

The Costs of Cancer in the Hispanic/Latino Community

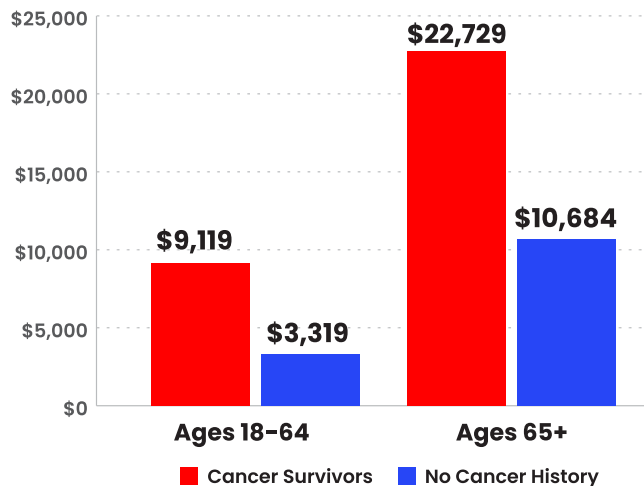


As a leading cause of death and disease in the United States (U.S.), cancer takes a huge toll on the health of patients and survivors, and it also has a great impact on their finances. The costs of cancer do not impact all patients equally. Evidence consistently shows that certain factors – like race/ethnicity, health insurance status, income and where a person lives – impact cancer diagnosis, treatment, survival and financial hardship experienced by people with cancer and their families. This fact sheet explores the costs of cancer in the Hispanic/Latino community, which includes all persons of Hispanic origin including those identifying as Mexican, Puerto Rican, Cuban, Salvadoran and Dominican.

Hispanic/Latino people facing cancer and survivors experience high costs, and are more likely than White counterparts to be uninsured and experience serious financial hardship.

Overall, Hispanic cancer survivors have more than double the health care expenditures as Hispanic individuals who have not been diagnosed with cancer.¹ And it is estimated that the economy loses \$8.8 billion annually because of the lives of working-age Hispanic individuals lost to cancer.²

Annual Average Health Care Expenditures for Hispanic Cancer Survivors, 2018–2019



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018–2019. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-216. July 2022.

The Costs of Cancer in My Own Words

Laura Rodriguez

Oklahoma



When Laura Rodriguez was 10 weeks pregnant in February 2019, she felt pain and a lump in her left breast. She knew that breast tenderness is common during pregnancy, but she could

tell something was wrong and wanted to get it checked out. At the time, Laura was working as a dental assistant and in school to become a respiratory therapist and did not have access to private or employer-sponsored health insurance. Fortunately, Oklahoma offers low-income pregnant women Medicaid coverage, which allowed her to quickly get screened for breast cancer, discovering she had three tumors. Laura’s cancer was aggressive and spreading quickly, and months later she had to have a mastectomy and began the first of four rounds of chemotherapy. All the while she maintained a healthy pregnancy and later gave birth to a healthy baby boy named Jaxson.

One week after giving birth, Laura had to go back to work, and had to shift her focus to her own health. No longer pregnant, she was able to get the full recommended cancer treatment. And because some Oklahomans with breast cancer with low incomes are eligible for Medicaid, she was able to maintain her coverage even after giving birth. By February 2020, she was told that she was cancer-free. The Breast and Cervical Cancer Treatment Program saved her life while keeping her care accessible and affordable.

Cancer's Impact on the Hispanic/Latino Community³

The cancer death rate in the U.S. began declining in 1991 overall, but not until the late 1990s among Hispanic people. Trends in cancer rates among Hispanic people in the U.S. are difficult to interpret because cancer risk in recent immigrants differs substantially from established residents and patterns in immigration frequently shift.

About 1 in 3

Hispanic men and women will be diagnosed with cancer in their lifetime, and **1 in 5 men** and **1 in 7 women** will die from the disease.



- ▶ In 2021, there were projected to be 80,200 new cancer cases diagnosed in Hispanic men and 96,400 cases in Hispanic women. Similar to the U.S. population overall, prostate and breast cancers were the most common cancers in Hispanic men and women, respectively.
- ▶ Cancer is the leading cause of death among Hispanic people in the U.S., accounting for 20% of deaths.
- ▶ While Hispanic men and women are less likely than non-Hispanic Whites to be diagnosed with the most common cancers (lung, colorectal, breast and prostate), they have a higher risk for cancers associated with infectious agents, such as liver, stomach and cervix.

“

My Medicaid coverage left me cancer-free and debt-free. I know some people have large bills. For instance, I got a peek into what a single lifesaving chemotherapy treatment could have cost me when I was mistakenly billed \$10,000. I have been very fortunate. Affordable health care means consistency in care, not just for me but my family. While I was receiving my cancer surgeries and treatment, my children were dealing with the fear of losing their mother and fortunately were able to access individual and family therapy as well. Medicaid was there for my children, too.

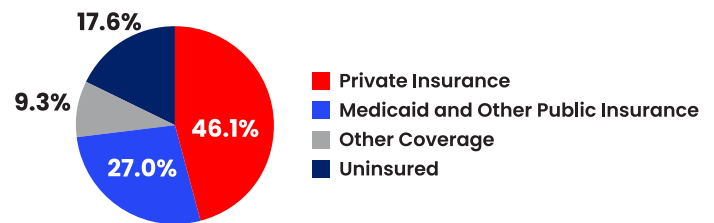
LAURA RODRIGUEZ, OKLAHOMA

Health Insurance Coverage in the Hispanic/Latino Community

The details of an individual's health insurance coverage – or lack thereof – have a huge impact on what costs that person pays for treating their cancer.

- ▶ Patients who are uninsured can be responsible for all of their treatment costs, which can be very large sums of money. In 2012-2014, 13% of Hispanic individuals newly diagnosed with cancer were uninsured – compared to only 3% of non-Hispanic Whites.⁴
- ▶ For Hispanic people who are insured, the type and details of their insurance coverage are an important determinant of their out-of-pocket costs. More than half of Hispanic individuals with a history of cancer, ages 18-64, do not have private insurance.

Insurance Type, Hispanic Individuals with a History of Cancer, Ages 18-64



Source: National Center for Health Statistics: National Health Interview Survey, 2019-2020. Public-use data file and documentation. Retrieved from: <https://www.cdc.gov/nchs/nhis/2020nhis.htm>, July 2022.

- ▶ More and more individuals are enrolled in high-deductible health plans (HDHPs), despite their high upfront costs for patients and mounting evidence that these plans cause patients to delay important cancer care and have worse cancer outcomes.^{5,6,7} More than 38% of privately insured Hispanic cancer survivors have an HDHP.⁸

What Hispanic/Latino People with Cancer & Survivors Pay Out-of-Pocket for Care

Cancer treatment is often complex, involves many services and is expensive. Research consistently shows that individuals who have been diagnosed with cancer have higher out-of-pocket costs than those without a cancer history.⁹ These increased costs often continue even years after the patient has finished active cancer treatment.

- ▶ The median annual household income for Hispanic individuals in the U.S. in 2020 was \$55,321, which is only 73% of the annual income for non-Hispanic White individuals, and also lower than the overall median of \$67,521.¹⁰
- ▶ Younger Hispanic people with a cancer history spend an average of \$616 every year on out-of-pocket medical expenses (which does not include monthly health insurance premiums).¹¹ Older Hispanic people with a cancer history spend almost twice as much (\$1,131) on out-of-pocket medical expenses.¹²

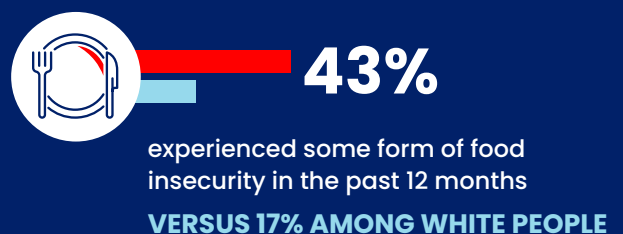
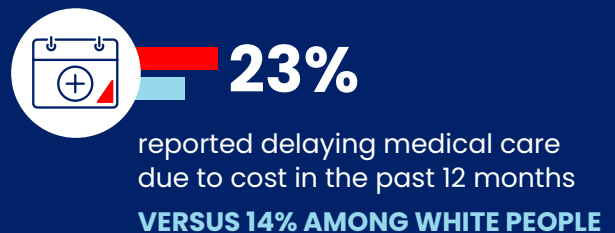
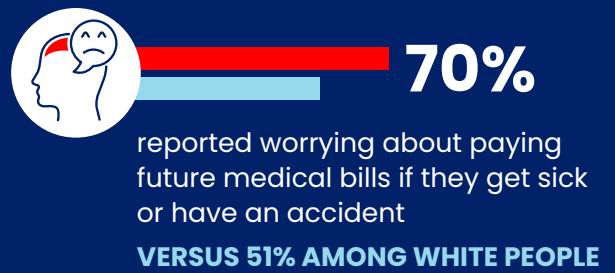
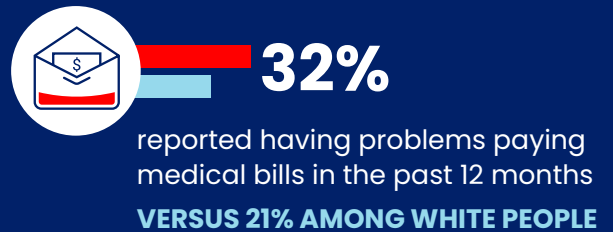
Average Annual Out-of-Pocket Expenses, Hispanic Individuals, 2018-2019



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018-2019. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-216. July 2022.

The Impacts of the Costs of Cancer on Hispanic/Latino Communities

The high costs of cancer have many adverse impacts. Research shows that among Hispanic individuals ages 18-64 with a history of cancer:¹³



ACS CAN Supports Policies That Will Reduce the Costs of Cancer in Hispanic/Latino Communities

The American Cancer Society Cancer Action Network (ACS CAN) wants to make sure that everyone has a fair and just opportunity to prevent, detect, treat and survive cancer. To reduce the costs of cancer in Hispanic/Latino communities, ACS CAN supports:

► Providing adequate and fair funding for Medicaid programs in the U.S. Territories.

Currently, Medicaid funding in the U.S. Territories (Puerto Rico, Virgin Islands, Guam, the Northern Mariana Islands and American Samoa) is capped, and is consistently too low to provide real access to care for the number of residents who qualify. ACS CAN strongly supports permanently eliminating Medicaid funding limitations for the territories and providing parity in payments for them. ACS CAN also supports efforts to make sure territories are not punished for providing treatment services for women served in the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).

► **Expanding Medicaid in the 12 remaining states that have not done so.** The health coverage provided by Medicaid helps to improve outcomes and reduce the burden of cancer by offering access to prevention services and timely cancer screening and early detection services, as well as affordable treatment services and care. In 12 states, there are more than 2.2 million people who should be able to see a doctor but cannot. They don't qualify for Medicaid, but also don't fall into the income bracket that allows them to receive marketplace subsidies. This is the Medicaid coverage gap – 60% of these uninsured individuals are people of color, and the vast majority live in the American South, which includes a large Black/African American population. All states should expand Medicaid, and Congress must close the coverage gap for lower-income Americans who live in states that have failed to expand.

► Increasing funding for lifesaving cancer screening programs, including the NBCCEDP. Hispanic women have the highest incidence rate of cervical cancer.

The NBCCEDP provides timely access to breast and cervical cancer screening and diagnostic services to low-income,

In Their Own Words: Experience with Costs and Debt

The American Cancer Society Cancer Action Network (ACS CAN) gives voice to people with cancer and survivors on critical public policy issues that affect their lives. In February 2022 we conducted a survey of cancer survivors on cost and debt issues. Hispanic cancer survivors told us they had problems affording treatment, dealing with worry and anxiety and medical debt.¹⁴

Problems affording treatment

It was difficult to afford my health care expenses.

32%

The cost of a treatment influences whether I get a treatment that my health care provider recommends.

46%

I delayed or did not pay other household expenses (like utility bills) to use the money for health care costs instead.

16%

Medical debt

I have current or past medical debt associated with my cancer care.

71%

► I have been contacted by a collections agency about debt related to my cancer care.

67%*

► I declared bankruptcy due to health care costs or debts.

9%*

**Note: This is the percentage of survey respondents who indicated they have current or past medical debt.*

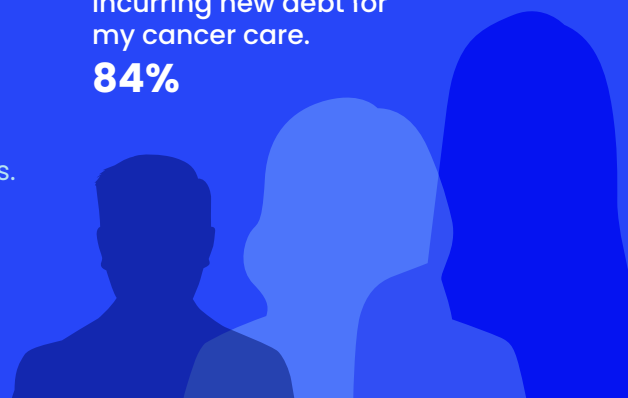
Worry and anxiety

I am concerned about my ability to pay for current or future health care costs related to my cancer.

85%

I am concerned about incurring new debt for my cancer care.

84%



uninsured and underinsured women in all 50 states, the District of Columbia, 6 U.S. territories and 13 tribes. Additionally, it uses population-based approaches, such as public education, outreach, patient navigation and care coordination, to increase screening and reach underserved populations. ACS CAN urges Congress to adequately fund the CDC's cancer programs, including the NBCCEDP.

▶ **Expanding access to care, including for those who are undocumented.** In 2019, there were 21.3 million noncitizens in the U.S., and more than 4 in 10 (46%) undocumented immigrants were uninsured. A critical factor for eliminating disparities and ensuring health equity is to guarantee that all individuals have access to affordable coverage, regardless of immigration status. Access to care for those who are undocumented can also lessen the burden on the health care system. By ensuring that everyone has access to care, serious diseases like cancer can be detected and treated earlier – often resulting in better outcomes and less costs to the system. At the federal level, ACS CAN supports the Health Equity and Accountability Act (HEAA) and its focus on health inequalities, societal injustices and their intersection with immigration status, age, disability, sex, gender, sexual orientation and socioeconomic status. ACS CAN urges Congress to pass this legislation.

▶ **Ensuring working people with cancer, survivors and caregivers have paid leave.** Cancer treatment is time consuming – often requiring time off from work for doctor's visits, surgery and recovery, chemotherapy and radiation. The flexibility to balance cancer treatment and employment is essential. Studies show that people with cancer who have paid leave have higher rates of job retention and lower rates of financial burden.^{15,16} Yet not all people facing cancer, survivors and caregivers who work have access to paid leave, and without it they risk losing employment or not getting the care they need. ACS CAN supports policies at the national, state and local levels that increase access to job-protected paid family and medical leave that can be used for cancer treatments, survivorship care and caregiving, as well as other illnesses.

According to data from the 2011 and 2017–2018 American Time Use Survey, researchers found paid family and medical leave racial inequities across industries and employment contexts – with Hispanic workers 23.4% less likely to report access to paid family and medical leave than White workers.¹⁷

▶ **Addressing patient costs to diversify participation in clinical trials.** While patient willingness to enroll in clinical trials is high, some people with cancer decline due to costs. They are frequently responsible for non-medical costs such as transportation and lodging associated with trial enrollment. These costs can occur when no local trials are available and patients have to travel to distant trial sites, or when there is a need for more frequent clinic visits for additional trial-related treatment or monitoring. The additional costs can lead to unequal participation rates between high- and limited-income people facing cancer and the patients most impacted tend to be those traditionally underrepresented. To address this issue, the DIVERSE Trials Act would allow clinical trial sponsors to provide financial support to trial participants and the technology needed to participate in trials remotely. Offering to reimburse patients for non-medical costs associated with trials can increase overall enrollment and thereby help make it less costly for patients to access innovative therapies through clinical trials during their cancer treatment. The bill also further requires the FDA to issue guidance on the use of decentralized trial tools to address disparities in clinical trial participation. This guidance would help make participation in clinical trials easier for patients by reducing or removing the need to travel to specific trial sites.

▶ **Ensuring complete and timely collection and publication of demographic data that help identify disparities.** Ensuring detailed race and ethnicity data are available, as well as accurate, objective and impartial, is critical to evidence-based health equity work. ACS CAN supports funding and policies to promote timely collection and publication of demographic data that aid researchers and policymakers in identifying disparities to improve health equity in cancer prevention, detection and treatment. Separating out racial and ethnic information on certain groups would be helpful to target cancer prevention and control efforts – potentially helping health systems develop screening measures and prevention programs that would better identify diagnoses at earlier stages when less invasive and less costly treatment options are available to patients. Adding subgroups to the required minimum reporting categories can provide opportunities for improved reporting of information pertaining to the health of the nation's diverse population.

► **Improving access to and ensuring long-term sustainable payment of patient navigation services.** Patient navigation has become increasingly recognized for improving patient outcomes, reducing unnecessary treatment costs and increasing patient satisfaction. However, patient navigation is still absent or limited in many cancer programs and hospital settings due to cost concerns and a lack of long-term funding to pay for these services. Instead, patient navigation programs are often financed via short-term funding like private or governmental

grants. ACS CAN supports and advocates to improve health equity by increasing access to quality cancer care among communities that have been under-resourced by extending the reach of navigation services. The expansion and sustainability of patient navigation services will only be achieved by ensuring that these services can be paid for the long term, thereby ensuring everyone everywhere will have access to the patient navigation services needed to ensure better patient experience and outcome due to a cancer diagnosis.

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About ACS CAN

The American Cancer Society Cancer Action Network (ACS CAN) makes cancer a top priority for policymakers at every level of government. ACS CAN empowers volunteers across the country to make their voices heard to influence evidence-based public policy change that improves the lives of people with cancer and their families. We believe everyone should have a fair and just opportunity to prevent, find, treat, and survive cancer. Since 2001, as the American Cancer Society’s nonprofit, nonpartisan advocacy affiliate, ACS CAN has successfully advocated for billions of dollars in cancer research funding, expanded access to quality affordable health care, and advanced proven tobacco control measures. We’re more determined than ever to stand together with our volunteers to end cancer as we know it, for everyone.

Join the fight by visiting www.fightcancer.org.