilization data with information from the NC Central Cancer Registry to seek means to increase its reach and effectiveness. Specifically, the program seeks to answer the following questions:

- ◆ How many patients are eligible for the CCP each year, and how many are enrolled?
- ◆ Are patients with specific cancer types enrolled more frequently than others?

- ◆ Are there any racial, ethnic, or geographic disparities in who is enrolled in the CCP?
- ◆ What types of cancer patients are using the authorized service day limit?
- ◆ What are the current coverage gaps due to policy changes by other parties who provide indigent cancer care?

The Program expects its evaluation to be completed in December 2001. Preliminary results suggest that the Program enrolls between one-half to three-quarters of eligible patients. Uninsured breast and cervical cancer patients are more likely to be enrolled than prostate or lung cancer patients. Nearly one half of the patients enrolled for treatment are patients with pre-cancerous conditions of the cervix. The racial and ethnic distribution of CCP patients is similar to the overall population distribution of the state, suggesting that minorities are under-represented in the CCP. Marked geographical disparities in enrollment, visible in the Figure, may reflect the distribution of uninsured patients as well as variations in referral patterns due to lack of awareness by providers.

The results of our evaluation will allow us to plan and design outreach interventions, as well as to formulate policy and regulatory changes for better fulfillment of the Program's mission. To successfully achieve its mission of insuring access

to quality cancer care for indigent North Carolinians, it is important that the Program's policies respond to changes in cancer treatment standards as well as health care funding policies.

References

- 1 American Cancer Society. Cancer Facts & Figures 2000. Atlanta, GA: American Cancer Society, Inc.
- 2 Institute of Medicine and National Research Council. Ensuring Quality Cancer Care. Washington, DC: National Academy Press, 1999.
- 3 Roetzheim R, Pal N, Tennant C, et al. Effects of health insurance and race on early detection of cancer. *J Natl Cancer Inst* 1999;91:1409-15.
- 4 Roetzheim R, Pal N, Gonzalez E, et al. Effects of health insurance and race on colorectal cancer treatments and outcomes. *Am J Public Health* 2000;90:1746-54.
- 5 Ayanian J, Kohler B, Abe T, Epstein A. The relation between health insurance coverage and clinical outcomes among women with breast cancer. *N Engl J Med* 1993;329:326-31.
- 6 Ayanian A, Weissman J, Schneider E, Ginsburg J, et al. Unmet health needs of uninsured adults in the United States. *JAMA* 2000;284:2061-9.
- 7 Woolhandler S, Himmelstein D. Reverse targeting of preventive care due to lack of insurance. *JAMA* 1988;259:2872-4.