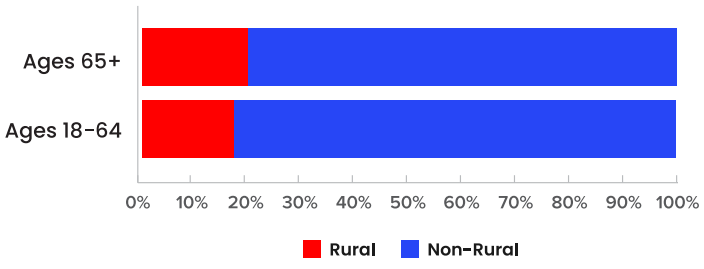
The Costs of Cancer in Rural Communities

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 rural communities. Rural is defined by the 2013 NCHS Urban-Rural Classification Scheme for Counties as large fringe metro, medium and small metro and nonmetropolitan classified.

People facing cancer and survivors who live in rural communities are more likely to have limited incomes and to die from cancer than their urban counterparts. They also experience serious financial hardship.

According to the National Health Interview Survey, just under 20% of individuals with a history of cancer lived in rural areas in the U.S. in 2019-2020.[1]

Rurality of Individuals with a Cancer History



The Costs of Cancer in My Own Words

Sarah Graves

South Dakota

At age 28, Sarah Graves had just gotten married and was helping her new husband build his construction business. Sarah also worked part time and cared for her young daughter. She and her husband chose to forego health insurance because the additional expense would have been a strain on their budget.

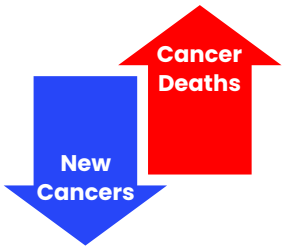
Less than two months after getting married, Sarah was diagnosed with chronic myeloid leukemia. She was hospitalized almost immediately, and her first bill was just over$70,000. Her husband eventually had to shut down his own business and started working for a private construction company with hopes of signing up his family for health insurance. However, because his position was classified as seasonal he wasn't eligible for health insurance benefits. Soon Sarah learned that she needed a lifesaving bone marrow transplant. In order to qualify for the transplant procedure, She had to have health insurance for at least one year. Otherwise, the $1 million procedure would have been out of reach, and all expenses would have been out of pocket. Sarah ended up taking on a full-time job so she could get health insurance benefits. She worked as much as she could while receiving treatment and taking a daily chemotherapy pill.

Sarah's cancer recently returned, and Sarah learned that her husband was diagnosed with a brain tumor. Between Sarah and her husband, they are $800,000 in medical debt and are currently filing for bankruptcy. She now works full time as a receptionist for a health care clinic and shares resources with patients also struggling to afford care.

Cancer's Impact on Rural Communities

Progress in reducing death for some cancers has been slower in rural communities compared with urban areas, resulting in increasing rural-urban disparities.[2]

- Rural areas have lower rates of new cancer cases compared to urban areas, but the cancer death rate in rural areas is higher.[3,4]



- The disparity in rural cancer death rates is especially visible for cancers that have effective programs for prevention, early detection and treatment: lung, cervical, colorectal and prostate.[5]

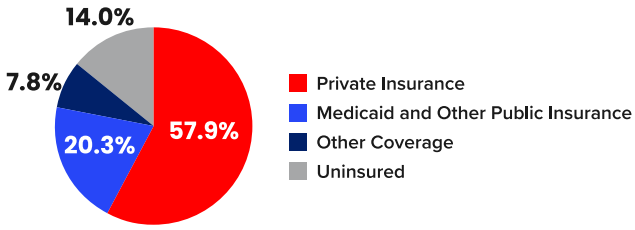
> "I am paying down my medical debt now, but you definitely have to make some sacrifices. You don't get to afford the extra things in life – your extra things are that debt. When I look at my bills, there's no end in sight. My advice to other patients is, do your research, because there are programs that help. Be prepared, because those bills are going to take your breath away. Mentally prepare yourself, and just know you're doing what you can.
>
> **SARAH GRAVES, SOUTH DAKOTA**

Health Insurance Coverage in Rural Communities

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, 4.7% of individuals ages 18-64 living in a nonmetro area newly diagnosed with cancer were uninsured.[6]
- For those individuals in rural communities who are insured, the type and details of their insurance coverage can be an important determinant of their out-of-pocket costs. The majority of rural residents with a history of cancer, ages 18-64, have private insurance.
- More and more individuals are enrolled in high-deductible health plans (HDHPs), despite their high upfront costs and mounting evidence that these plans cause patients to delay important cancer care and have worse cancer outcomes.[7,8,9] More than 43% of privately insured cancer survivors living in rural communities have an HDHP.[10]

Insurance Type, Cancer Survivors Living in Rural Areas, Ages 18-64



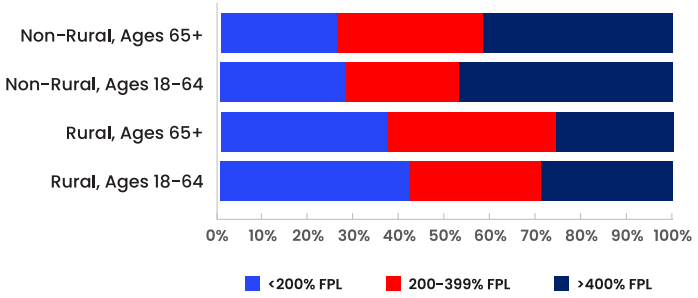
Source: National Center for Health Statistics: National Health Interview Survey, 2019-2020. Public-use data file and documentation. Retrieved from: https://www.cdc.gov/nchs/nhis/2020nhis.htm. July 2022.

Income Levels of Rural People with Cancer & Survivors

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.[11] These increased costs often continue even years after the patient has finished active cancer treatment. This is why income levels of a person facing cancer/survivor are an important factor in their ability to afford treatment.

- The average per-capita income for individuals living in rural areas in the U.S. in 2020 was $45,917, which was lower than the average per-capita income for urban areas ($61,717).[12]
- Cancer survivors who live in rural communities are significantly more likely to have lower incomes than non-rural cancer survivors.[13]

Income Levels, Individuals with a History of Cancer by Rurality



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.

ACS CAN Supports Policies That Will Reduce the Costs of Cancer in Rural 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 rural communities, ACS CAN supports:

- **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.

The Impacts of the Costs of Cancer on Rural Communities

The high costs of cancer have many effects on people with cancer and survivors. Research shows that among individuals living in rural communities ages 18-64 with a history of cancer:[14]

26.2%

reported having problems paying medical bills in the past 12 months

VERSUS 17.8% AMONG INDIVIDUALS WITHOUT A HISTORY OF CANCER

59.5%

reported worrying about paying future medical bills if they get sick or have an accident

VERSUS 50.8% AMONG INDIVIDUALS WITHOUT A HISTORY OF CANCER

17.4%

reported skipping, taking less, delaying or not getting a medication due to cost in the past 12 months

VERSUS 10.3% AMONG INDIVIDUALS WITHOUT A HISTORY OF CANCER

18%

reported delaying medical care due to cost in the past 12 months

43%

experienced some level of food insecurity in the past 12 months

- **Limiting the sale of noncomprehensive insurance plans.** Farm Bureau plans often exclude important benefits, require high out-of-pocket costs and in general provide severely inadequate coverage. However, their cheaper premiums often attract enrollees that are unaware they are enrolling in a noncomprehensive plan. ACS CAN urges policymakers to consider prohibiting or limiting the availability of these and other non-ACA compliant plans, or requiring these plans to follow ACA rules.

- **Increasing access to quality cancer care for marginalized people through telehealth services and telemedicine.** Telehealth provides people with cancer and survivors with a convenient means of accessing preventive, primary and cancer care – particularly important option for individuals who have been under-resourced, including residents of rural communities. ACS CAN supports legislation that makes it easier for patients to have long-term access to appropriate telehealth services, including bringing broadband technology to rural areas.

- **Addressing patient costs to diversify participation in clinical trials.** While patient willingness to enroll in clinical trials is high, some people with cancer decline to participate 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 low-income people with 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 people with cancer for non-medical costs associated with trials can increase overall enrollment and thereby help make it less costly for them 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.

  The DIVERSE Trials Act would particularly benefit rural communities because trial sponsors could provide patients with the technology necessary to facilitate remote participation in clinical trials.

- **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.

References

1 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.

2 Moy E, Garcia MC, Bastian B, et al: Leading causes of death in nonmetropolitan and metropolitan areas: United States, 1999-2014. MMWR Surveill Summ 66:1-8, 2017.

3 Blake KD, Moss JL, Gaysynsky A, et al: Making the case for investment in rural cancer control: An analysis of rural cancer incidence, mortality, and funding trends. Cancer Epidemiol Biomarkers Prev 26:992-997, 2017.

4 Moy E, Garcia MC, Bastian B, et al: Leading causes of death in nonmetropolitan and metropolitan areas: United States, 1999-2014. MMWR Surveill Summ 66:1-8, 2017.

5 Henley SJ, Jemal A: Rural cancer control: Bridging the chasm in geographic health inequity. Cancer Epidemiol Biomarkers Prev 27:1248-1251, 2018.

6 Mallin K, Browner A, Palis B, et al: Incident cases captured in the national cancer database compared with those in U.S. Population based central cancer registries in 2012-2014. Ann Surg Oncol 26:1604-1612, 2019.

7 Zheng, S; Ren, ZJ; Heineke, J; Geissler, KH. Reductions in Diagnostic Imaging with High Deductible Health Plans. Medical Care. February 2016 - Volume 54 - Issue 2 - p 110–117. doi: 10.1097/MLR.0000000000000472.

8 Zheng Z, Jemal A, Banegas MP, Han X, Yabroff KR. High-Deductible Health Plans and Cancer Survivorship: What Is the Association With Access to Care and Hospital Emergency Department Use?. J Oncol Pract. 2019 Aug 8;:JOP1800699. doi: 10.1200/JOP.18.00699. [Epub ahead of print] PubMed PMID: 31393809.

9 Wharam JF et al. Vulnerable And Less Vulnerable Women In High-Deductible Health Plans Experienced Delayed Breast Cancer Care. March 2019. Health Affairs. https://doi.org/10.1377/hlthaff.2018.05026.

10 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.

11 Ekwueme DU, Zhao J, Rim SH, de Moor JS, Zheng Z, Khushalani JS, Han X, Kent EE, Yabroff KR. Annual Out-of-Pocket Expenditures and Financial Hardship Among Cancer Survivors Aged 18-64 Years - United States, 2011-2016. MMWR Morb Mortal Wkly Rep. 2019 Jun 7;68(22):494-499. doi: 10.15585/mmwr.mm6822a2. PMID: 31170127; PMCID: PMC6553808.

12 U.S. Department of Agriculture, Economic Research Service. State Fact Sheets: United States. Income. Data updated June 3, 2022. https://data.ers.usda.gov/reports.aspx?ID=17854.

13 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.

14 Note that all differences between populations presented in this graphic are statistically significant. Source for all data in this section: 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.

Support for this project was provided by Bristol Myers Squib.

American Cancer Society Cancer Action Network

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.**