

# The Costs of Cancer in the Black Community

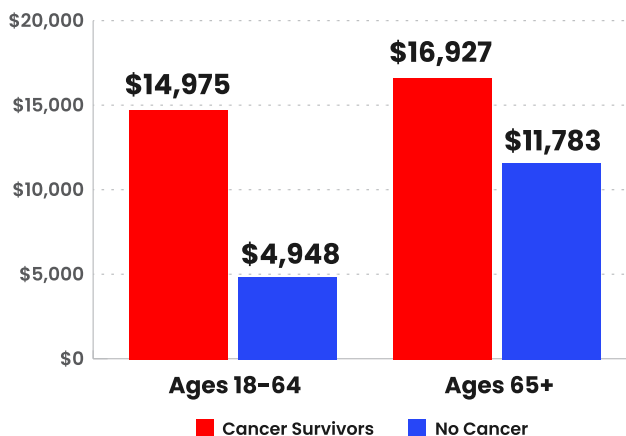


As a leading cause of death and disease in the United States (U.S.), cancer takes a huge toll on the health of patients and survivors, and it also has a great impact on their finances. The costs of cancer do not impact all patients equally. Evidence consistently shows that certain factors – like race/ethnicity, health insurance status, income and where a person lives – impact cancer diagnosis, treatment, survival and financial hardship experienced by people facing cancer and their families. This fact sheet explores the costs of cancer in the Black community, which includes those identifying as Black or African American – descendants of individuals brought to the U.S. as slaves, as well as recent immigrants mostly of African or Caribbean descent.<sup>1</sup>

**Black people with cancer and survivors have high health care costs and experience considerable financial hardship. National surveys also show that Black people are more likely to have medical debt and experience aggressive debt collection practices.<sup>2</sup>**

Overall, Black cancer survivors have significantly more health care expenditures, or costs, than Black individuals who have not been diagnosed with cancer.<sup>3</sup> And it is estimated that the economy loses \$14.2 billion annually because of the lives of working-age Black people lost to cancer.<sup>4</sup>

## Annual Average Health Care Expenditures for Black Individuals

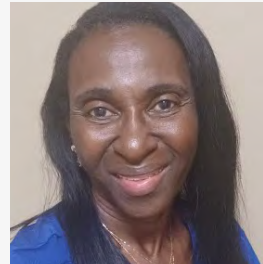


Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018-2019. Public-use data file and documentation. Retrieved from: [https://meps.ahrq.gov/data\\_stats/download\\_data\\_files\\_detail.jsp?cboPufNumber=HC-216](https://meps.ahrq.gov/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-216). July 2022.

## The Costs of Cancer in My Own Words

### Barbara Bowers

Tallahassee, Florida



Barbara Bowers started treatment for her breast cancer in 2008 in Tallahassee, Florida. Before her cancer diagnosis, Barbara was healthy, exercised, ate right and got her

regular mammograms – but then her cancer treatment turned her life upside down. Now, as a cancer survivor, Barbara shares how she wishes she'd had more resources to help her navigate the costly and bumpy road of her cancer journey.

Barbara filed for bankruptcy in 2014 and still owes about \$38,000 from her cancer treatment. Her treatment involved two surgeries, chemotherapy, radiation and a blood transfusion. Barbara had health insurance coverage with a \$20,000 deductible and additional copays from her surgeon and oncologist, as well as radiation and medication costs. For the first time in her life, she got behind on her rent, utilities and other bills. Today Barbara's still paying off her medical debt to clear up her credit score so that she can purchase a house or a car. Her medical debt has significantly impacted her credit score and has resulted in calls from collection agencies, as well as her being denied credit cards due to the bankruptcy.

## Cancer's Impact on the Black Community<sup>5</sup>

According to the American Cancer Society, Black people have the highest death rates and shortest survival rates of any racial/ethnic group in the U.S. for most cancers. In most cases, Black people are more likely than White people to be diagnosed with an advanced stage of cancer, when treatment is usually more extensive and less successful.

### About 1 in 3

Black men and women will be diagnosed with cancer in their lifetime, and **1 in 5 Black men and 1 in 6 Black women will die from the disease.**



- ▶ In 2022, there are projected to be 111,990 new cancer cases diagnosed in Black men and 112,090 cases in Black women. Similar to the U.S. population overall, prostate and breast cancers are the most common cancers in Black men and women, respectively.
- ▶ Cancer is the second-leading cause of death among Black people in the U.S., accounting for 20% of deaths.
- ▶ Black women have 8% lower cancer incidence than White women, but 12% higher cancer mortality.
- ▶ Black people have lower five-year cancer survival rates than White people (63% versus 68%) overall and for each stage of diagnosis for most cancer sites.

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Because of the debt from my cancer treatment, I can't move forward. I feel like I'm standing still in time, but the years keep moving forward. I have a lot of shame from getting cancer and having to file for bankruptcy. I feel like I did all the right things and still got breast cancer. The debt compounds the shame. I was never in debt before I got cancer, but once I started treatment I didn't have the money to pay the bills. Yet, I needed the treatment. The issues and problems associated with my breast cancer have left a heavy burden on my shoulders.

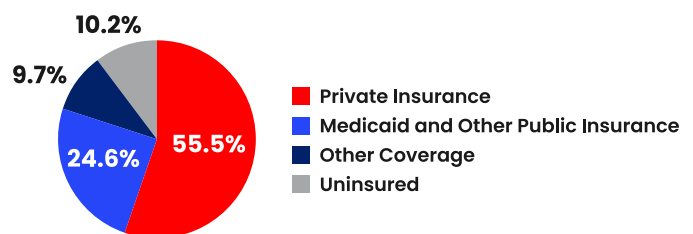
**BARBARA BOWERS, FLORIDA**

## Health Insurance Coverage in the Black 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 without insurance are responsible for all of their treatment costs, which can be very large sums of money. In 2012-2014, 5.8% of Black individuals ages 18-64 newly diagnosed with cancer were uninsured – compared to only 3% of non-Hispanic whites.<sup>6</sup>
- ▶ For Black people who are insured, the type and details of their insurance coverage can determine a great deal of their costs. The majority of Black people with a history of cancer, ages 18-64, have private insurance.

### Insurance Type, Black 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 people are enrolled in high-deductible health plans (HDHPs), despite their high upfront costs for patients and mounting proof that these plans cause patients to delay important cancer care and have worse cancer outcomes.<sup>7,8,9</sup> More than 56% of privately insured Black cancer survivors have an HDHP.<sup>10</sup>

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If I'd gotten diagnosed later and had a different marketplace plan, debt would have been a greater concern. I can't help but think of the thousands of people in North Carolina without health care coverage. People who may be walking around with undetected cancers just like I did. This is why expanding Medicaid is so crucial. It would help people who work really hard but still can't afford private insurance. Yet they make too much to qualify for Medicaid. I know from personal experience that expanding access to health care could mean the difference between life and death for so many people in North Carolina. I'm alive because I was able to get coverage when I did. It's that simple. We must expand Medicaid in North Carolina.

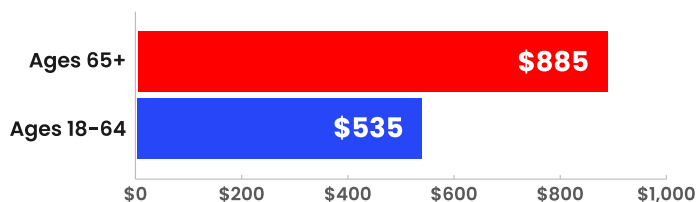
**DONNAMARIE WOODSON, NORTH CAROLINA**

## What Black 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.<sup>11</sup> These increased costs often continue even years after the patient has finished active cancer treatment.

- ▶ The median annual household income for Black individuals in the U.S. in 2020 was \$45,870, which is only 61% of the median income for non-Hispanic whites, and is also lower than the overall median of \$67,521.<sup>12</sup>
- ▶ Younger Black people with a cancer history spend an average of \$535 every year on out-of-pocket medical expenses (which does not include monthly health insurance premiums).<sup>13</sup> Older Black people with a cancer history spend \$885 on out-of-pocket medical costs.<sup>14</sup>

## Average Annual Out-of-Pocket Expenses, Black Cancer Survivors



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](https://meps.ahrq.gov/data_stats/download_data_files_detail.jsp?cboPufNumber=HC-216). July 2022.

## The Costs of Cancer in My Own Words

### Donnamarie Woodson

North Carolina



DonnaMarie Woodson is a seven-year colon and breast cancer survivor living in North Carolina, which is one of the 12 states that has not yet expanded Medicaid.

DonnaMarie had been without health care coverage for several years and had fallen behind in her preventive screenings. In 2015, when Affordable Care Act plans became available, she qualified for a marketplace insurance plan and was finally able to schedule a colonoscopy. It was during that colonoscopy that DonnaMarie discovered she had stage 3 colon cancer that required immediate surgery. During her prep for surgery, it was also discovered that she had stage 1 breast cancer.

Fortunately, DonnaMarie's cancer treatments for both cancers were successful. But if she hadn't gotten insurance coverage when she did, that might not have been the case as she could not have the colonoscopy without it. After her cancer care, DonnaMarie did have some medical debt, but was fortunate enough to be able to make payment arrangements and not have to declare bankruptcy.

## ACS CAN Supports Policies That Will Reduce the Costs of Cancer in the Black Community

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 the Black community, 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.
- ▶ **Eliminating coverage and cost barriers to comprehensive, lifesaving cancer screening services.** Non-Hispanic Black individuals have the highest incidence and death rates for colorectal cancer (CRC).<sup>16</sup> About half of the racial disparity in CRC death rates is attributed to a combination of less screening and lower state-specific survival among Black individuals. ACS CAN supports policies that ensure all patients, regardless of their insurance coverage, have no cost barriers to comprehensive screening services.
- ▶ **Increasing prostate cancer screening for high-risk individuals.** Black men in the U.S. and Caribbean have the highest documented prostate cancer incidence rates in the world. They are over twice as likely to die from prostate cancer and are more likely to be diagnosed at an advanced stage compared to non-Hispanic White men. ACS CAN supports federal research efforts to identify better early detection tools for prostate cancer, especially tools that can differentiate between latent and aggressive forms of prostate cancer.

## The Impacts of the Costs of Cancer on the Black Community

The high costs of cancer have many adverse impacts. Research shows that among Black people ages 18-64 with a history of cancer:<sup>15</sup>



**30%**

reported having problems paying medical bills in the past 12 months

- ▶ **THIS IS SIGNIFICANTLY HIGHER THAN THE PERCENTAGE AMONG WHITE PEOPLE (21%)**



**53%**

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



**17%**

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



**12%**

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



**28%**

experienced some level of food insecurity in the past 12 months

► **Increasing funding for lifesaving cancer screening programs, including the NBCCEDP.** In a major shift, breast cancer has surpassed lung cancer as the leading cause of cancer death among Black women as of 2019.<sup>17</sup> The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides timely access to breast and cervical cancer screening and diagnostic services to low-income, 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.

► **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 facing cancer who have paid leave have higher rates of job retention and lower rates of financial burden.<sup>18,19</sup> 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.

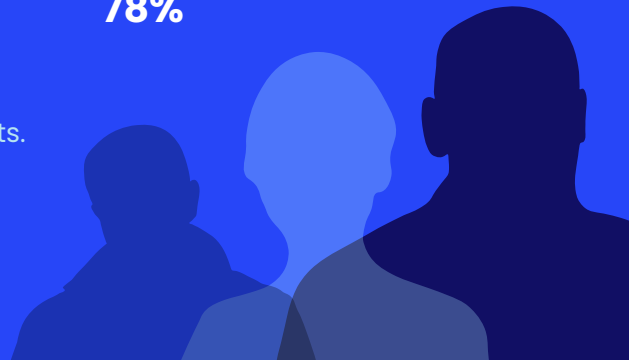
According to data from the 2011 and 2017–2018 American Time Use Survey, researchers found paid family and medical leave (PFML) racial inequities across industries and employment contexts – with Black/African American workers 12.7% less likely to report access to PFML than White workers.<sup>20</sup> Research also shows that Black households carry medical debt disproportionately compared to other groups with 1 in 3 Black adults having past-due medical bills, compared to fewer than 1 in 4 White adults.<sup>21</sup>

## 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. Black cancer survivors told us they had problems affording treatment, dealing with worry and anxiety, and medical debt.<sup>22</sup>

Problems affording treatment	Medical debt	Worry and anxiety
<p>It was difficult to afford my health care expenses.</p> <p><b>36%</b></p> <p>The cost of a treatment influences whether I get a treatment that my health care provider recommends.</p> <p><b>56%</b></p> <p>I delayed or did not pay other household expenses (like utility bills) to use the money for health care costs instead.</p> <p><b>19%</b></p>	<p>I have current or past medical debt associated with my cancer care.</p> <p><b>58%</b></p> <ul style="list-style-type: none"> <li>► I have been contacted by a collections agency about debt related to my cancer care.</li> </ul> <p><b>56%*</b></p> <ul style="list-style-type: none"> <li>► I declared bankruptcy due to health care costs or debts.</li> </ul> <p><b>7%*</b></p>	<p>I am concerned about my ability to pay for current or future health care costs related to my cancer.</p> <p><b>80%</b></p> <p>I am concerned about incurring new debt for my cancer care.</p> <p><b>78%</b></p>

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



- ▶ **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 limited-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 patients 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.
- ▶ **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.
- ▶ **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.



## References

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Support for this project was provided by Bristol Myers Squibb.



### 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](http://www.fightcancer.org).**