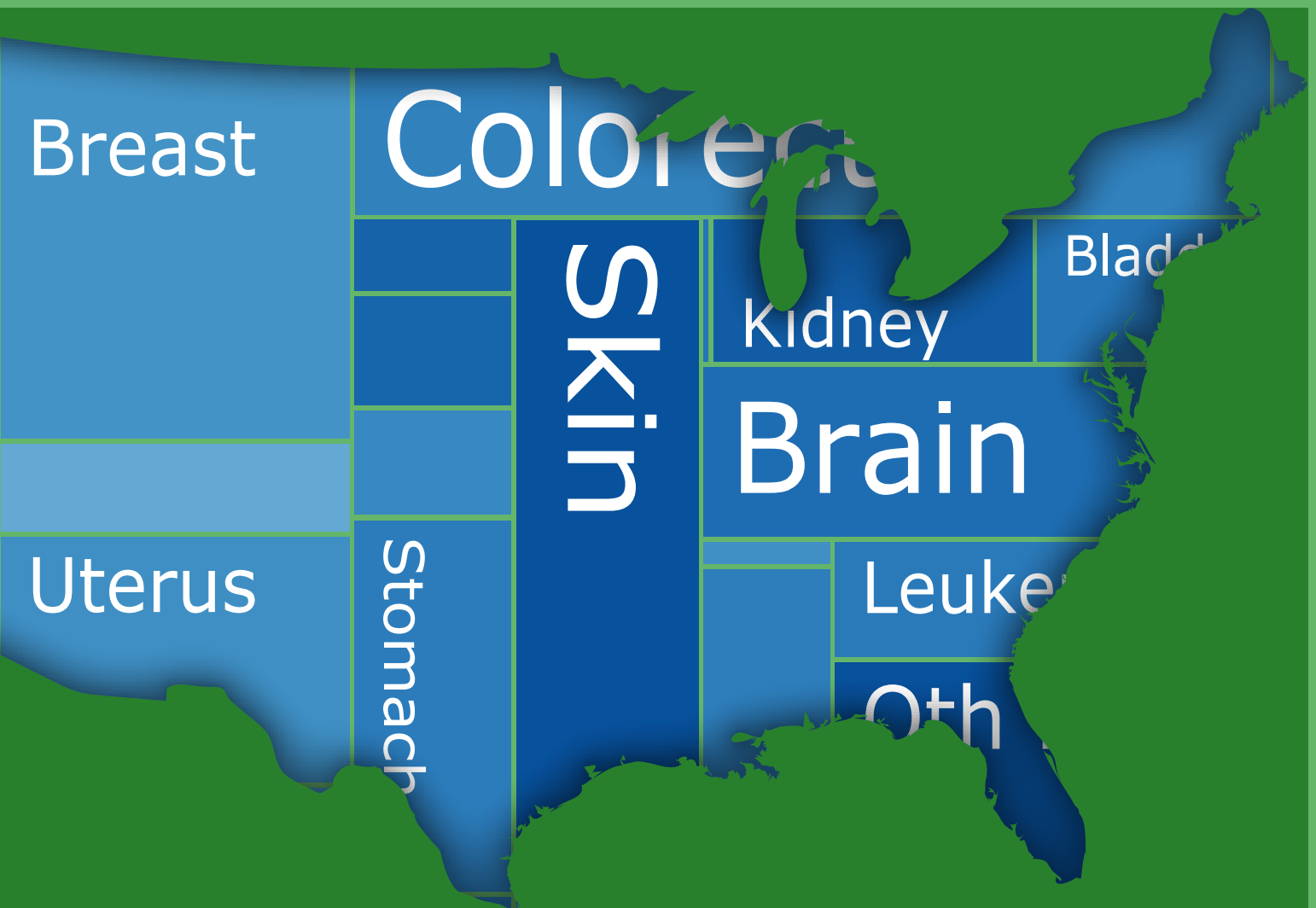


The State(s) of Cancer in America

Disparities in Mortality by County
and \$115 Billion in Spending Raise Issues
of Cost, Quality, and Value of Services



A Special Report for

The Association of Health Care Journalists

by The Institute for Health Metrics and Evaluation (IHME)
at the University of Washington

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Introduction

For many, they are the most disturbing words they will ever hear:
“You have cancer.”

About 40% of Americans will be diagnosed with cancer sometime during their lives. On any given day, there are about 91 million people worldwide living with cancer, including 14 million in the United States.

Between 1980 and 2014, nearly 20 million people in the US died of cancer, according to a study published in *JAMA* in January 2017 by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. Even with that significant death toll, there was good news in the findings: the national mortality rate from all cancers combined fell by 20%. And thousands of counties across the US saw declines in the rate of cancer deaths.

Despite these strong national trends, 160 counties showed increases in all-cancer death rates over the same period. And death rates in two cancers, liver and mesothelioma, increased in nearly every county in the country. These divergent trends raise questions about the availability of care across the six stages of the cancer continuum: prevention and risk reduction; screening; diagnosis; treatment; survivorship; and end-of-life care.

Moreover, as treatment strategies become more advanced and effective, the cost of cancer in the US has risen, though not significantly overall, as compared to other diseases and injuries. The average yearly increase between 1996 and 2013 was 3%; total spending on cancer in 2013 in the US was ranked 11th among all health conditions. Individuals, insurance companies, and the government spent more than \$115 billion in 2013 on cancer diagnosis, treatment, and care. By comparison, cardiovascular disease ranked number one in spending at \$231 billion, though with a lower annualized rate of increase of 1%.

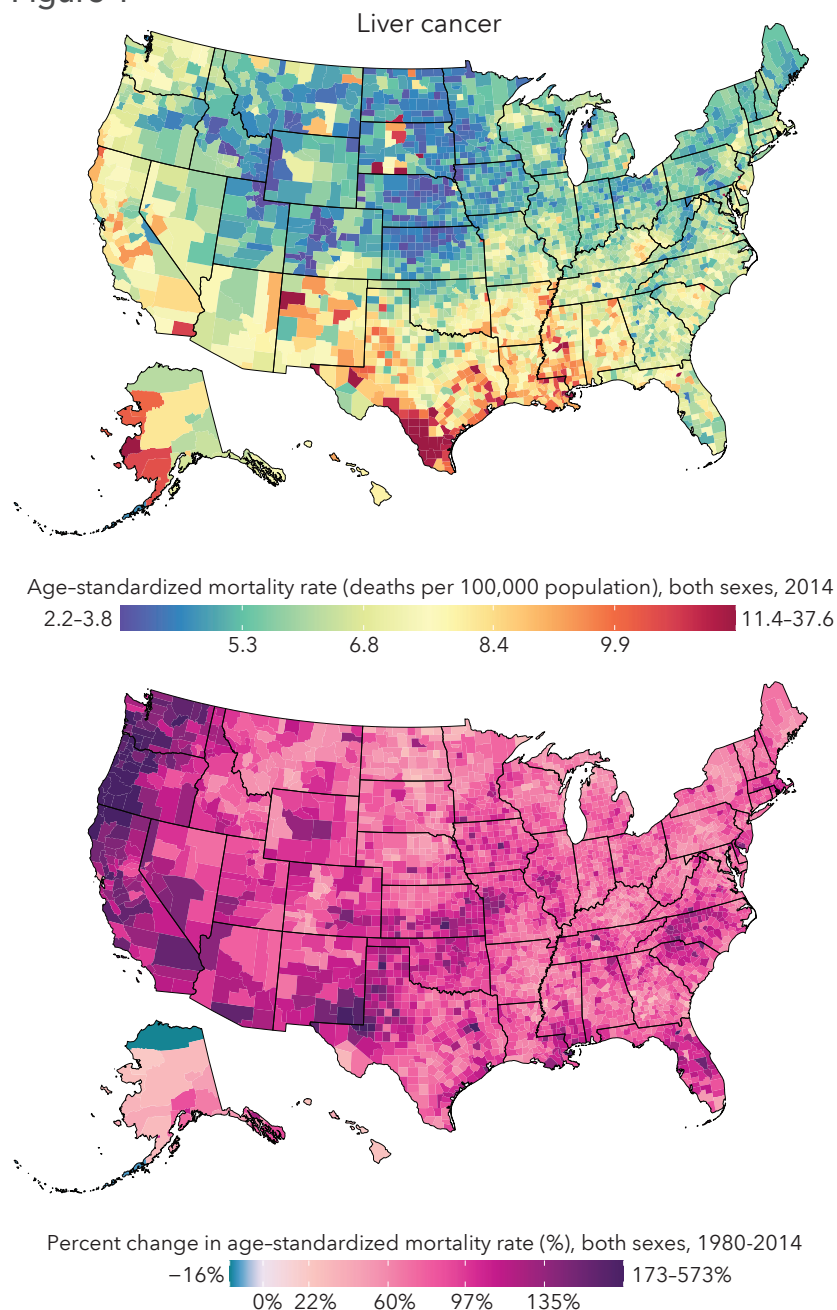
There are wide and, many would argue, unacceptable discrepancies in the rates of mortality across counties in the US. Consider:

- More Americans than ever before – in nearly every US county – are dying of liver cancer. Clusters of counties with disturbing increases in deaths are found in several states, including California and Texas. While alcohol is a well-known risk factor for liver cancer, often counties with high or increasing death rates from liver cancer differ from those known for high rates of alcohol consumption (Figure 1).
- Death rates from breast cancer are increasing in groups of counties along the Mississippi River, as opposed to an overall decrease since 1980 across the country. Nationally, breast cancer survival has been an area of promise for so much of the country, but that promise has not been fulfilled for all who are diagnosed.
- Deaths from lung, tracheal, and bronchial cancer have been falling in much of the country, driven by a decrease in smoking. This is especially true in states that have aggressive anti-smoking laws. California, for example, does not have a single county where death rates from lung cancer increased between 2004 and 2014. But hundreds of counties in

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Figure 1



Source: Mokdad AH, Dwyer-Lindgren L, Fitzmaurice C, et al. Trends and Patterns of Disparities in Cancer Mortality Among US Counties, 1980-2014. *JAMA* 2017; 317: 388-406.

the Midwest and South, concentrated from the Dakotas to Oklahoma and from Ohio to the Florida panhandle, have seen rising death rates.

- Counties with high and rising mortality from kidney cancer span from Oklahoma to Texas, Louisiana, and Mississippi. Moreover, certain areas in Alaska and the Dakotas with large Alaska Native and Native American populations showed rates higher than the national average.

What are the reasons for such high rates of cancer mortality in certain counties and regions?

Certainly, one is the combination of risk factors in people's diets, lifestyles, and exposure to tobacco and other carcinogens. Another may be poor prevention programs in an individual's community. In many instances the detection and treatment of cancer occur at late stages because screening programs are not used effectively. Moreover, a lack of awareness among the local residents regarding the signs and symptoms of certain cancers also contributes to delayed detection. Shortages of clinicians and poor access to health services can lead to missed diagnoses and poor treatment as well.

Treatment strategies in communities depend heavily on the knowledge and skills of both primary care physicians and specialists in various areas of oncology. Many communities do not have ready access to advanced treatment services and facilities. The best cancer care in the US includes specialized and multidisciplinary clinical teams, often only found among the 69 cancer centers designated by the National Cancer Institute. Most of these centers are in urban areas and, therefore in some cases, hundreds of miles from people in urban communities.

But much of what can be controlled starts with risk factors for the different cancers. According to the annual Global Burden of Disease (GBD) study, of the years of healthy life lost to cancer every year in the US – either to death or illness – about 48% are attributable to risk factors and 76% of this attributable burden is due to behavioral risk factors, starting with tobacco use and followed by dietary issues. Additionally, a significant amount of disease burden is related to obesity.

Three important risk factors

Smoking

It has been more than 53 years since the first Surgeon General's Report on Smoking and Health associated smoking with lung cancer and heart disease. According to the US National Library of Science, then-Surgeon General Luther Terry later commented that the report was issued on a Saturday to minimize the effect on the stock market, but to capitalize on public attention through the news media. The report "hit the country like a bombshell. It was front-page news and a lead story on every radio and television station in the United States and many abroad."

Today, smoking remains the leading cause of lung cancer incidence and mortality, according to the annual Global Burden of Disease study (GBD). GBD includes more than 2,200 researchers in 130 countries, and is coordinated by IHME. In the US, per capita cigarette consumption peaked in 1963 at more than 4,300, according to the US Centers for Disease Control and Prevention; total number of cigarettes consumed peaked nearly 20 years later – 640 billion in 1981.

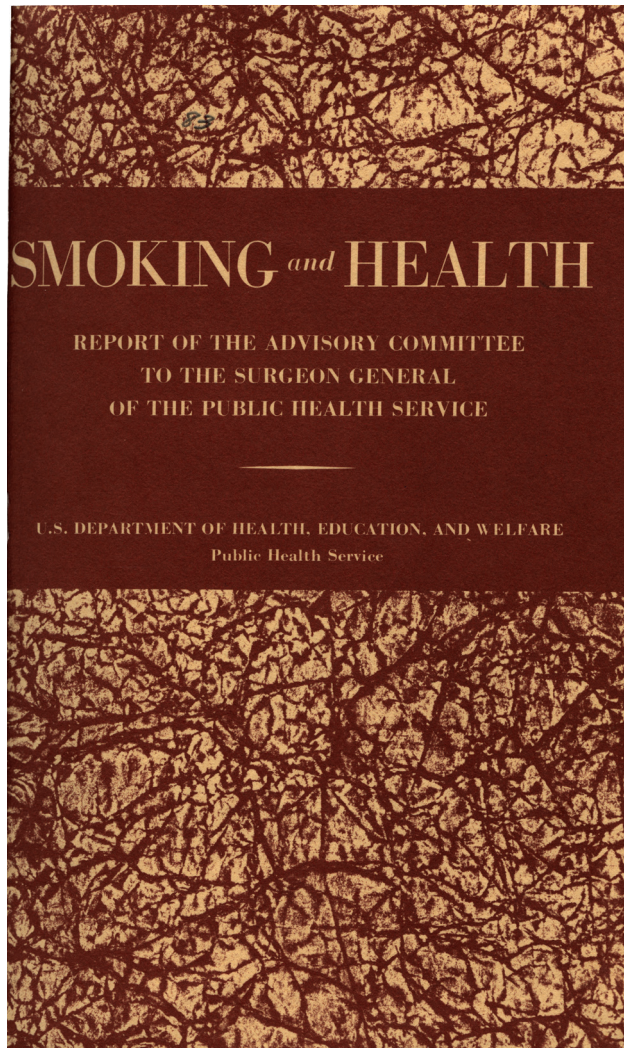
Although smoking prevalence is declining nationally, it remains high in parts of the South, with clusters of counties in Kentucky and West Virginia



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– Surgeon General
Luther Terry, 1964

Over the past several years, the potential health effects of nicotine-related products such as e-cigarettes, hookah, and snuff have been debated among researchers, advocates, and government health officials.



United States. Surgeon General's Advisory Committee on Smoking and Public Health. United States. Public Health Service. Office of Surgeon General. "Smoking and Health: Report of the Advisory Committee to the Surgeon General of the Public Health Service" [Cover]. 1964. https://profiles.nlm.nih.gov/ps/access/NNBCXB_.jpg.

showing greater prevalence of smoking as well as some of the highest mortality rates in the nation. Also, many rural areas still have high rates of smoking-related lung cancer deaths. For example, in Powell County, Kentucky, the death rate for lung cancer is approximately 151 deaths per 100,000 residents, as compared to Jefferson County, which includes the state's largest city, Louisville, and has a mortality rate of about 75 deaths per 100,000. Both are far above the US national rate of 54 deaths per 100,000 people.

Moreover, recent studies have shown that cigar smoking and use of smokeless tobacco and e-cigarettes are increasing in the US. Over the past several years, the potential health effects of nicotine-related products such as e-cigarettes, hookah, and snuff have been debated among researchers, advocates, and government health officials.

Diet

Diet represents another key risk factor for cancer mortality. Among the dietary guidelines to help prevent cancer, the American Cancer Society suggests the following:

- Every meal should include at least half a plate of fruits and vegetables.
- Drink four ounces of 100% fruit or vegetable juice once or twice a day.
- Layer lettuce, tomatoes, beans, onions, and other vegetables on sandwiches and wraps.
- Add tomato sauce and extra vegetables to pastas and vegetable soups.
- Consider having a vegetarian meal when dining out.
- For snacks, consider fresh vegetables and fruits, as well as dried fruits and vegetable juice.

Regrettably, there are no adequate data on dietary consumption at the county level. The Behavioral Risk Factor Surveillance System, administered by the Centers for Disease Control and Prevention, includes some questions on fruit and vegetable consumption, but these are not extensive enough to allow a proper local-area dietary analysis.

Looking more broadly, disparities in income, along with social and cultural issues, also contribute to potential cancer risks. These issues include access to and costs of healthy foods, combined with people being persuaded by aggressive marketing to consume unhealthy foods and beverages, such as those with added sugars and little, if any, nutritional value. Moreover, as the cost of living in the US increases and more households have two wage earners, many people have less time to plan and prepare healthy meals.

According to the article, “American Cancer Society guidelines on nutrition and physical activity for cancer prevention,” published in 2012 in *CA: A Cancer Journal for Clinicians*, “While all Americans face obstacles to making healthy choices, the challenges are compounded for lower-income and racial/ethnic minority groups, who frequently face additional barriers to making healthy food and physical activity choices. Access to supermarkets has been associated with more healthful diets, greater consumption of vegetables and fruits, and lower rates of obesity, and numerous studies have shown that communities with a greater proportion of ethnic minority and low socioeconomic status residents can be characterized as ‘food deserts’ (i.e., they tend to have fewer supermarkets that carry healthy, affordable, high-quality foods).”

Obesity

Obesity is a major risk factor for colon, liver, esophageal, and kidney cancers, among others, and the burden of obesity is increasing in the US. In addition to the obvious causes, poor diet and lack of exercise, medical issues such as an underactive thyroid gland may also contribute to weight gain.

In the US in 2015, high body mass index (BMI) is the third top risk for overall health burden, behind poor diet and tobacco smoke. It accounts for nearly 10% of total health burden – measured by the disability-adjusted life year (DALY), a combined measure of early death and years spent living

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with a condition – one DALY equals one lost year of healthy life. High BMI reached a total of over 8 million DALYS in 2015.

Is the likelihood that I will die of cancer determined by where I live?

Value of county-level data

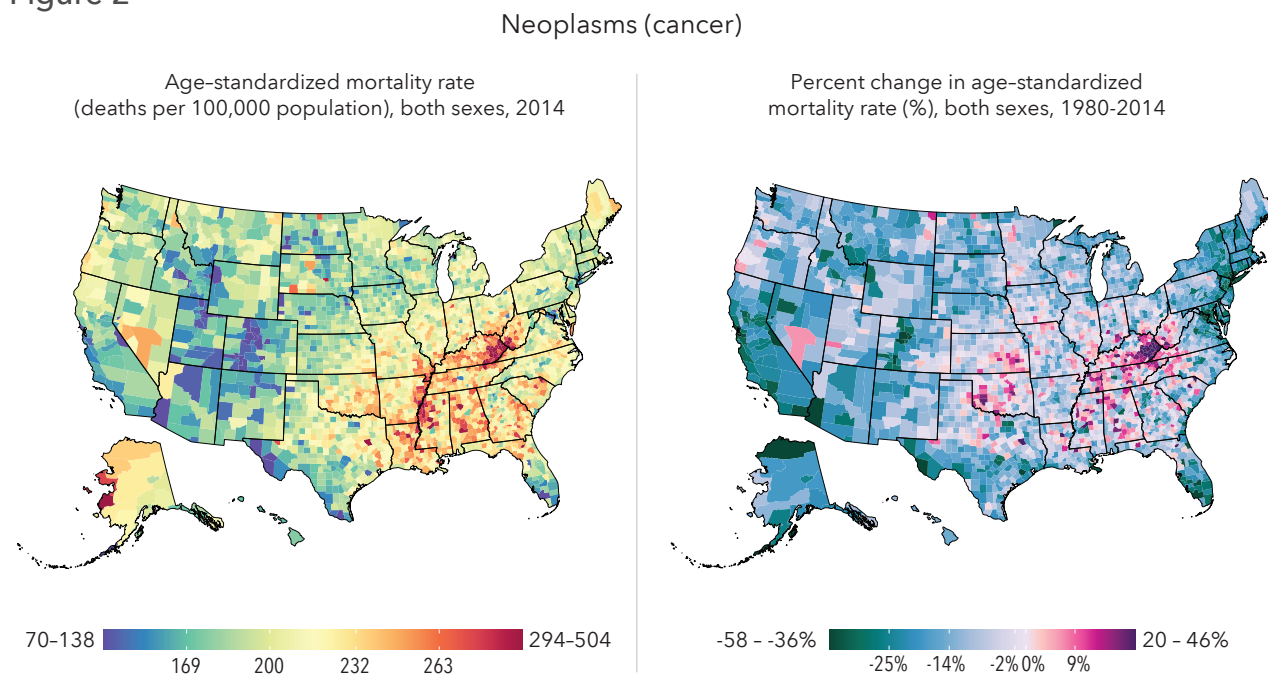
The IHME study published in *JAMA* in January 2017 used an innovative approach to estimate cancer mortality rates for every US county from 1980 to 2014.

County-level cancer mortality estimates are valuable tools that can be utilized by state and local policymakers and public health leaders to design new programs and refine existing ones. In addition, such data and analyses are useful for clinicians to better understand the needs of their patients and the broader community and in identifying existing and potential cancer hot spots requiring further investigation.

The pattern of changes across counties varies tremendously, thereby raising the question illustrated in Figure 2, “Is the likelihood that I will die of cancer determined by where I live?”

Some cancers’ rates declined in nearly all US counties, such as those for breast, cervical, prostate, testicular, colon and rectum, larynx, lip and oral cancers. However, two cancers, liver cancer and mesothelioma (involving tissue covering several internal organs, such as lungs), increased. For most other types, rates increased in some counties and declined in others. In

Figure 2



Source: Mokdad AH, Dwyer-Lindgren L, Fitzmaurice C, et al. Trends and Patterns of Disparities in Cancer Mortality Among US Counties, 1980-2014. *JAMA* 2017; 317: 388-406.

many instances, responses from the public health and clinical communities depend on mortality evidence to identify drivers of such trends so that they may be addressed.

Table 1

Selected states and stats: breast cancer

State	Deaths per 100,000	County	Deaths per 100,000
Colorado	12	Summit	5*
Illinois	15	Franklin	17
Ohio	16	Mahoning	18
Michigan	14	Wayne	18
Missouri	15	Saline	19
Kentucky	15	Harlan	19
Kansas	14	Wyandotte	20
Pennsylvania	15	Philadelphia	20
Mississippi	17	Madison	29**

*Lowest in nation
 **Highest in nation

Source: Mokdad AH, Dwyer-Lindgren L, Fitzmaurice C, et al. Trends and Patterns of Disparities in Cancer Mortality Among US Counties, 1980-2014. JAMA 2017; 317: 388-406.

Highest breast cancer death rate in the nation:

Madison County, Mississippi

29 deaths per 100,000 people

(state average 17 deaths per 100,000)

Lowest breast cancer death rate in the nation:

Summit County, Colorado

5 deaths per 100,000 people

(state average 12 deaths per 100,000)

Financial costs of treating, living with, and dying from cancer

Issues regarding access to and quality of care, combined with the cost of health care generally, fuel a contentious debate currently among government leaders on the state and federal levels, as well as individuals and organizations representing pharmaceutical and medical device companies, practitioners, insurance companies, and others. All of these stakeholders and others had roles in the \$115 billion spent in the US on cancer in 2013.

In a study by IHME published in JAMA in December of 2016, cancer was one of the top 20 conditions in the US in 2013 that made up more than half the total spending – \$2 trillion – on health care. The most expensive among the nearly 30 types of cancer expenditures reviewed was colon and rectal cancer at nearly \$19 billion, representing a 2% average yearly increase between 1996 and 2013. Of that near \$19 billion, the slight majority, 52%, was spent on inpatient care, as opposed to just under 42% for ambulatory care, 5% on nursing facility care, and 1% each on pharmaceuticals and emergency care. Just over half (55%) of the patients were over age 65.

Table 2: Personal health care spending in the US for cancers, 2013

Rank*	Cause	2013 Spending (billions of US dollars)	Annualized rate of change, 1996-2013 (%)	Ambulatory care (Percent of 2013 spending)
1	Colon and rectum cancers	18.5	2.0%	41.7%
2	Trachea, bronchus, and lung cancers	13.1	2.0%	48.6%
3	Breast cancer	12.1	1.0%	71.1%
4	Other neoplasms	11.6	5.5%	28.9%
5	Non-melanoma skin cancer	8.2	7.1%	96.8%
6	Brain and nervous system cancers	5.7	3.2%	24.4%
7	Uterine cancer	5.6	1.2%	25.1%
8	Prostate cancer	5.4	0.8%	55.2%
9	Stomach cancer	3.9	2.3%	20.6%
10	Leukemia	3.9	2.5%	2.3%
11	Kidney cancer	3	4.3%	30.6%
12	Non-Hodgkin lymphoma	2.9	2.2%	20.1%
13	Bladder cancer	2.8	2.7%	50.7%
14	Pancreatic cancer	2.7	2.5%	28.0%
15	Liver cancer	2.4	6.1%	6.6%
16	Cervical cancer	2.1	-0.6%	39.8%
17	Ovarian cancer	1.5	1.5%	26.2%
18	Malignant skin melanoma	1.3	2.5%	71.6%
19	Gallbladder and biliary tract cancer	1.2	1.6%	25.9%
20	Mouth cancer	1.2	1.2%	30.4%
21	Other pharynx cancer	1.2	3.8%	28.1%
22	Multiple myeloma	0.9	2.9%	0.0%
23	Mesothelioma	0.9	2.9%	11.2%
24	Nasopharynx cancer	0.8	3.9%	43.7%
25	Larynx cancer	0.8	1.5%	20.1%
26	Esophageal cancer	0.7	1.3%	0.0%
27	Thyroid cancer	0.6	3.1%	15.9%
28	Hodgkin lymphoma	0.2	1.1%	0.0%
29	Testicular cancer	0.1	2.8%	19.2%

*Ranked from largest spending to smallest spending. Reported in 2015 US dollars.

Inpatient care (Percent of 2013 spending)	Pharmaceuticals (Percent of 2013 spending)	Emergency care (Percent of 2013 spending)	Nursing facilities care (Percent of 2013 spending)	Ages <20 (Percent of 2013 spending)	Ages ≥65 (Percent of 2013 spending)
52.0%	0.7%	0.6%	5.0%	0.4%	54.5%
46.0%	0.9%	0.5%	4.1%	0.4%	54.5%
23.5%	2.7%	0.0%	2.7%	0.2%	30.5%
69.0%	0.4%	0.0%	1.8%	11.5%	35.9%
2.5%	0.3%	0.0%	0.5%	0.0%	73.6%
65.4%	1.7%	0.0%	8.5%	9.6%	26.9%
71.6%	0.6%	1.3%	1.4%	0.2%	16.2%
35.9%	2.7%	0.5%	5.7%	0.1%	66.4%
60.9%	0.2%	0.2%	18.1%	0.3%	69.7%
94.8%	0.0%	0.0%	2.9%	18.1%	28.5%
67.7%	0.1%	0.0%	1.6%	3.4%	43.0%
76.5%	0.0%	0.0%	3.5%	2.8%	52.9%
45.6%	0.1%	0.0%	3.5%	0.1%	74.0%
65.2%	1.6%	2.2%	3.1%	0.7%	53.0%
61.1%	3.5%	12.5%	16.3%	12.2%	48.3%
40.9%	0.3%	0.1%	18.9%	0.7%	23.2%
69.8%	0.3%	0.0%	3.6%	0.7%	37.9%
26.5%	0.3%	0.0%	1.6%	1.0%	29.6%
67.0%	1.4%	3.3%	2.5%	0.5%	59.7%
65.3%	0.2%	0.0%	4.0%	0.7%	40.4%
24.5%	1.6%	44.0%	1.8%	5.0%	20.6%
94.9%	0.0%	0.0%	5.1%	0.0%	45.3%
74.8%	0.2%	0.9%	12.9%	0.6%	54.1%
21.9%	5.5%	26.2%	2.6%	10.0%	22.6%
71.1%	0.1%	0.0%	8.6%	0.5%	52.1%
91.5%	0.0%	2.6%	5.9%	0.9%	51.3%
81.1%	0.9%	0.0%	2.2%	1.2%	36.1%
97.6%	0.0%	0.0%	2.4%	12.9%	14.4%
77.9%	0.0%	2.1%	0.7%	9.0%	3.3%

Source: Dieleman JL, Baral R, Birger M, et al. US Spending on Personal Health Care and Public Health, 1996-2013. JAMA 2016; 316: 2627-46.

It is widely known that Americans spend more on health care than any other nation. Yet, there are significant disparities in outcomes, as well as in access to and quality of care, including cancer care.

In contrast, the least expensive cancer, testicular cancer, cost \$100 million in 2013, with a near 3% average annual growth between 1996 and 2013. Of that \$100 million, nearly 80% was spent in 2013 on inpatient care, 19% on ambulatory care, 2% on emergency care, and 1% on nursing facility care. About 9% of the patients were under 20 years of age.

Among all cancers, one of the most common, non-melanoma skin cancer, had the highest average annual increase between 1996 and 2013 – 7%. Nearly 100% of the total amount spent in 2015 (\$8 billion) was on ambulatory care, and nearly 74% of the patients treated were 65 years or older.

Overall, health spending is expected to increase by an average of 6% for 2017 through 2019, according to the US Department of Health and Human Services. Looking ahead, the agency forecasts an average growth in costs of 6% between 2020 and 2025. Spending is projected to grow more than 1% faster than the US gross domestic product (GDP) per year, resulting in the health share of GDP exceeding 20% by 2025.

It is widely known that Americans spend more on health care than any other nation. Yet, there are significant disparities in outcomes, as well as in access to and quality of care, including cancer care.

The Institute of Medicine in 2013 published a comprehensive study, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. Among its conclusions was that care is “often not as patient-centered, accessible, coordinated, or evidence-based as it could be.” The study identified several problematic trends:

- The number of older adults is expected to double between 2010 and 2030, contributing to a 30% increase in the number of cancer survivors from 2012 to 2022 and a 45% increase in cancer incidence by 2030.
- Shortages among many professionals involved in providing care are growing, and training programs lack the ability to rapidly expand.
- Care is often fragmented and poorly coordinated, and those administering a substantial amount of direct care often do so with limited training and support.
- Advances in understanding the biology of cancer have increased the volume of information clinicians must master to treat cancer.
- The few tools available for improving the quality of care – metrics, clinical guidelines, and information technology – are not widely used and have serious limitations.

All cancers are treatable, and many patients, through screening, early detection and treatment, become cancer-free. According to the organization Susan G. Komen, the five-year survival rate for women diagnosed with early-stage breast cancer was about 74% in 1980. In 2015, that number was 99%. In contrast, the American Cancer Society states that one-year survival for pancreatic cancer patients is 20%, and five-year survival is only 7%.

Conclusion

In the US, one's socioeconomic status, as well as one's state or even county of residence are determining factors in level and quality of care; in short, a lifeline or a death sentence based on affluence and geography. As leaders on the state and federal levels debate how to increase Americans' access to health care, while maintaining costs – or at least slowing increases in costs – they must consider data on the years of healthy life lost to cancer. Unless and until such discrepancies are addressed, the availability of excellent cancer care throughout the US will remain an elusive ideal.

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