

Special Section: Insurance and Cost-Related Barriers to Cancer Care

Introduction

Paying for the costs of treatment is not usually the first concern that comes to mind when someone is diagnosed with cancer, but for many, it becomes an important one. Some individuals with modest incomes and no health insurance are able to obtain Medicaid or other forms of assistance after diagnosis, and most individuals with health insurance will have a substantial portion of their costs covered. Nonetheless, many individuals face cancer without adequate health insurance, and even those with standard private insurance policies may face high out-of-pocket costs associated with deductibles, co-pays, and annual or lifetime caps. For many cancer patients, health insurance status and other financial barriers delay or limit access to treatment and supportive services, and for almost all patients, cancer treatment presents a significant financial burden.

Since 2005, the American Cancer Society has documented the circumstances of more than 13,000 uninsured and underinsured cancer patients through the Health Insurance Assistance Service (HIAS), a program of the Society's National Cancer Information Center (NCIC).

- MaryAnn*, a patient with stage IV breast cancer, not only had to fight her cancer, but also had to grapple with inadequate insurance. In September, MaryAnn was halfway through her cancer treatment when she reached her policy's annual benefit maximum of \$50,000. She couldn't afford to pay for the treatments on her own. MaryAnn had no other coverage options, and her treatment was delayed.
- Martin*, diagnosed with melanoma, is uninsured and unable to access cancer treatments. He has trouble working because of his cancer diagnosis and earns about \$400 a month when he is able to work. Martin applied for Medicaid, but did not qualify for assistance under his state's Medicaid program. Without insurance coverage or a cash payment up front, the hospital will not provide the cancer treatment Martin needs. There are no insurance options for Martin, and he is unable to access treatment for his cancer.

- Linda*, a 17-year breast cancer survivor, had a catastrophic health insurance policy. Linda wanted a plan that was more comprehensive to cover her cancer screenings and regular check-ups. She applied for a policy in the individual market, but was denied because of her previous cancer diagnosis. With a pre-existing condition, it is unlikely Linda will find a comprehensive insurance policy in a market that allows medical underwriting and she is not eligible for any public programs.

While the HIAS can suggest options for dealing with the costs of cancer treatment to many callers, unfortunately, there are no options to address the needs of about 30% of people who seek help. Of those callers who had options suggested, 7 out of 10 found the options either unaffordable or inadequate. Lack of health insurance is an important barrier to cancer prevention and early detection; some of the patients who are struggling to pay for their cancer treatment could have prevented their cancers altogether or been diagnosed at an earlier stage had they had better access to health care.

Recognizing that reducing barriers to cancer care is critical in the fight to eliminate suffering and death due to cancer, the American Cancer Society and its sister advocacy organization, the American Cancer Society Cancer Action NetworkSM, are working together to bring the need for meaningful health care reform to the forefront of public and political debate. One important goal of this campaign is to educate Americans about the extent of the access to health care problem and to motivate them to take action in support of change. This Special Section of *Cancer Facts & Figures*, which provides an overview of systems of health insurance in the United States, describes the impact of being uninsured or underinsured on cancer prevention, diagnosis, treatment, and outcomes.

Although this section focuses on associations between health insurance and cancer care and outcomes, it is important to recognize that health insurance is not the only barrier that needs to be addressed to ensure that everyone receives the full benefit of high-quality care.¹ Other factors include level of education and knowledge about health, trust in the health care system, language and cultural barriers, and geographic and transportation barriers. These factors are particularly important in relation to addressing health disparities among racial and ethnic minorities and the poor. Although addressing insurance and cost-related barriers to high-quality prevention, early detection, and treatment is not the only

*Note: Actual call to NCIC from a cancer patient. All names have been changed.

measure that will be needed to address these disparities, it is an important foundation that will support other efforts to promote equitable and high-quality care for racial and ethnic minorities and other medically underserved communities.

What Are the Major Systems of Health Insurance Coverage in the United States?

The major systems of health insurance coverage in the US are employer-sponsored health insurance, Medicare insurance, Medicaid and SCHIP insurance, and private non-group health insurance. In addition to these broad categories of health insurance, which cover 95% of the insured US population younger than 65, there are other forms of federal insurance, including coverage through the Veteran's Administration and Indian Health Service, as well as state insurance programs, including high-risk pools, which in total cover about 5% of the population.

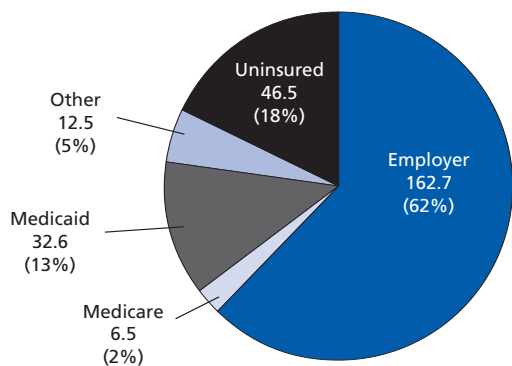
Employer-sponsored health insurance: Most Americans younger than 65 receive their health insurance coverage through their own employer or the employer of a family member (Figure 1). Nearly all companies with more than 200 employees offer health insurance coverage.² The employer-based system of health insurance has several advantages, most notably the creation of work-based risk pools, in which healthy low-risk participants subsidize the health costs of sick and high-risk participants.³ However, there are some serious disadvantages to this system. Not all companies offer health benefits, not all workers are eligible for coverage, and not all employees choose to participate or can afford their share of the health premium.⁴ In 2007, the average costs to employers and employees

respectively were \$3,785 and \$694 per year for individual coverage and \$8,824 and \$3,281 per year for family coverage.⁵ Moreover, the cost of health insurance premiums has been rising much faster than the rate of overall inflation and workers' earnings (Figure 2).⁵ Another important disadvantage of employer-sponsored health insurance is that people who develop a serious illness, such as cancer, may not be able to keep their employment and may lose access to their insurance. While the Consolidated Omnibus Budget Reconciliation Act (COBRA) allows employees to retain their health insurance benefits after they leave their job if they pay the full cost of the premium,⁶ for many individuals the cost is prohibitive. Another disadvantage of employer-sponsored insurance is that it may not be possible to use the same health care providers when employment changes.

Medicare: Medicare is a form of publicly sponsored insurance which covers most Americans aged 65 and older. About 2% of those younger than 65 also qualify due to long-term disability and certain medical conditions. United States citizens and permanent residents are eligible for Medicare if they or their spouse paid into Social Security for 40 quarters (10 years). Individuals eligible for Social Security benefits are automatically enrolled in Medicare Part A (hospital insurance) when they turn 65. Medicare Part B provides other types of medical insurance coverage, including coverage for physician's services (inpatient or outpatient), administration of drugs that are not usually self-administered by the patient, outpatient hospital services, diagnostic tests, and specific preventive services including mammograms, Pap tests, and colorectal cancer screening. Beneficiaries must enroll in Medicare Part B and pay a monthly premium based on their income. Medicare Part A is financed primarily through payroll taxes while Part B is financed by beneficiary premiums and by federal general revenues. Medicare Part C, also known as Medicare advantage, was established in 1997 to allow beneficiaries to enroll in private health insurance plans, and Medicare Part D was enacted in 2003 to provide prescription drug coverage through private drug plans.⁷

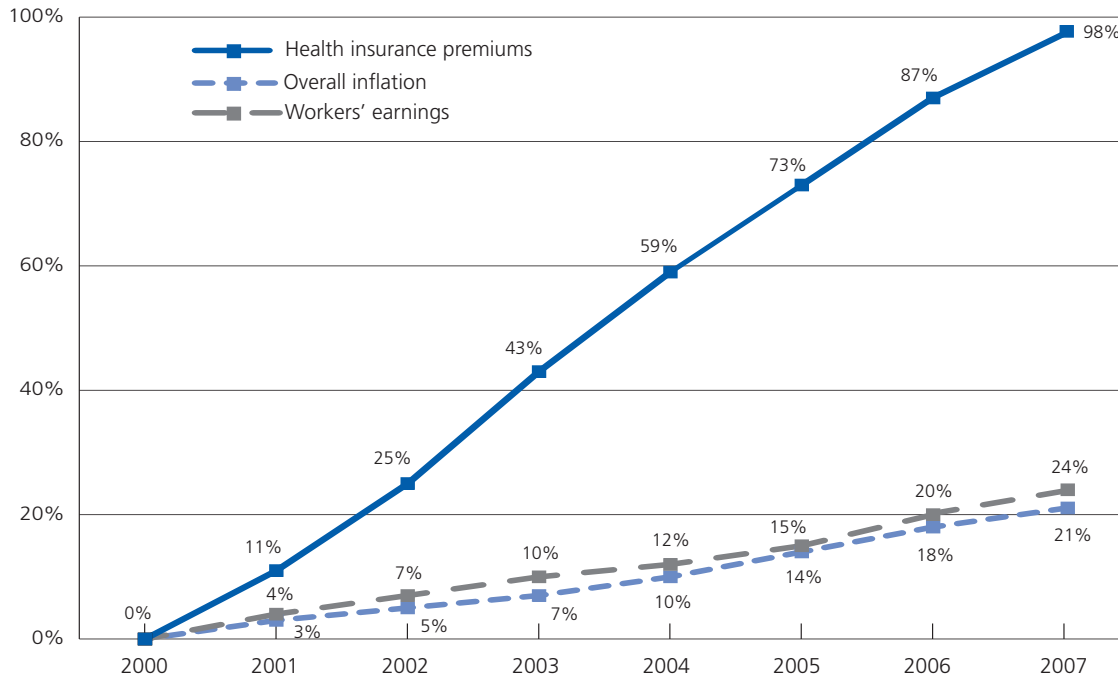
Health care premiums and out-of-pocket costs that Medicare beneficiaries who do not have supplemental insurance are responsible for are set on an annual basis. In 2008, Medicare beneficiaries are responsible for paying a \$1,024 deductible for the first 1-60 days of inpatient hospital care. For stays longer than 60 days, beneficiaries pay an increasing percentage of the cost. Part B premiums are set at \$96.40 per month for most

Figure 1. Health Insurance Coverage Among Individuals Younger than 65, 2006 (in millions)



Reference: Collins SR, White C, Kriss JL. Whither Employer-Based Health Insurance? The Current and Future Role of US Companies in the Provision and Financing of Health Insurance. The Commonwealth Fund. September 2007.
Source: Current Population Survey, March 2007.

Figure 2. Cumulative Changes in Health Insurance Premiums, Overall Inflation, and Workers' Earnings, 2000-2007



Note: Data on premium increases reflect the cost of health insurance for a family of four.

Reference: Adapted from Economic challenges facing middle class families: Hearing before the Committee on Ways and Means of the US House of Representatives, 110th Cong. (January 31, 2007). (Testimony of Diane Rowland: Health care: squeezing the middle class with more costs and less coverage.)

Source: Employer Health Benefits, 2007 Annual Survey. Kaiser Family Foundation and Health Research and Educational Trust. September 2007.

beneficiaries, with a sliding scale up to \$238.40 for those with high incomes. Care at skilled nursing facilities is not covered by Medicare for the first 20 days; in days 21-100, Medicare will cover \$256 per day. Medicare beneficiaries must also pay 20% of the Medicare allowable costs for services covered under Part B, which can be considerable in the case of a major illness such as cancer.⁸

Medicaid (Title XIX): Medicaid is a federally aided, state-operated and administered program that provides benefits for certain indigent or low-income persons in need of health and medical care. The program, authorized by Title XIX of the Social Security Act, does not cover all of the poor, however, but only persons who meet specified narrow eligibility criteria.⁹ Eligible groups include low-income children, families, and pregnant women; elderly and disabled people who need long-term care services; and low-income elders who need assistance with the costs of Medicare coverage. Within broad federal guidelines, states establish their own eligibility standards; determine the type, amount, duration, and scope of services; set the payment rate for services; and administer their own programs. Thus, each state's Medicaid program is unique.⁷

In 1997, the State Children's Health Insurance Program (SCHIP) was established by Congress to expand

coverage to uninsured low-income children. States were allowed to expand income-eligibility levels and receive enhanced matching funds for children by either expanding their Medicaid programs or creating new programs separate from Medicaid. All 50 states and the District of Columbia have implemented SCHIP programs, although the extent of coverage varies.¹⁰ As a result of SCHIP and other programs, as of 2001, almost all children from families with incomes below 200% of the federal poverty level are eligible for either Medicaid or SCHIP. Medicaid and SCHIP insurance is an important source of coverage for children with cancer. Based on the National Cancer Database (NCDB), approximately 25% of children under 18 years of age diagnosed with cancer are covered by Medicaid and SCHIP programs (see Data Sources for more information on the NCDB).¹¹

Consistent with the emphasis of the Medicaid program on providing health care to children and families with children, the probability of having Medicaid coverage is highest for children under age 18 and higher for women than for men (Figure 3). The proportion of adults aged 45-64 with Medicaid coverage ranges from 5% for white men to 15% among African American and Hispanic women.¹² A recent study found that only 8% of uninsured

childless adults were eligible for Medicaid or Medicare assistance.¹²

In most states, people who develop serious illnesses, including cancer, can qualify for Medicaid if, after medical expenses, their income falls below the state-established medically needy limit, which is typically well below the federal poverty level. To qualify for Medicaid as medically needy, individuals or families may be required to “spend down” to Medicaid eligibility by offsetting their excess income with medical and/or remedial care expenses.⁷

The Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA), enacted in February 2000, permits states to provide medical assistance through Medicaid to eligible women who are screened through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). All of the states are participating in this program.¹³ However, it is estimated that only 13.2% of eligible women received a mammogram in 2002-2003,¹⁴ due in part to inadequate funding of the program. There are also differences in implementation of the BCCPTA between states, which may limit opportunities for some women to benefit from the program.¹⁵

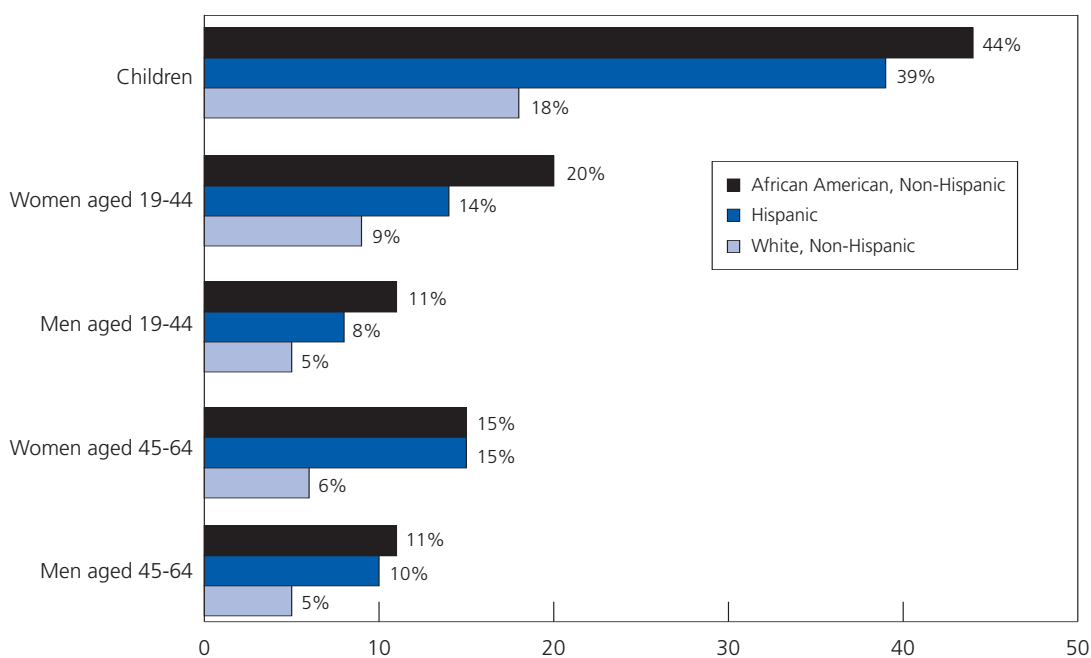
Private, non-group health insurance: Individuals and families who do not have health insurance coverage

through their employer or other public programs may seek coverage under the individual (non-group) insurance market. Less than 5% of US adults younger than 65 have this type of insurance, in part because the premiums are much higher than those for employer-sponsored insurance.² A survey of older adults (aged 50-70) in 2004 found that more than half (54%) of people with private, non-group insurance paid more than \$3,600 per year for individual policies and 26% paid more than \$6,000 per year.¹⁶ Private, non-group insurance can be difficult to obtain and/or extremely costly, particularly for individuals with preexisting health conditions, and therefore is not a viable option for many Americans who lack employer-sponsored coverage.

Who Is at Risk of Being Uninsured?

Almost everyone is at some risk of being uninsured. However, the risk of being uninsured varies by age, gender, race/ethnicity, and poverty status, as well as other characteristics. Among individuals younger than 65, those under the age of 18 have the lowest probability and those aged 18-24 have the highest probability of being uninsured (Figure 4).¹⁷ Fourteen percent of people age 45-64 are uninsured. The probability of being uninsured varies inversely according to income, but increased from 2001-2005 at all income levels (Figure 5).¹⁸ African Americans, Hispanics, Asian Americans and Pacific

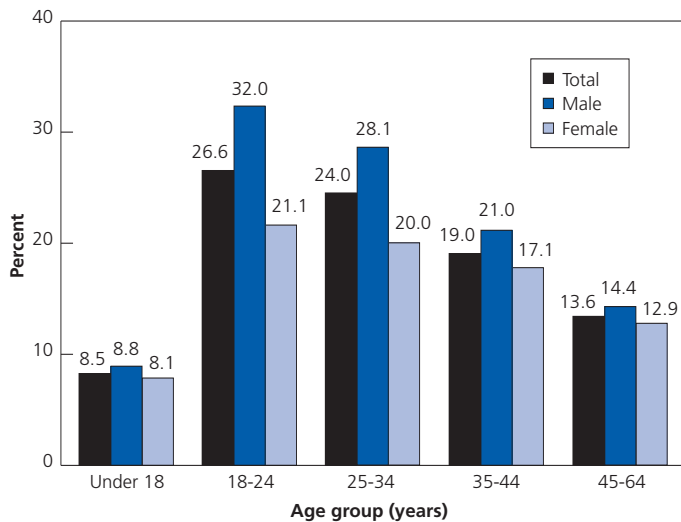
Figure 3. Medicaid Coverage of the Nonelderly by Age, Sex, and Race/Ethnicity, 2005



Reference: James C, Thomas M, Lillie-Blanton M, Garfield R. Key Facts: Race, Ethnicity & Medical Care. The Henry J. Kasier Family Foundation, January 2007.

Source: Current Population Survey, March 2005.

Figure 4. Percentage of Persons Younger than 65 Without Health Insurance Coverage at the Time of Interview by Age Group and Sex, January-March, 2007

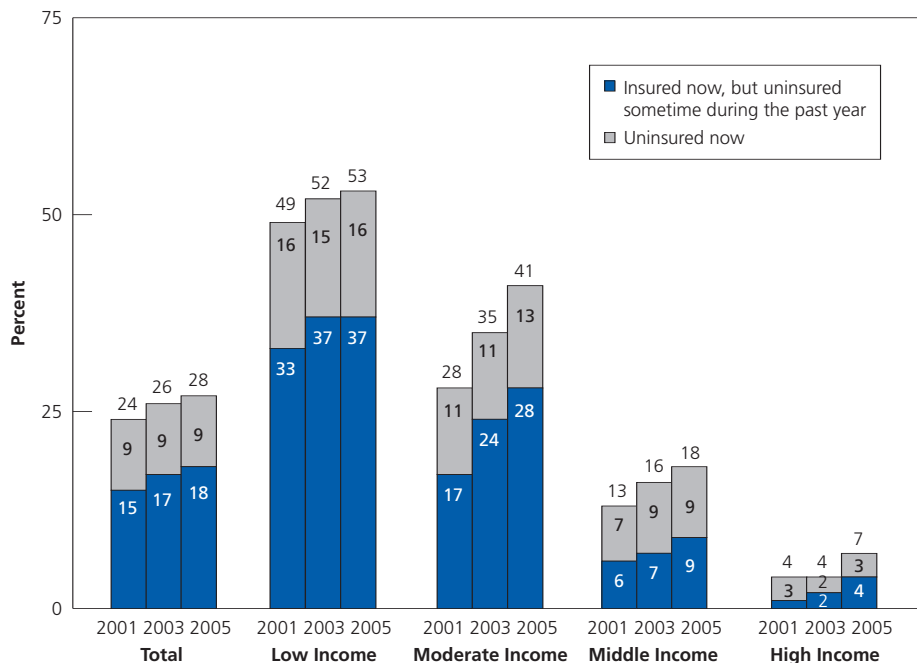


Reference: Cohen RA, Martinez ME. Health insurance coverage: Early release of estimates from the National Health Interview Survey, January-March 2007, September 2007.
Source: Family core component of the 2007 National Health Interview Survey. Data are based on household interviews of a sample of the civilian noninstitutionalized population.

Islanders, and American Indians/Alaska Natives are much more likely to be uninsured than non-Hispanic whites (Figure 6). The most common reason that working individuals are uninsured is that their employers do not offer health insurance benefits.¹⁹ Lack of employer-based health insurance is common for workers in small companies, low-wage workers, and part-time workers, as well as the self-employed.¹⁹ When employees are offered employer-sponsored health insurance, uptake rates are generally more than 80%.¹⁹

There are numerous ways in which individuals or families can lose their health insurance. For example, an individual may lose or leave a job where insurance was offered; lose Medicaid eligibility when they or their children grow up; lose insurance through their spouse due to separation, divorce, or death; or be priced out of the market when the cost of premiums becomes unaffordable.⁴ Parental health insurance coverage of children who are not students ends at age 18, as does coverage for many children

Figure 5. Uninsured Rates Among Adults Aged 19-64 by Income Level, 2001-2005



Note: Income refers to annual income in 2001 and 2003. Low income is <\$20,000, moderate income is \$20,000-\$34,999, middle income is \$35,000-\$59,999, and high income is \$60,000 or more. In 2005, low income is <\$20,000, moderate income is \$20,000-\$39,999, middle income is \$40,000-\$59,999, and high income is \$60,000 or more.

Reference: Collins SR, Davis K, Dody MM, Kriss JL, Holmgren AL. Gaps in Health Insurance: An All-American Problem. The Commonwealth Fund. April 2006.

Source: The Commonwealth Fund Biennial Health Insurance Surveys (2001, 2003, and 2005).

insured under Medicaid/SCHIP. Employer-based coverage sometimes fails to protect families from large medical expenses because illness may lead to job loss and the consequent loss of coverage.²⁰

Who Is at Risk of Being Underinsured?

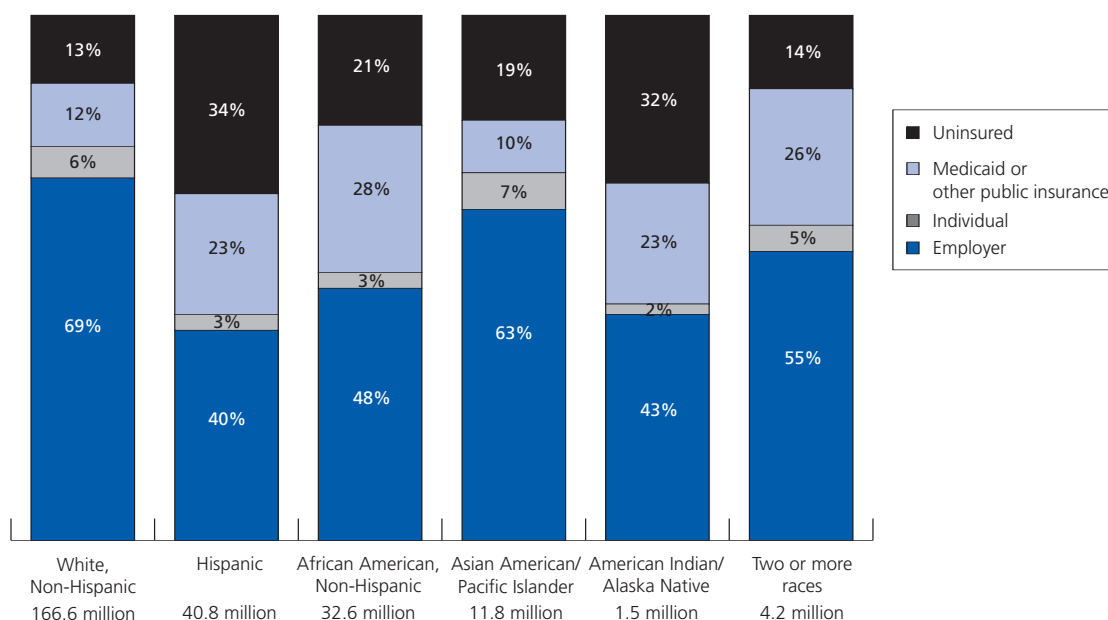
Health insurance generally does not provide total dollar coverage of health care costs. Covered services, deductibles, co-pays, and yearly or lifetime caps can vary considerably among the types of insurance that are available. Caps on total lifetime coverage or disease-specific coverage (e.g. \$1,000,000) may be exceeded if prolonged, expensive medical care is needed. Almost everyone is at risk of being underinsured in the event of a major illness, but many individuals and families are underinsured even without experiencing a major illness. The term underinsured refers to people who have some form of health insurance, but who lack coverage for certain procedures or cannot afford the cost sharing associated with covered benefits, or both.²¹ One common definition is that a person or family is underinsured if they would have to spend more than 10% of family income on out-of-pocket medical expenses in the event of a catastrophic illness.²²

A recent study analyzed data from the Medical Expenditure Panel Surveys (MEPS), sponsored by the Agency for Health Care Research and Quality (AHRQ) for 1996 and

2003.²² The MEPS household survey collects detailed information on health insurance coverage, health care utilization, and expenditures by sources of payment and additional data on health status, medical conditions, and other sociodemographic household characteristics.²² According to this study, the percentage of non-elderly families who had out-of-pocket health care expenditures (not including their insurance premiums) greater than 10% of after-tax family income increased from 6.7% in 1996 to 8.5% in 2003. When the cost of insurance premiums was included in calculating total expenses, the percent spending over 10% of after-tax income on health care rose from 15.8% in 1996 to 19.2% in 2003. Nearly one-quarter (24%) of the poor (family income <100% of federal poverty line) and 10% of the near-poor (family income 100% to <200% of the federal poverty line) reported total health care expenses exceeding 20% of family income. At all income levels, the burden was greatest for people with serious illness. Among people with cancer, 28.8% had total burdens exceeding 10% of family income, and 11.4% had total burdens exceeding 20% of family income.²²

Even among the elderly population who have Medicare insurance, out-of-pocket health care costs can be considerable. In 2003, about 29.3% of all elderly persons had out-of-pocket spending on medical care in excess of

Figure 6. Health Insurance Coverage of the Nonelderly by Race/Ethnicity, 2005



Note: Nonelderly includes individuals up to age 65. "Other public insurance" includes Medicare and military-related coverage; SCHIP is included in Medicaid.
Reference: James C, Thomas M, Lillie-Blanton M, Garfield R. Key Facts: Race, Ethnicity & Medical Care. The Henry J. Kaiser Family Foundation, January 2007.
Source: Current Population Survey, March 2005.

\$5,000, and 7.3% of all elderly persons had out-of-pocket spending on medical care in excess of \$10,000.²³

Medical debt is an important cause of bankruptcy filing in the US. A study of causes of bankruptcy among 931 people who filed for bankruptcy in the US in 2001 found that about half cited medical causes as an important reason for bankruptcy. Three-fourths of those with medical debt were insured at the onset of the bankrupting illness; 60.1% had private coverage, 5.7% had Medicare, 8.4% Medicaid, and 1.6% veterans/military coverage. About one-third of individuals who had private insurance at the onset of their illness lost coverage during the course of their illness. On average, the mean out-of-pocket expenditure for all debtors citing medical expenses for bankruptcy was \$11,854. For debtors citing cancer as the medical condition associated with the bankruptcy, it was \$35,878.²⁰ Compounding the financial consequences for individuals and families without health insurance are pricing policies in which uninsured patients are charged more for services. In 2004, a survey found that the rates charged to uninsured and other “self-pay” patients for hospital services were often 2.5 times what most health insurers actually paid and more than three times the hospital’s Medicare-allowable costs.²⁴

Even the very poor are at risk of medical debt and aggressive debt recovery practices. A cross-sectional study of patients being seen at 10 safety net provider sites in

Baltimore, Maryland, found that 42% reported that they currently had a medical debt (average \$3,409), and 39.4% reported ever having been referred to a collection agency for a medical debt. The mean annual income in the patients interviewed was \$7,864, and 47.2% reported that they were homeless. Among individuals who had current medical debt or who had been referred to a collection agency in the past, 24.5% no longer went to that site for care, 18.6% delayed seeking care when needed, and 10.4 % reported “only going to emergency rooms now.”²⁵

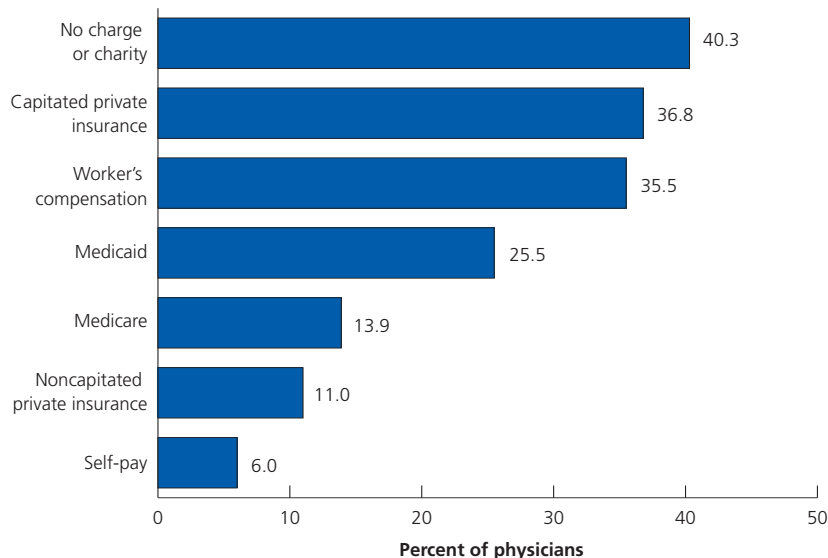
How Does Health Insurance Impact Access to Health Care?

Individuals who are uninsured, underinsured, or insured by government programs may face significant barriers to obtaining health care. Some private physicians do not accept new patients unless they have private insurance or are able to pay the full cost at the time of the visit. For example, a recent national survey of office-based physicians found that, although 96% were accepting new patients, 40.3% did not accept “no charge” or charity patients, 25.5% did not accept Medicaid patients, and 13.9% did not accept patients covered by Medicare (Figure 7).²⁶ Patients who are unable to afford outpatient care in private practice settings often seek care in hospital emergency departments, which are required by law only to examine patients to determine if a medical emergency exists.²⁷ Consequently, many patients

initially seen in emergency departments are referred to outpatient providers for follow-up care, but uninsured or Medicaid-insured patients may be excluded from care by the system.

A recent study employed scripted interviewers to contact clinics stating that they had been seen in a community emergency room the previous night and were seeking a follow-up appointment for a serious medical condition such as pneumonia or suspected ectopic pregnancy.²⁸ Callers claiming to have private insurance were almost twice as likely to receive prompt appointments as those stating that they had Medicaid insurance (63.6% versus 34.2%). Uninsured callers who said that they could pay cash for the entire charge at the time of the visit were equally likely to receive an appointment as those with private insurance, while only 25.1% of

Figure 7. Percentage of Office-based Physicians Not Accepting New Patients by Payment Method, 2003-2004



Source: Hing E, Burt CW. Characteristics of office-based physicians and their practices: United States, 2003-04. Series 13, No. 164. Hyattsville, MD: National Center for Health Statistics, 2007.

uninsured individuals who offered to pay \$20 at the time of the visit were offered appointments.

As more Americans go without health insurance and as access to affordable health care decreases, millions of Americans turn to the health care “safety net” for their health care needs. At the core of the safety net are health centers, public hospital systems, and local health departments. In addition, some communities are served by school- and church-based health clinics, private physicians, and nonprofit hospitals committed to serving vulnerable patients. Although such programs provide lifesaving services, some are understaffed, have inadequate resources, and are unable to provide specialty care. Recent studies suggest that the resources available in the health care safety net are declining, even as the need is growing.²⁷ In addition, although poverty is increasing in both urban and suburban neighborhoods, particularly in Midwestern and Southern metropolitan areas, there has been a shift in location of the largest concentrations of poverty. The poor are increasingly moving to suburban and rural areas to find jobs and affordable housing as economic forces make cities less affordable. It is more difficult for those who are poor and live in suburban or rural areas to access safety-net health clinics and hospitals because these services are disproportionately concentrated in central-city neighborhoods.²⁹

Impact of Health Insurance Status on Cancer

Lack of access to health care can adversely affect cancer incidence and mortality throughout the spectrum from cancer prevention and early detection to treatment, survivorship, and palliative care. Lack of health insur-

ance, even for intermittent periods, is associated with lower likelihood of having a “medical home” or usual source of health care. Individuals without health insurance are less likely to have preventive care and to have adequate management for chronic conditions. Based on the 2006 National Health Interview Survey (NHIS), 53.6% of uninsured individuals aged 18-64 had no usual source of health care, compared with 9.9% of privately insured and 10.8% of Medicaid-insured individuals. Among individuals who had been uninsured for >12 months, 58.7% had no usual source of care (Table 1). Individuals who were uninsured at the time of the interview were more likely than insured individuals to report that they did not get care due to cost, delayed care due to cost, did not get prescription drugs due to cost, and had no health care visits in the past 12 months due to cost. Although patients with Medicaid were less likely than privately insured patients to report that they had no health care visits in the past 12 months, they were more likely to report that they did not get care due to cost, delayed care due to cost, or did not get prescription drugs due to cost. However, patients with Medicaid insurance reported much greater access to health care than those who were uninsured.

Cancer prevention: Smoking, poor nutrition, and physical inactivity are important risk factors for cancer. Health care encounters provide an opportunity to counsel individuals on tobacco cessation, nutrition, physical activity, and weight loss. Individuals who are uninsured are less likely to report that they had a health care encounter in the past year than those with either private or Medicaid insurance. Among individuals who had a health care encounter, the uninsured were less likely than privately or Medicaid-insured individuals to

Table 1. Access to Health Care and Preventive Services by Health Insurance Status in Adults Aged 18-64, 2006

Proportion (%)	All	Private	Medicaid	Uninsured (at time of interview)	Uninsured for >12 months
Have no usual source of care	18.9	9.9	10.8	53.6	58.7
Did not get care due to cost	8.4	3.8	10.3	22.8	24.4
Delayed care due to cost	10.7	6.1	11.1	25.8	27.1
Did not get prescription drugs due to cost	9.3	4.4	15.2	22.9	23.1
Had no health care visits in the past 12 months	21.6	16.6	12.5	43.2	49.0
Counseling by a health care provider*					
Smokers advised to quit [†]	58.2	58.1	67.0	50.4	48.2
Obese adults (BMI>30) advised to lose weight [‡]	51.7	53.9	51.2	40.3	35.6

*Among individuals with at least one health care visit in the past 12 months.

[†]Adults who reported that they were advised to quit using tobacco by a health care provider in the past 12 months; Information available only in NHIS 2005.

[‡]Adults who reported that they were advised to control or lose weight by a doctor or health professional in the past 12 months.

Source: National Health Interview Survey Public Use Data File 2005, 2006, National Center for Health Statistics, Centers for Disease Control and Prevention, 2006, 2007.

be advised to quit smoking or to lose weight (Table 1). An analysis of data from an earlier (2000) NHIS survey found that individuals with no insurance or with Medicaid insurance were less likely to use tobacco cessation aids in a quit attempt during the past year.³⁰

Early detection and screening: Analyses of the NHIS and the Behavioral Risk Factor Surveillance Survey (BRFSS) have consistently found that individuals without health insurance have lower rates of cervical, breast, and colorectal cancer screening than individuals with health insurance.³¹⁻³⁴ A few studies reported screening rates for Medicaid insured patients that were lower than those for privately insured patients, but higher than for uninsured patients.^{35,36} Studies of individuals aged 65 and older, using other surveys and data sources, found that individuals who were dually insured by Medicare and Medicaid or uninsured were less likely to receive cancer screening tests than comparison groups (those with Medicare alone or those with Medicare plus supplemental private insurance, depending on the study).³⁶⁻³⁸

Analyses of the NHIS 2005 survey also found that the likelihood of receiving recommended cancer screening tests varies markedly by insurance status (Table 2). About three-quarters (74.5%) of women aged 40-64 who had private health insurance had received a mammogram in the past 2 years, compared with 56.1% of women with Medicaid insurance and 38.1% of uninsured women. Similarly, 87.9% of women who had private health insurance had a Pap test in the past 3 years, compared with 82.5% of women with Medicaid insurance and 68.0% of uninsured women. Among men and women aged 50-64 with private insurance, 48.3% had had a recommended colorectal cancer screening test in the past 10 years, compared with 39.6% of individuals with Medicaid insurance and only 18.8% of those who were uninsured. The percent of men aged 50-64 who had a PSA test for prostate cancer followed a

similar pattern; 37.1% among the privately insured, 20.8% among the Medicaid-insured, and 14.0% among the uninsured.

Given that health insurance status is associated with other characteristics, including income, race/ethnicity, immigration status/country of birth, and level of education, it is possible that differences in screening rates reflect differences in knowledge about cancer prevention, culture, or other barriers to care. However, when data from the NHIS 2005 are analyzed to estimate the likelihood of receiving mammography and colorectal cancer screening by race/ethnicity (non-Hispanic white, non-Hispanic black, and Hispanic), level of education, and insurance status (Figure 8 and Figure 9) it is apparent that having health insurance is an important predictor of screening across all major racial and ethnic populations. Moreover, at every level of education, individuals with health insurance are about twice as likely as those without health insurance to have had mammography or colorectal cancer screening.

Stage at diagnosis and survival: Information on the relationship between stage at diagnosis and insurance status is quite limited because population-based cancer incidence registries do not collect information on insurance status. Several studies have examined the relationship between Medicaid enrollment status and stage at diagnosis by matching cancer registry data with state-based Medicaid records. One such study, based on linkage of state of Michigan Medicaid and cancer registry records, found that Medicaid-insured patients younger than 65 who were diagnosed with cancer during 1996-1998 were more likely to be diagnosed with late stage cancer of the breast, uterus, cervix, lung, and prostate than patients without Medicaid coverage (including uninsured and privately insured).³⁹ However, this study could not differentiate among patients who were enrolled in Medicaid prior to their diagnosis from those

Table 2. Cancer Screening by Health Insurance Status in Adults Younger than Age 65, 2005

Proportion (%)	All	Private	Medicaid	Uninsured (at time of interview)	Uninsured for >12 months
Women 40-64 who had a mammogram in the past 2 years	67.9	74.5	56.1	38.1	32.9
Women 18-64 who had a Pap test in the past 3 years	83.6	87.9	82.5	68.0	62.7
Adults 50-64 who had a colorectal cancer screening test*	44.2	48.3	39.6	18.8	14.9
Men 50-64 who had a PSA test in the past year	33.5	37.1	20.8	14.0	11.5

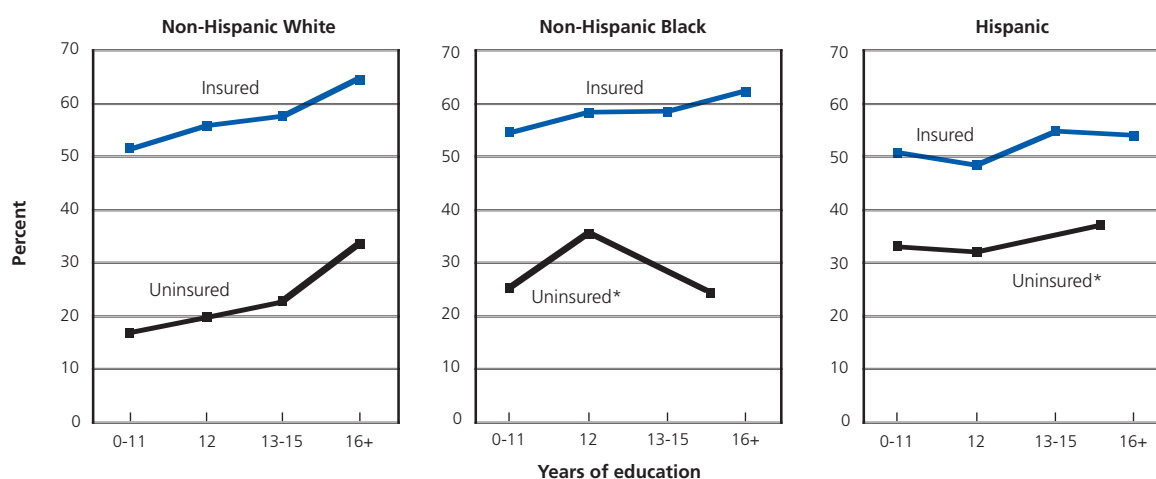
*Had a fecal occult blood test in the past year or an endoscopy in the past 10 years.

Source: National Health Interview Survey Public Use Data File 2005, National Center for Health Statistics, Centers for Disease Control and Prevention, 2006.

enrolled as a result of diagnosis. Later stage at diagnosis among patients enrolled as a result of diagnosis does not reflect the extent to which Medicaid insurance provides access to health care, including prevention and early detection. A subsequent study in the Michigan registry-Medicaid linked data found that for all cancer cases diagnosed in 1996 and 1997, 64% were enrolled before being diagnosed with cancer (pre-enrolled); just over one-third of the Medicaid sample enrolled in the month of diagnosis or after (late-enrolled). A greater proportion of colorectal and lung cancer patients were late-enrolled

(46% and 42% respectively).⁴⁰ In this study, the odds of later stage at diagnosis was higher among individuals who were late-enrolled in Medicaid compared to those who were pre-enrolled; nonetheless, pre-enrolled Medicare beneficiaries were more likely to be diagnosed at a later stage than those without Medicaid insurance (the majority of whom would be expected to be privately insured).⁴⁰ A further study of the same population found that both pre-enrolled and late-enrolled Medicaid patients were at substantially increased risk of dying within 8 years of diagnosis compared to patients who

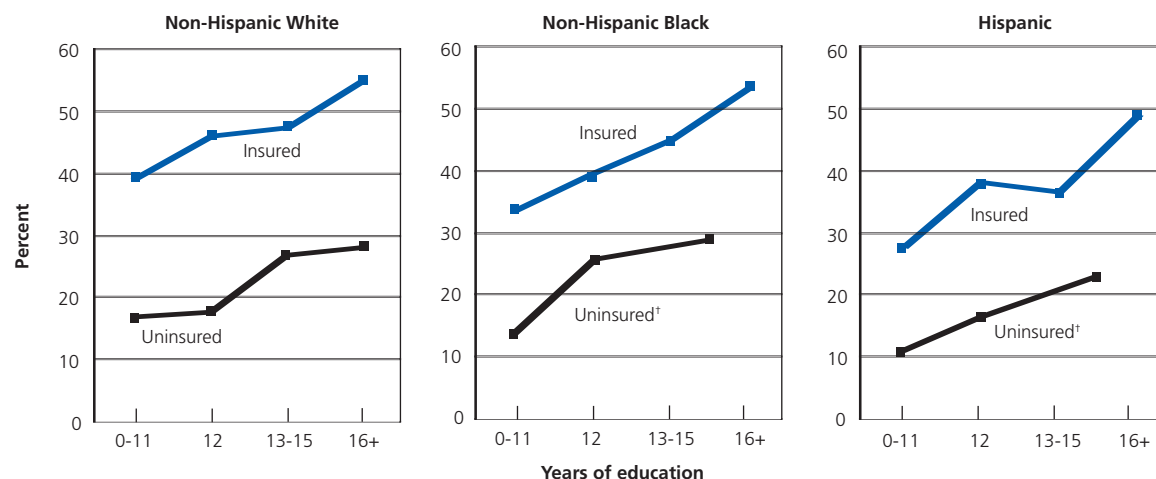
Figure 8. Mammogram Within the Last Year, Women Ages 40-64 Years, by Race/Ethnicity, Years of Education, and Insurance Status, 2003-2005



*Groups have been combined (years of education 13+) due to small sample sizes.

Source: National Health Interview Survey 2003 and 2005, National Center for Health Statistics, Centers for Disease Control and Prevention, 2006.

Figure 9. Colorectal Cancer Screening*, Ages 50-64 Years, by Race/Ethnicity, Years of Education, and Insurance Status, 2003-2005



*Either a fecal occult blood test within the past year or an endoscopy within the past 10 years.

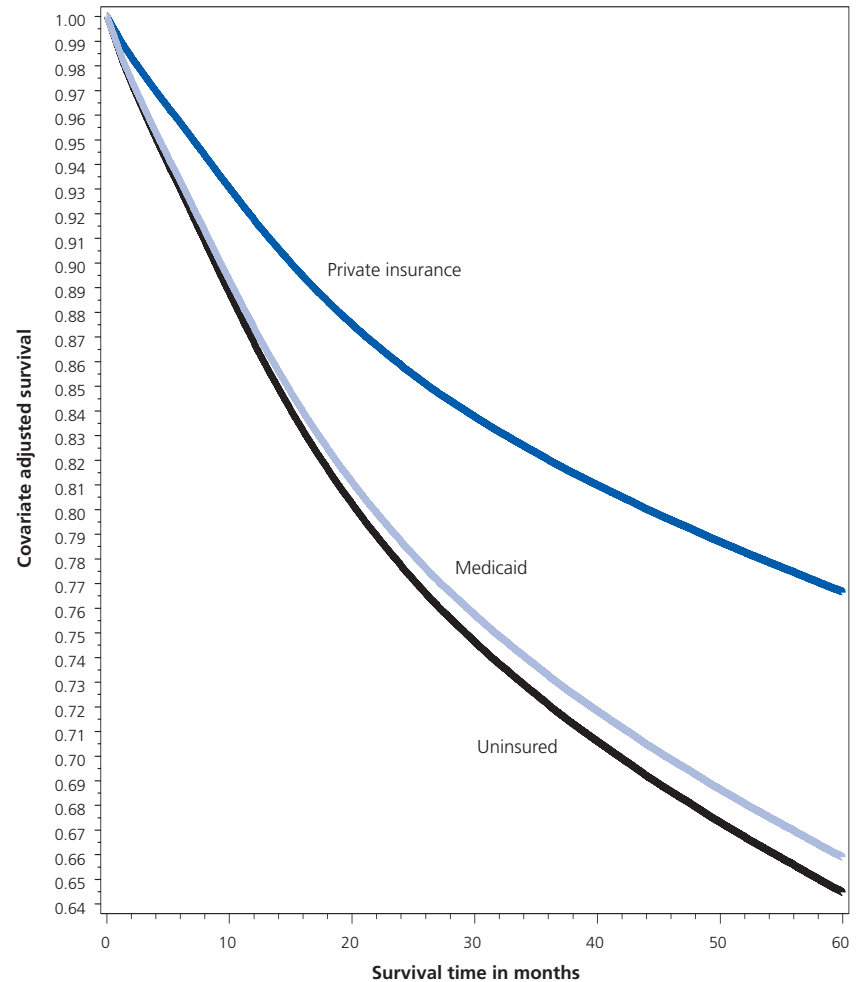
†Groups have been combined (years of education 13+) due to small sample sizes.

Source: National Health Interview Survey 2003 and 2005, National Center for Health Statistics, Centers for Disease Control and Prevention, 2006.

were not Medicaid-enrolled. Although survival was somewhat poorer in the late-enrolled compared to the pre-enrolled group, this difference was not statistically significant.⁴¹ A study of stage at diagnosis for cervical cancer patients diagnosed in California in 1996-1999 found that women insured by Medicaid were significantly more likely than women without Medicaid coverage (including uninsured and privately insured) to be diagnosed at late stage.⁴² However, when risks were analyzed by duration of Medicaid enrollment, increased risk of late stage diagnosis was confined to those enrolled at the time of, or less than 12 months before, diagnosis, and was not apparent for those who had been enrolled in Medicaid for 12 or more months. A study linking data from the Florida state cancer registry with inpatient and outpatient discharge abstracts to ascertain insurance status found that persons who were uninsured were more likely to be diagnosed with late stage breast, colorectal, and prostate cancer and melanoma and that patients who were Medicaid insured were more likely to be diagnosed with late stage breast cancer and melanoma. This study could not examine duration of Medicaid enrollment before diagnosis.⁴³

The National Cancer Database (NCDB), a registry containing information about cancer patients treated at more than 1,500 Commission on Cancer-approved facilities in the US, has collected information on patient insurance status at the time of diagnosis since 1996.⁴⁴ Several recent studies have used this database to examine the relationship between insurance status and stage at diagnosis. Patients diagnosed with oropharyngeal and laryngeal cancer in 1996-2003 who were uninsured or covered by Medicaid were significantly more likely to be diagnosed with late stage and larger tumors.^{45,46} A study of breast cancer patients diagnosed in 1998-2003 and included in the NCDB found that women who were uninsured or had Medicaid insurance were about 1.5 times more likely to be diagnosed with stage II versus stage I disease and 2.5 times more likely to be diagnosed with stage III/IV versus stage I disease compared to those with private insurance.⁴⁷

Figure 10. Cancer Survival Among Individuals Ages 18-64 Years by Insurance Status*

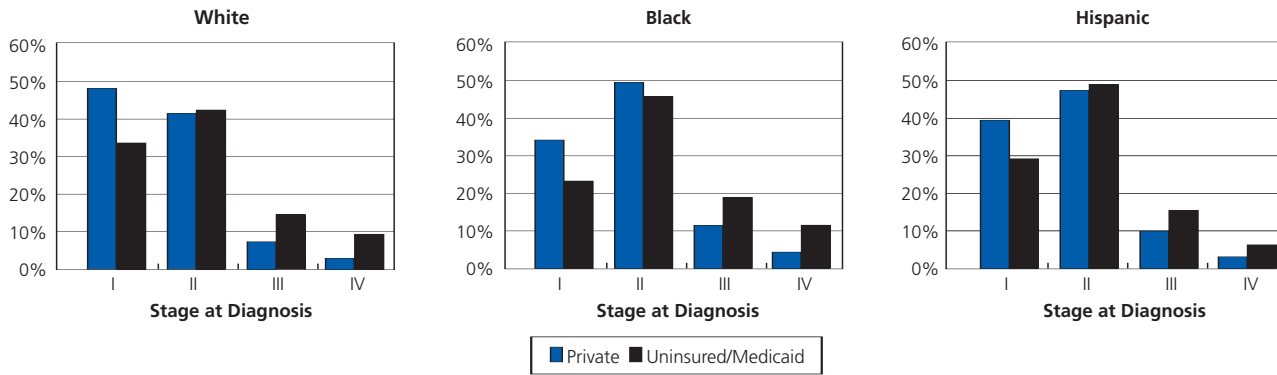


*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information on stage, age, race/ethnicity, or zip code.
Source: National Cancer Database.

Data from the NCDB were also used to investigate the relationship between insurance status, stage at diagnosis, and survival. These analyses were restricted to patients diagnosed in 1999-2000, the most recent years of diagnosis for which at least 5 years of follow up was available. Survival analyses controlled for age at diagnosis, race/ethnicity, sex, and zip code level income. In addition, analyses were performed with and without control for stage at diagnosis to better understand how much of the survival differences by insurance status could be explained by differences in stage at diagnosis.

In analyses of cancer survival for all cancer sites combined, patients who were uninsured and those who were Medicaid-insured at the time of diagnosis were 1.6 times as likely to die in 5 years as those with private insurance (Figure 10). About 76% of patients with private

Figure 11. Breast Cancer Stage Distribution Among Women Ages 18-64 by Race/Ethnicity and Insurance Status*



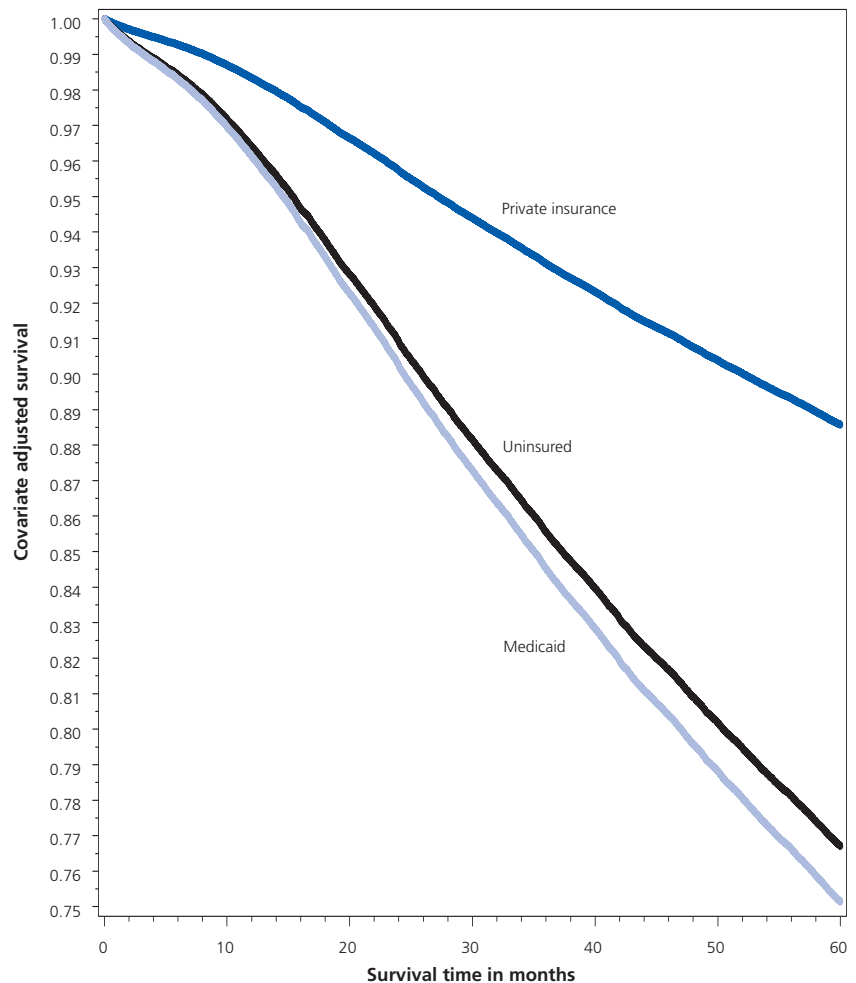
*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information or stage, age, race/ethnicity, or zip code.

Source: National Cancer Database.

insurance survived for 5 years after diagnosis, compared with 66% of those with Medicaid insurance and 65% of those who were uninsured at the time of diagnosis. More detailed analyses were done for breast and colorectal cancers, two important cancers for which both early detection and quality of treatment are known to influence survival.

Figure 11 shows the stage distribution of breast cancer cases diagnosed among white, black, and Hispanic women in 1999-2000. In each racial/ethnic group, patients with private insurance were more likely to be diagnosed with stage I breast cancer and less likely to be diagnosed with stage III and IV cancer than those who were uninsured or who had Medicaid insurance. Breast cancer survival for all stages combined was also associated with insurance status (Figure 12). Among patients with private insurance, 89% survived 5 years, compared with 77% of patients who were uninsured and 75% of those who had Medicaid insurance; the difference in survival between uninsured patients and those with Medicaid insurance was not statistically significant. Patterns of survival by insurance type were similar for white, black, and Hispanic women, although black women had lower survival rates than white women or all women combined; among black women with private insurance, 81% survived 5 years, compared with 65% of uninsured

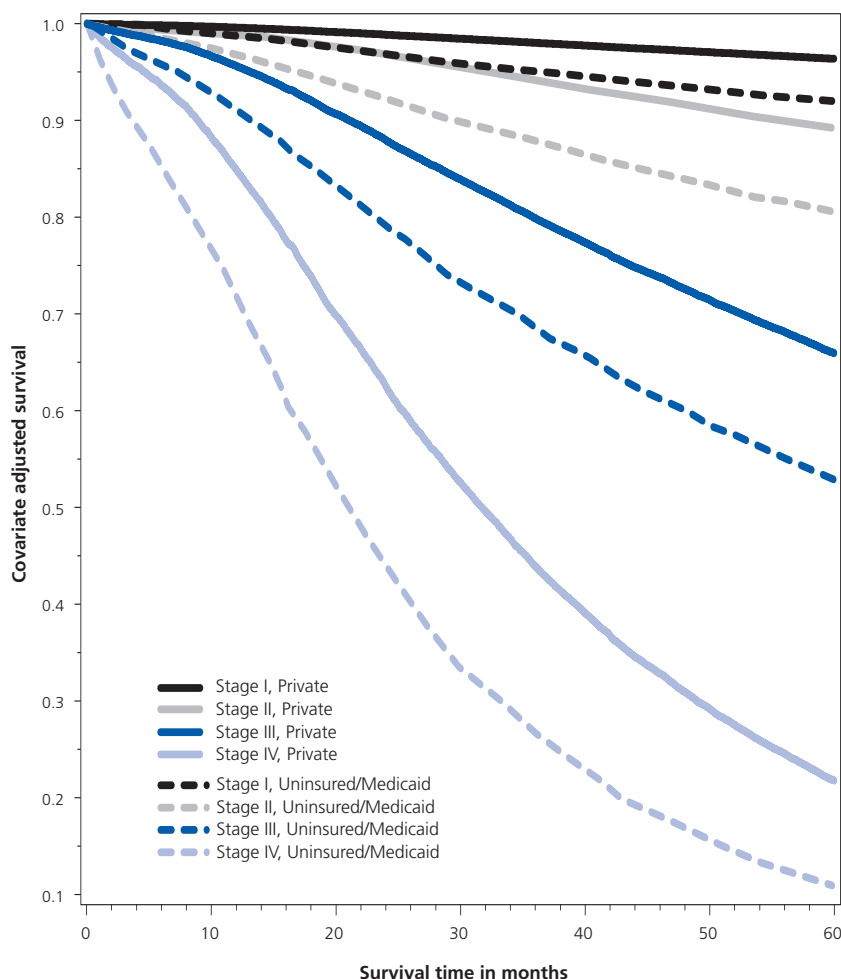
Figure 12. Breast Cancer Survival Among Women Ages 18-64 Years by Insurance Status*



*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information on stage, age, race/ethnicity, or zip code.

Source: National Cancer Database.

Figure 13. Breast Cancer Survival Among Women Ages 18-64 Years by Stage and Insurance Status*



*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information on stage, age, race/ethnicity, or zip code.

Source: National Cancer Database.

patients and 63% of Medicaid-insured patients (data not shown). When data were analyzed within each stage, survival was consistently lower for women who were uninsured or who had Medicaid insurance, compared to those who were privately insured (Figure 13).

Figure 14 shows the stage distribution of colorectal cancer cases diagnosed among white, black, and Hispanic patients in 1999-2000. In each racial/ethnic group, patients with private insurance were more likely to be diagnosed with stage I and less likely to be diagnosed with stage IV colorectal cancer than those who were uninsured or who had Medicaid insurance. Survival for all stages combined was also associated with insurance status (Figure 15). Among patients with private insurance, 65% survived 5 years, compared with 50% of patients who were uninsured and 46% of those with Medicaid insurance; the difference in survival

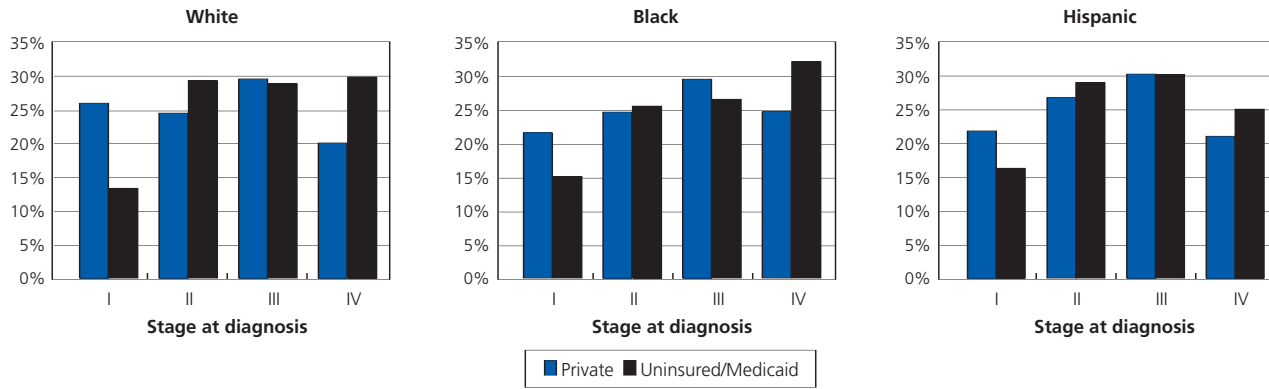
between uninsured patients and those with Medicaid insurance was not statistically significant. Patterns of survival by insurance type were similar for white, black, and Hispanic men and women, although black men and women had lower survival rates than whites or all races/ethnicities combined; among black patients, 60% of those with private insurance survived 5 years, compared with 41% of uninsured patients and Medicaid-insured patients. When data were analyzed within each stage, survival was consistently lower for men and women who were uninsured or who had Medicaid insurance, compared to those who were privately insured (Figure 16). In fact, patients who were diagnosed with stage I cancer who were uninsured or Medicaid-insured were more likely to die within the first 5 years than privately insured patients diagnosed with stage II cancer, and privately insured patients with stage III disease had similar survival to Medicaid-insured or uninsured patients with stage II disease.

The results of the analysis of breast and colorectal cancer survival by insurance status among patients diagnosed in 1999 and 2000 and reported to the NCDB were similar to those of a previous study that examined 3-year cancer survival by insurance status among patients diagnosed in Kentucky in 1995-1998 and followed through 1999.⁴⁸ The latter study found that

3-year relative survival among breast cancer patients was 90.6% for privately insured patients, 75.5% for patients with Medicaid insurance, and 77.7% among the uninsured. For colorectal cancer patients, 3-year survival was 70.9% for those with private insurance, 53.0% for those with Medicaid insurance, and 52.8% for those who were uninsured.

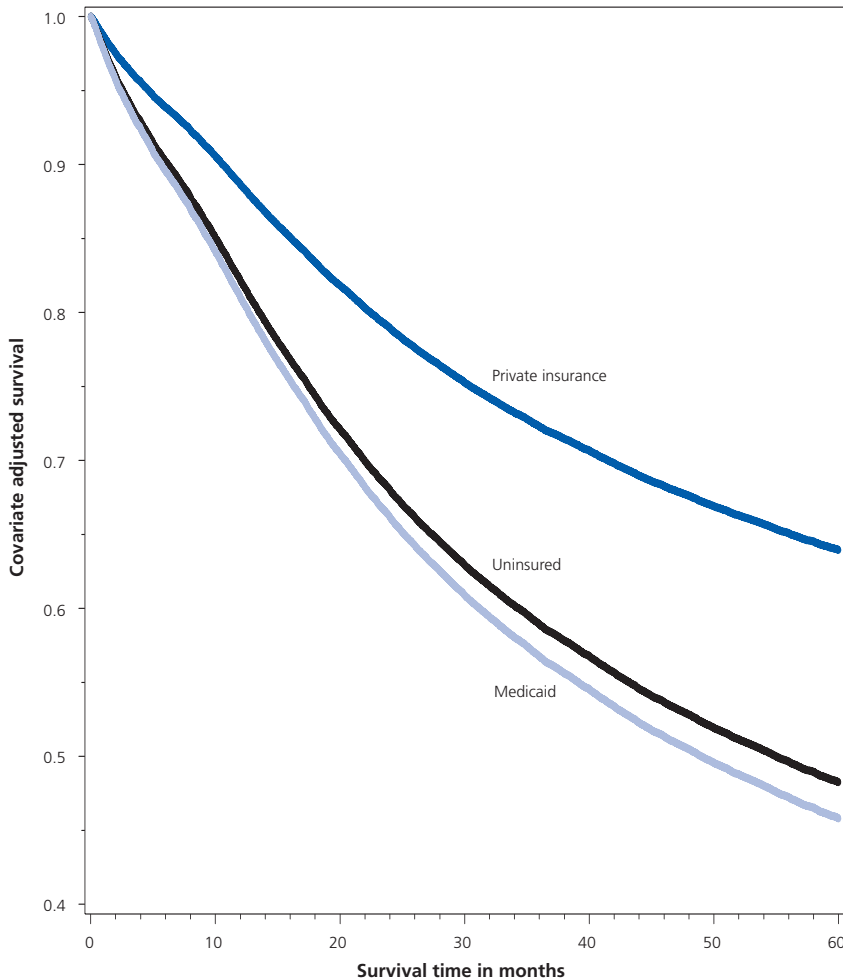
Although neither the NCDB analyses nor the Kentucky Registry study was able to control for sociodemographic factors other than race/ethnicity, sex, and age, or for the presence of other health conditions that might impact survival, both studies were able to control for stage, and the NCDB analysis controlled for zip code level of income. In addition, when survival by insurance status was examined using the NCDB for a cancer with very high survival (stage I and II thyroid cancer), the largest

Figure 14. Colorectal Cancer Stage Distribution Among Patients Ages 18-64 by Race/Ethnicity and Insurance Status*



*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information on stage, age, race/ethnicity, or zip code.
Source: National Cancer Database.

Figure 15. Colorectal Cancer Survival Among Patients Ages 18-64 Years by Insurance Status*



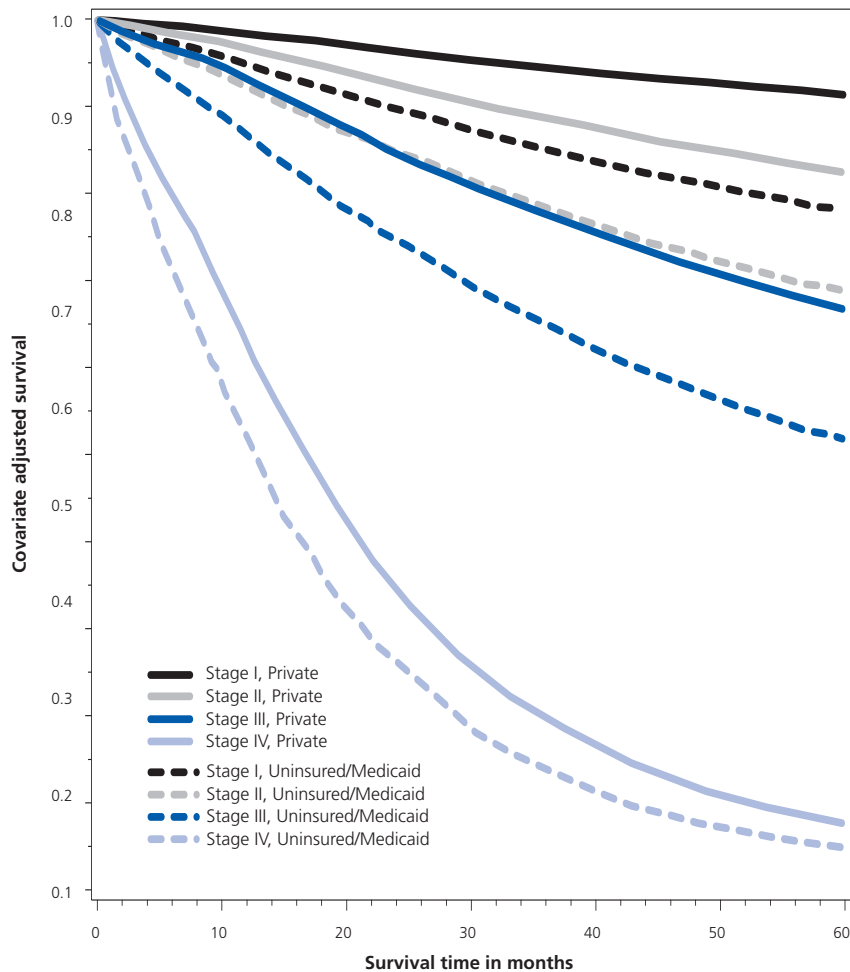
*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information on stage, age, race/ethnicity, or zip code.
Source: National Cancer Database.

difference in predicted 5-year survival based on differences in insurance status was only 2%. Thus it does not appear likely that the large differences in survival between insurance groups are accounted for by factors other than those related to diagnosis and treatment of their cancer.

How Does Insurance Type Influence Stage at Diagnosis and Survival?

Later stage at diagnosis for cervical, breast, colorectal, and prostate cancer among patients who are uninsured or who have Medicaid insurance can be explained in part by lower access to and/or use of cancer screening services. Analyses of NHIS 2005 data presented in this report, as well as prior studies, found that screening rates were substantially lower among uninsured than among privately insured individuals, and that Medicaid-insured patients consistently had screening rates that were lower than those for the privately insured but substantially higher than those for the uninsured. Later stage at diagnosis may also be associated with lack of follow up or delay in follow up of abnormal screening test results. A review of studies evaluating follow-up care for an abnormal cancer screening result found that less than 75% of patients received such care, and identified barriers to follow up at the provider, patient, and health care system levels.⁴⁹ Appropriate follow up of an

Figure 16. Colorectal Cancer Survival Among Patients Ages 18-64 Years by Stage and Insurance Status*



*Patients diagnosed from 1999-2000; excluded from the analysis: unknown stage; race/ethnicity other than white, black, or Hispanic; missing information on stage, age, race/ethnicity, or zip code.
Source: National Cancer Database.

abnormal screening test requires a number of critical steps where the process can break down. The primary care provider and/or patient must be informed of the abnormal result, the appropriate follow-up diagnostic evaluation must be recommended, a provider and site for the diagnostic evaluation must be identified, and the patient must make and keep the appointment. Patients without health insurance and those whose health insurance is not widely accepted face additional cost and administrative and access barriers that may be insurmountable for many.

The finding that patients with Medicaid coverage experience later stage at diagnosis than do patients with private insurance does not mean that patients who are enrolled in Medicaid are not benefitting from being insured. Data from the NHIS found that patients enrolled in Medicaid had higher rates of mammography

and colorectal cancer screening than do the uninsured. Patients coded as having Medicaid insurance in the NCDB and other cancer registries represent a mixture of those who were enrolled for a period of time before diagnoses and those who qualified for Medicaid when they were diagnosed with a serious medical condition such as cancer. There is no information on the percent of patients in each state who are enrolled in Medicaid after a cancer diagnosis. A study in Michigan found that 36% of cancer patients with Medicaid coverage were enrolled in Medicaid after being diagnosed with cancer,⁴⁰ but this proportion may vary by state or cancer site.

Patients with Medicaid insurance face additional barriers to care beyond those directly related to insurance or the health care system. Barriers such as lack of transportation, low literacy, and poor and unstable housing may also contribute to worse outcomes for Medicaid enrollees. Lack of non-emergency medical transportation to health care facilities is a frequent barrier for this population, which can cause delays in screening, diagnosis, and treatment.^{50,51} Many Medicaid enrollees have difficulty with reading comprehension. One study found that Medicaid enrollees had a mean reading level of grade 5.4.^{52,53} Such low literacy levels are associated with difficulty in enrollment,

poor compliance due to difficulty comprehending prescriptions and other medical instructions, and low use of preventive services. In addition, Medicaid enrollees are more likely to experience housing instability, a factor that has been associated with postponing needed medical care and medications.⁵⁴

Some characteristics of the Medicaid system may reduce its apparent effectiveness in improving health outcomes. A review of the impact of health insurance coverage on health by the Institute of Medicine in 2002 noted that Medicaid-insured patients may appear to have poorer outcomes because many patients become eligible for Medicaid as a result of poor health (i.e. because their illness interferes with employment or because the cost of treatment results in them being classified as medically needy). Some programmatic features of Medicaid also

contribute to poorer access to preventive services and treatment for Medicaid-insured compared to privately insured individuals. Medicaid reimbursements are generally less than reimbursements for Medicare or private insurance. In many states, payment rates below the cost of the care delivery result in low provider participation. When this occurs, Medicaid enrollees may find themselves limited to the same set of overtaxed safety-net providers as uninsured adults, with related delays in getting appointments and referrals to specialists. Medicaid's limited coverage periods also weaken the positive effects of insurance. One study based on a federal survey found that the median length of time that adults younger than 65 maintained Medicaid enrollment was just five months;⁵⁵ Medicaid requires eligibility certifications as frequently as monthly, and some people lose coverage simply because they did not meet administrative requirements. As a consequence of the intermittency of Medicaid coverage, adults identified as covered by Medicaid at one point in time may not achieve the benefits that continuous health coverage can provide such as repeated screenings and a regular source of medical care.

Health insurance status may be associated with cancer survival through a variety of mechanisms. Later stage at diagnosis observed for Medicaid-insured and uninsured patients would lead to lower overall survival even if quality and success of treatment were equivalent to that among the privately insured. However, analyses of NCDB data for breast and colorectal cancer find that even within stage at diagnosis, survival is poorer for patients with no health insurance or with Medicaid insurance. Lower survival within cancer stage may result from a variety of factors related to access to care and quality of care, including adequacy of staging (leading to understaging); differences in tumor size, grade, or other prognostic factors within stage groupings; delays in initiation of treatment; differences in receipt of treatment consistent with recommended guidelines; quality and outcome of specific treatments (such as completeness of surgical resection); differences in provision of supportive care; and completion of (i.e., compliance with) the full course of therapy. As noted above, other factors that may contribute to choice and completion of treatment for some individuals who are uninsured or insured by Medicaid include low literacy, lack of transportation, language barriers, and other factors not directly related to insurance or health care barriers.

Limitations of Existing Data on Insurance Status and Cancer Treatment

Data are extremely limited on the relationship between insurance status and variations in cancer treatment. These limitations are due in part to the incompleteness of treatment information in cancer registry records, which makes it difficult to study treatment patterns or concordance with treatment guidelines using registry data alone. The most commonly used data resource for studying cancer treatment is the SEER-Medicare database, which by definition includes only Medicare insured patients. Among the limited number of studies conducted, one found that insurance status and poverty level were predictors of delays of greater than three months from initial diagnosis to start of treatment among women with invasive breast cancer.⁵⁶ Overall, studies of variations in treatment among patients with breast and colorectal cancer have not found consistent variations in treatment and concordance with treatment guidelines by insurance status.⁵⁷⁻⁶¹ However, there is considerable variation between studies in insurance groups included and treatments evaluated. One study reported that patients who are uninsured or who have Medicaid insurance are less likely to receive surgery for lung and pancreatic cancer at high-volume facilities;⁶² another found that the likelihood of initial presentation of colon cancer as a surgical emergency due to bowel perforation, peritonitis, or obstruction was 2.1 times higher among Medicaid enrollees and 2.6 times higher among uninsured patients than among privately insured patients under the age of 65.⁶³

Although variations in health insurance coverage likely contribute to racial and ethnic disparities in cancer outcomes, disparities persist for several outcomes even when accounting for differences in insurance status. Racial and ethnic disparities in health and healthcare occur in the context of broader historic and contemporary social and economic inequality, including persistent racial and ethnic discrimination in many sectors of American life.⁶⁴ Even in the absence of financial barriers to care, cultural and language differences between providers and racial and ethnic minority patients may result in poor communication, undermining informed decision-making and the patient's adherence to treatment regimens. Experiences of discrimination may directly affect health and access to care, and may also reduce trust in the health care system.⁵⁵ Even if health insurance and financial barriers can be overcome, further research and interventions will be needed to address these issues.

Although there is substantial evidence that insurance status is an important factor in access to and use of cancer care, there is little information on how economic issues impact treatment choices at the level of the individual patient. For example, to what extent do individuals forego treatment or select less than optimal treatment because they are unable to find a health care provider who is willing to provide it, or because they are afraid of the level of medical debt that they would incur? As the cost of some new cancer therapies can exceed \$100,000 a year, to what extent will availability and type of insurance coverage, as well as individual financial resources, determine who has access to the most effective therapies?

Overcoming Barriers to Cancer Prevention, Early Detection, and Treatment

Expanding Access to Health Care

With more than 47 million Americans uninsured,⁶⁵ it is not surprising that much of the focus in the current health care reform debate is on increasing the number of individuals with health insurance coverage and reducing the costs of coverage. While reducing the number of uninsured is critical, the issue is more complex than that. Although availability and affordability are essential, adequacy of coverage must also be addressed in order to resolve the health care crisis. Inadequate insurance, with limited benefits or high cost sharing, leaves cancer patients without access to timely, lifesaving treatment. One in five insured persons diagnosed with cancer uses all or most of their savings because of the financial cost of dealing with cancer.⁶⁶ The problems are significantly worse for those without insurance. Those who are poor and uninsured are less likely to receive cancer prevention services, more likely to be diagnosed with cancer at late stages of disease, and less likely to survive five years after diagnosis.

Defining Meaningful Health Insurance

The American Cancer Society believes meaningful reform solutions must include adequate, available, affordable, and administratively simple health insurance coverage for all without regard to health status or previous medical claims.

Society Threshold Questions for Meaningful Health Insurance Reform

- Does the proposal contain the essential components?
- Is coverage available to all?

- Is there a benefit package that ensures adequate coverage for cancer patients and others with potentially serious medical problems?
- Is the provider's coverage affordable?
- Is the administrative process simple for patients and providers?
- Does the reform plan reduce or eliminate the ability of insurers to "cherry pick" among applicants?
- Is the overall proposed financing realistic and adequate to sustain the proposed reforms?

Adequate health insurance ...

... ensures timely access to the full range of evidence-based health care services – including prevention and primary care – necessary to maintain health, avoid disease, overcome acute illness, and live with chronic illness. Coverage should be comprehensive, not run out, and fully cover catastrophic expenditures.

Available health insurance ...

... is accessible, renewable, portable, and continuous. It must not be based on, or constrained by, actual or perceived health status or history of health care services use.

Affordable health insurance ...

... provides everyone the ability to purchase meaningful private health insurance based on his or her ability to pay. Premium pricing should not be based on an individual's actual or perceived health status or history of health care services utilization. Annual total out-of-pocket costs (includes co-pays and deductibles) must be reasonable.

Administratively simple health insurance ...

... requires transparency and simplicity in private health insurance products, both pre- and post-enrollment. Consumers must be able to compare and contrast different health insurance plans and easily navigate health insurance transactions and transitions.

Limiting "cherry picking" means ...

... limiting "market segmentation" to prevent discrimination against individuals with health risks or perceived health risks.

Insurance risks must be pooled in a manner that assures cancer patients and others with serious medical conditions can continue to have access to adequate insurance at affordable rates without undoing vital consumer protections already in place.

Adequate financing means ...

... proposals that seek to broaden and improve coverage significantly are likely to require additional funding.

There are many ways to fund proposals and at this time, the American Cancer Society does not endorse one over another. However, the funding must be realistically achievable.

In addition to addressing the issues surrounding insurance, the American Cancer Society is expanding and enhancing its commitment to quality health care with several crucial efforts that are already under way.

- Offering up-to-date cancer information that helps patients easily understand their disease and enables them to effectively work with their health care provider to make treatment decisions
- Helping those diagnosed with cancer find hope and inspiration by connecting them with others who have “been there”
- Making trained patient navigators available to help people get the care they need
- Offering a Health Insurance Assistance Service to callers from many states to help cancer patients and their loved ones who are struggling with state and federal insurance issues
- Increasing funding for the National Breast and Cervical Cancer Early Detection Program, which provides low-income, uninsured, and underinsured women access to mammograms and follow-up care, regardless of their ability to pay
- Supporting legislation that will provide free or low-cost colorectal cancer screening
- Working through awareness and advocacy to eliminate disparities in the cancer burden
- Fighting any bills that threaten existing coverage requirements
- Advocating for increased federal funding of cancer research

The American Cancer Society, along with its sister advocacy organization, the American Cancer Society Cancer Action Network (ACS CAN), is dedicated to ensuring that primary care, prevention, early detection, and quality care are available to all. Effective solutions to the current crisis must address adequacy in addition to availability and affordability of health insurance.

American Cancer Society Programs

The American Cancer Society is committed to reaching out to those individuals who are under- and uninsured to help increase access to quality medical care, including

cancer screening, diagnostic, and treatment services. The Society has placed increased emphasis on working with collaborators at the national, state, and local levels on outreach activities, identifying a growing number of resources to assist individuals in need, and making services and information more accessible through adapting for literacy levels and language needs.

Information

National Cancer Information Center and www.cancer.org

The American Cancer Society is dedicated to making certain everyone can access quality health information. Anyone can call toll-free 1-800-227 (ACS)-2345 and speak with a person who can offer cancer information as well as refer callers to resources in their community, including transportation, support groups, or low-cost or free screenings if they are available. Cancer information specialists answer calls in both English and Spanish, and translation services are available for callers who speak other languages. This information is also available on the American Cancer Society Web site, www.cancer.org.

Health Insurance Assistance Service

The National Cancer Information Center (NCIC) Health Insurance Assistance Service helps individuals in 27 states with questions and concerns about insurance.

Cancer Resource Network

The Society also provides the Cancer Resource Network, a network that encompasses multiple delivery channels that allow cancer patients, survivors, and caregivers to reach the Society and receive help with managing their cancer experience at every point in the cancer continuum. Materials for the Cancer Resource Network were developed specifically to reach out to the medically underserved.

Services in the Cancer Resource Network provide information on diagnosis and treatment, support programs, and assistance in identifying needed services and resources.

A number of services provided through the Cancer Resource Network help individuals navigate their health care and increase access to care. Examples include:

- The Patient Navigator Program, in which trained Society staff members, patient navigators, work with patients, families, and caregivers to identify and prioritize needs and challenges they are facing in navigating their cancer care

- Hope Lodge®, which provides free lodging to patients and caregivers who must travel away from home to obtain cancer treatment
- The Personal Health Manager, which provides newly-diagnosed cancer patients and their caregivers with a tool to help manage and organize the multitude of information they receive from various sources related to their diagnosis and treatment (written for lower literate adults – reading levels of 6-9 – and available in English and Spanish)

Prevention and Detection

The Society works nationwide and at the local level to increase awareness of the importance of lifestyle factors in cancer risk, as well as the importance of early detection screening tests.

“Team Up” is a pilot project in which the American Cancer Society, the Centers for Disease Control and Prevention, the National Cancer Institute, and the US Department of Agriculture have joined forces to determine the effectiveness of adapting and using evidence-based outreach interventions to serve rarely or never screened populations with breast and cervical cancer screening. The pilot is finishing up its fourth and final year of work in six states. As of June 2007, all six states successfully implemented the intervention and reached more than 300 underserved, rarely screened, or never screened women with cancer prevention services.

The Centers for Disease Control and Prevention National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides breast and cervical cancer screening to underserved women. The Society works with the NBCCEDP to increase awareness of and enrollment in the program where there are opportunities for more women to be screened. In many states, programs are at capacity, meaning women eligible for these services are not able to access them.

The Access to Health Care Campaign

Information regarding the issue of access to health care was created for an awareness campaign in the fall of 2007. A booklet explaining the issue and the Society’s activities was made available through the NCIC. In addition, a Web site was established to allow consumers to learn about the issue, speak up through message boards, or take action through the Society’s sister advocacy organization, ACS CAN.

Data Sources

Information on insurance status and relationships with access to health care, preventive services, and cancer screening was obtained by analysis of data from the National Health Interview Survey (NHIS) conducted in 2005 and 2006. The NHIS is a survey of the CDC’s National Center for Health Statistics (NCHS). The survey is designed to provide national prevalence estimates on personal, socioeconomic, demographic, and health characteristics of United States adults. Data are gathered through a computer-assisted personal interview of adults aged 18 and older living in households in the US.⁶⁷

Data from the National Cancer Database (NCDB) was used to examine the relationship between insurance status at the time of diagnosis and cancer survival for all cancers combined and for breast and colorectal cancer. The NCDB is a joint project of the Commission on Cancer of the American College of Surgeons and the American Cancer Society that collects information on demographic and clinical characteristics and first course of treatment for cancer patients diagnosed at approximately 1500 Commission on Cancer approved hospitals, representing almost 70% of all cancer patients treated in the US.⁴⁴ We selected cancer patients aged 18-64 reported to the NCDB during 1999 and 2000, the most recent years for which 5-year follow up is available. Patients were further restricted to those with private insurance, Medicaid insurance, and no insurance. Among the 719,915 patients who met these criteria, 7,886 were excluded because the time variable could not be calculated and 113,394 were excluded because they had other or unknown race (only white, black, and Hispanic patients were included) or missing area socioeconomic status data. A total of 598,635 cases were available for analysis, including 129,644 female breast cancer patients and 44,898 male and female colorectal cancer cases. Cox regression analysis (proportional hazards analysis) was used to model 5-year survival by insurance status, controlling for age, race, sex, and zip code based income. The proportional hazards assumption was tested prior to analysis and none of the variables included in the model violated the proportional hazards assumption when analyses were stratified by age group and site. Results for overall and stage-specific survival were plotted by insurance status.

References

1. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *J Natl Cancer Inst.* Mar 6 2002;94(5):334-357.

2. Collins S, White C, Kriss J. Whither employer-based health insurance? The current and future role of U.S. companies in the provision and financing of health insurance. New York: The Commonwealth Fund 2007.
3. Blumenthal D. Employer-sponsored health insurance in the United States – origins and implications. *N Engl J Med*. Jul 6 2006;355(1):82-88.
4. Committee on the Consequences of Uninsurance. Board on Health Care Services. Institute of Medicine of the National Academies. *Insuring America's Health. Principles and Recommendations*. Washington, D.C.: The National Academies Press; 2004.
5. *Employer Health Benefits 2007 Annual Survey*. Washington: The Kaiser Family Foundation and Health Research and Educational Trust; 2007.
6. FAQs about COBRA Continuation Health Coverage U.S. Department of Labor Employee Benefits Security Administration; www.dol.gov/ebsa; 2007.
7. Bishop H, Clark P, Leopold B, Oxman M, Szuberla G. *2007 CCH Medicare and Medicaid Benefits*. Chicago: Wolters Kluwer; 2007.
8. Medicare FAQ's: United States Department of Health and Human Services, <http://questions.medicare.gov>; 2007.
9. *Glossary of terms commonly used in Health Care*. Washington, DC: AcademyHealth; 2004.
10. Gilmer T, Kronick R, Rice T. Children welcome, adults need not apply: changes in public program enrollment across states and over time. *Med Care Res Rev*. Feb 2005;62(1):56-78.
11. Stewart A. Personal Communication to Elizabeth Ward; Percent of patients with cancer under age 18 covered by Medicaid insurance, National Cancer Database, 1996-2005; 2007.
12. Key Facts Race, Ethnicity and Medical Care. Available at: <http://www.kff.org/minorityhealth/6069.cfm>. Washington: The Kaiser Family Foundation; 2007.
13. National Breast and Cervical Cancer treatment program. Breast and Cervical Cancer Prevention and Treatment Act of 2000. www.cdc.gov/cancer/nbcedp/about/htm.
14. Tangka FK, Dalaker J, Chattopadhyay SK, et al. Meeting the mammography screening needs of underserved women: the performance of the National Breast and Cervical Cancer Early Detection Program in 2002-2003 (United States). *Cancer Causes Control*. Nov 2006;17(9):1145-1154.
15. French C, True S, McIntyre R, Sciulli M, Maloy KA. State implementation of the Breast and Cervical Cancer Prevention and Treatment Act of 2000: a collaborative effort among government agencies. *Public Health Rep*. May-Jun 2004; 119(3):279-285.
16. Collins S, Schoen C, Doty M, Holmgren A, How S. Paying more for less: Older adults in the private insurance market. Findings from the Commonwealth Survey of Older Adults New York: The Commonwealth Fund. Available at: http://www.Commonwealthfund.org/publications_show.htm?doc_id=282104; 2005.
17. Cohen RA MM. Health Insurance Coverage: Early Release of Estimates from the National Health Interview Survey, 2006: Centers for Disease Control and Prevention. Available at: www.cdc.gov/nchs/data/nhis/earlyrelease/insur200612.pdf; 2007.
18. Collins S, Davis K, Doty M, Kriss J, Holmgren A. *Gaps in Health Insurance: An All-American Problem. Findings from the Commonwealth Fund Biennial Health Insurance Survey* Washington: The Commonwealth Fund; 2006.
19. Clemens-Cope L, Garrett B. *Changes in Employer-Sponsored Health Insurance Sponsorship, Eligibility, and Participation: 2001-2005*. Washington: Kaiser Commission on Medicaid and the Uninsured; 2006.
20. Himmelstein DU, Warren E, Thorne D, Woolhandler S. Illness and injury as contributors to bankruptcy. *Health Aff (Millwood)*. Jan-Jun 2005;Suppl Web Exclusives:W5-63-W65-73.
21. Siminoff LA, Ross L. Access and equity to cancer care in the USA: a review and assessment. *Postgrad Med J*. Nov 2005;81(961): 674-679.
22. Banthin JS, Bernard DM. Changes in financial burdens for health care: national estimates for the population younger than 65 years, 1996 to 2003. *JAMA*. Dec 13 2006;296(22):2712-2719.
23. Banthin JS, Bernard D. *Medical Expenditures Panel Survey Statistical Brief #122. Out-of-Pocket Expenditures on Health Care and Insurance Premiums among the Elderly Population, 2003*. Washington, D.C.: Agency for Health Care Research and Quality; 2006.
24. Anderson GF. From 'soak the rich' to 'soak the poor': recent trends in hospital pricing. *Health Aff (Millwood)*. May-Jun 2007;26(3):780-789.
25. O'Toole TP, Arbelaez JJ, Lawrence RS. Medical debt and aggressive debt restitution practices: predatory billing among the urban poor. *J Gen Intern Med*. Jul 2004;19(7):772-778.
26. Hing E, Burt C. *Characteristics of Office-Based Physicians and Their Practices: United States 2003-2004. Series 12, No. 164*. Hyattsville, MD: National Center for Health Statistics; 2007.
27. Hoffman C, Sered S. *Threadbare: Holes in America's Health Care Safety Net*. Washington, DC: The Kaiser Commission on Medicaid and the Uninsured. The Kaiser Family Foundation; 2005.
28. Asplin BR, Rhodes KV, Levy H, et al. Insurance status and access to urgent ambulatory care follow-up appointments. *JAMA*. 2005;294(10):1248-1254.
29. Kuehn BM. Poverty shift may burden health system. *JAMA*. Mar 14 2007;297(10):1047-1048.
30. Cokkinides VE, Ward E, Jemal A, Thun MJ. Under-use of smoking-cessation treatments: results from the National Health Interview Survey, 2000. *Am J Prev Med*. Jan 2005;28(1):119-122.
31. Coughlin SS, Uhler RJ, Bobo JK, Caplan L. Breast cancer screening practices among women in the United States, 2000. *Cancer Causes Control*. Mar 2004;15(2):159-170.
32. Sambamoorthi U, McAlpine DD. Racial, ethnic, socioeconomic, and access disparities in the use of preventive services among women. *Prev Med*. Nov 2003;37(5):475-484.
33. Potosky AL, Breen N, Graubard BI, Parsons PE. The association between health care coverage and the use of cancer screening tests. Results from the 1992 National Health Interview Survey. *Med Care*. Mar 1998;36(3):257-270.
34. Schrag N, Pavluck A, Bian J, Ward E, Halpern M. A review of the relationship between insurance coverage and cancer care. Submitted for publication. 2008.

35. Ioannou GN, Chapko MK, Dominitz JA. Predictors of colorectal cancer screening participation in the United States. *Am J Gastroenterol*. Sep 2003;98(9):2082-2091.
36. Parker J, Gebretsadik T, Sabogal F, Newman J, Lawson HW. Mammography screening among California Medicare beneficiaries: 1993-1994. *Am J Prev Med*. Oct 1998;15(3):198-205.
37. Chen JY, Diamant A, Pourat N, Kagawa-Singer M. Racial/ethnic disparities in the use of preventive services among the elderly. *Am J Prev Med*. Dec 2005;29(5):388-395.
38. Koroukian SM, Xu F, Dor A, Cooper GS. Colorectal cancer screening in the elderly population: disparities by dual Medicare-Medicaid enrollment status. *Health Serv Res*. Dec 2006;41(6):2136-2154.
39. Bradley CJ, Given CW, Roberts C. Disparities in cancer diagnosis and survival. *Cancer*. Jan 1 2001;91(1):178-188.
40. Bradley CJ, Given CW, Roberts C. Late stage cancers in a Medicaid-insured population. *Med Care*. Jun 2003;41(6):722-728.
41. Bradley CJ, Gardiner J, Given CW, Roberts C. Cancer, Medicaid enrollment, and survival disparities. *Cancer*. Apr 15 2005;103(8):1712-1718.
42. O'Malley CD, Shema SJ, Clarke LS, Clarke CA, Perkins CI. Medicaid status and stage at diagnosis of cervical cancer. *Am J Public Health*. Dec 2006;96(12):2179-2185.
43. Roetzheim RG, Pal N, Tennant C, et al. Effects of health insurance and race on early detection of cancer. *J Natl Cancer Inst*. Aug 18 1999;91(16):1409-1415.
44. Stewart AK, Bland KI, McGinnis LS, Jr., Morrow M, Eyre HJ. Clinical highlights from the National Cancer Data Base, 2000. *CA Cancer J Clin*. May-Jun 2000;50(3):171-183.
45. Chen AY, Schrag NM, Halpern MT, Ward EM. The impact of health insurance status on stage at diagnosis of oropharyngeal cancer. *Cancer*. 2007;110(2):395-402.
46. Chen AY, Schrag NM, Halpern M, Stewart A, Ward EM. Health insurance and stage at diagnosis of laryngeal cancer: does insurance type predict stage at diagnosis? *Arch Otolaryngol Head Neck Surg*. 2007;133(8):784-790.
47. Halpern MT, Bian J, Ward EM, Schrag NM, Chen AY. Insurance status and stage of cancer at diagnosis among women with breast cancer. *Cancer*. Jul 15 2007;110(2):403-411.
48. McDavid K, Tucker TC, Sloggett A, Coleman MP. Cancer survival in Kentucky and health insurance coverage. *Arch Intern Med*. Oct 13 2003;163(18):2135-2144.
49. Yabroff KR, Washington KS, Leader A, Neilson E, Mandelblatt J. Is the promise of cancer-screening programs being compromised? Quality of follow-up care after abnormal screening results. *Med Care Res Rev*. Sep 2003;60(3):294-331.
50. Wallace R, Hughes-Cromwick H, Mull S, Khasnabis. Access to healthcare and non-emergency transportation: Two missing links. *Transportation Research Record*. 2005;1924:76-84.
51. Weiss BD, Palmer R. Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *J Am Board Fam Pract*. Jan-Feb 2004; 17(1):44-47.
52. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med*. Jan 26 1998;158(2):166-172.
53. Rimer BK, Trock B, Engstrom PF, Lerman C, King E. Why do some women get regular mammograms? *Am J Prev Med*. Mar-Apr 1991;7(2):69-74.
54. Kushel MB, Gupta R, Gee L, Haas JS. Housing instability and food insecurity as barriers to health care among low-income Americans. *J Gen Intern Med*. Jan 2006;21(1):71-77.
55. Care Without Coverage: Too Little, Too Late. Washington, DC: Committee on the Consequences of Uninsurance, Board on Health Care Services, Institute of Medicine; 2002.
56. Gwyn K, Bondy ML, Cohen DS, et al. Racial differences in diagnosis, treatment, and clinical delays in a population-based study of patients with newly diagnosed breast carcinoma. *Cancer*. 2004;100(8):1595-1604.
57. Harlan LC, Greene AL, Clegg LX, Mooney M, Stevens JL, Brown ML. Insurance status and the use of guideline therapy in the treatment of selected cancers. *J Clin Oncol*. Dec 20 2005;23(36):9079-9088.
58. Parviz M, Cassel JB, Kaplan BJ, et al. Breast conservation therapy rates are no different in medically indigent versus insured patients with early stage breast cancer. *J Surg Oncol*. Oct 2003;84(2):57-62.
59. Roetzheim RG, Gonzalez EC, Ferrante JM, Pal N, Van Durme DJ, Krischer JP. Effects of health insurance and race on breast carcinoma treatments and outcomes. *Cancer*. Dec 1 2000;89(11):2202-2213.
60. Richardson LC, Tian L, Voti L, et al. The roles of teaching hospitals, insurance status, and race/ethnicity in receipt of adjuvant therapy for regional-stage breast cancer in Florida. *Am J Public Health*. Jan 2006;96(1):160-166.
61. Wu X, Chen VW, Andrews PA, Chen L, Hsieh M, Fontham ET. Treatment patterns for stage III colon cancer and factors related to receipt of postoperative chemotherapy in Louisiana. *J La State Med Soc*. Sep-Oct 2004;156(5):255-261.
62. Liu JH, Zingmond DS, McGory ML, et al. Disparities in the utilization of high-volume hospitals for complex surgery. *JAMA*. 2006;296(16):1973-1980.
63. Diggs JC, Xu F, Diaz M, Cooper GS, Koroukian SM. Failure to screen: predictors and burden of emergency colorectal cancer resection. *Am J Manag Care*. 2007;13(3):157-164.
64. Smedley B, Stith A, Nelson A. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington, DC: The National Academies Press; 2003.
65. DeNavas-Walt C, Proctor B, Lee C. *Income, Poverty and Health Insurance Coverage in the United States: 2006*. U.S. Census Bureau; 2007.
66. USA Today/Kaiser Family Foundation/Harvard School of Public Health Cancer Survey (conducted August 1-September 14, 2006).
67. National Health Interview Survey: National Center for Health Statistics, Centers for Disease Control, Rockville, MD., <http://www.cdc.gov/nchs/nhis.htm>; 2007.