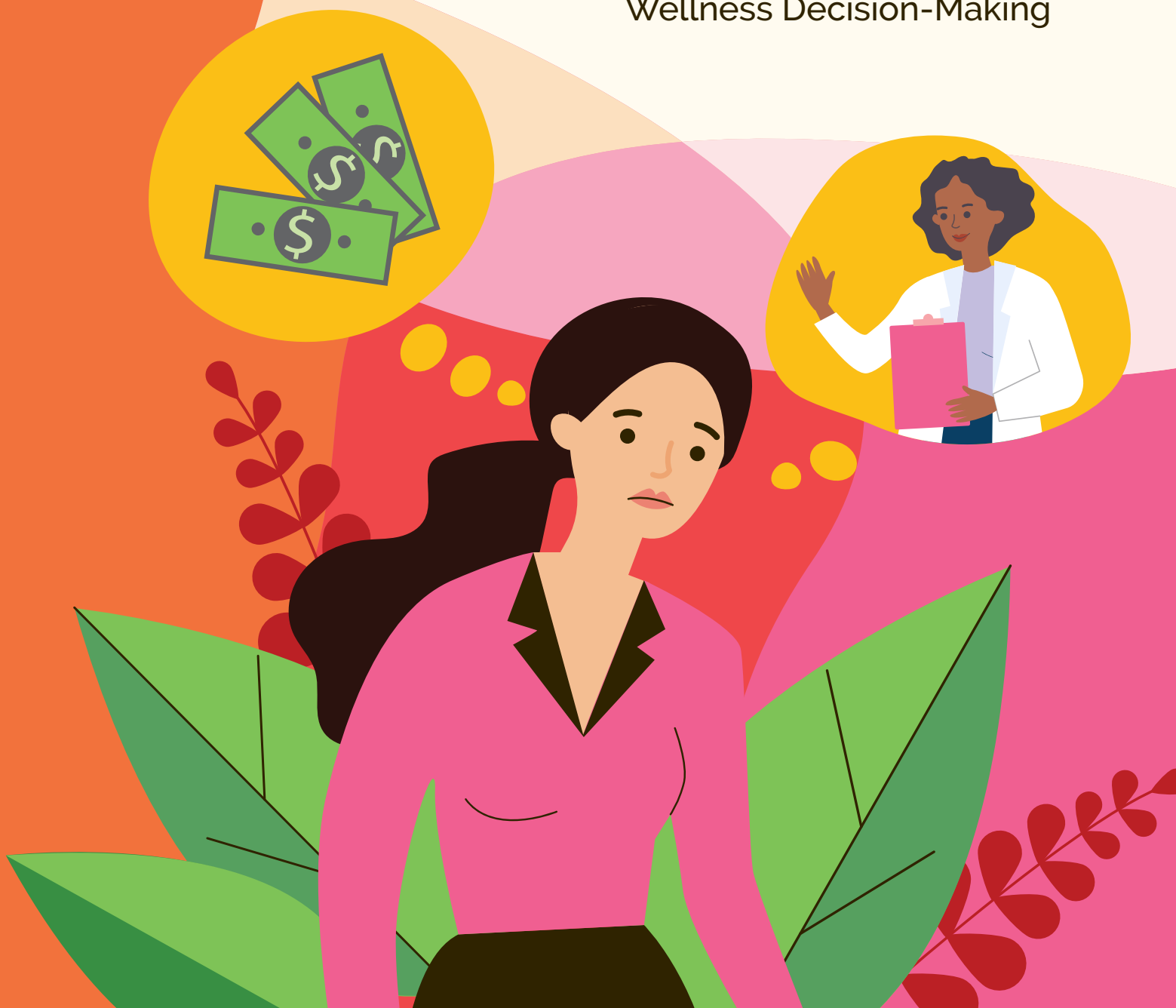


The Cost of Cancer:

The Impact of Cancer-Related
Financial Burdens on Health and
Wellness Decision-Making



A Collaboration Between HealthyWomen and CancerCare

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Executive Summary

A new cancer diagnosis strikes nearly two million Americans each year. Though cancer remains the second leading cause of death in the United States, screening, prevention and treatments have improved, and mortality rates from many types of cancer have dropped.¹ This means that more people are living with cancer.

Along with improved survival rates, though, is an unwelcome side effect: financial toxicity. Also referred to as "economic burden" and "financial hardship," the National Institutes of Health's National Cancer Institute has defined "financial toxicity" as "a term used to describe problems a patient has [that are] related to the cost of medical care," including debt and bankruptcy.²

Facing a cancer diagnosis, many cannot afford to focus solely on their health; they must also confront the direct and indirect financial costs associated with their diagnosis. These costs create true financial hardship and emotional burdens for cancer patients, survivors and caregivers. In fact, the National Cancer Institute has stated that cancer patients are more likely to face financial toxicity than individuals without cancer.³

In collaboration with CancerCare, HealthyWomen sought to understand the impact of costs on cancer patients, survivors and caregivers and to examine how cost burdens may disproportionately affect women and people of color in the United States. By quantifying consumers' experiences with the financial aspects of cancer care, we hope to raise awareness that cancer costs add economic and psychological burdens to the more obvious physical burdens of cancer on patients and caregivers.

To that end, we conducted a nationally representative survey between September 4 and 18, 2020, with 1,012 respondents that included patients currently with an active cancer diagnosis, patients in remission for less than five years, survivors (defined as those who have been in remission for five or more years), and unpaid caregivers. Of those, 75% were female, 62% were white, 16% were Hispanic/Latino, 13% were Black/African American, 6% were Asian/Asian American, and 4% identified as another race or ethnicity. The average age of respondents was 55.

Our findings confirm and add to a body of research that shows cancer is toxic, not only to people's bodies, but to their financial and emotional health as well. By shining a light on how costs amplify the challenges of cancer, we hope to offer support to people who are suffering and inspire solutions to reduce harm caused by the direct and indirect costs of fighting cancer.

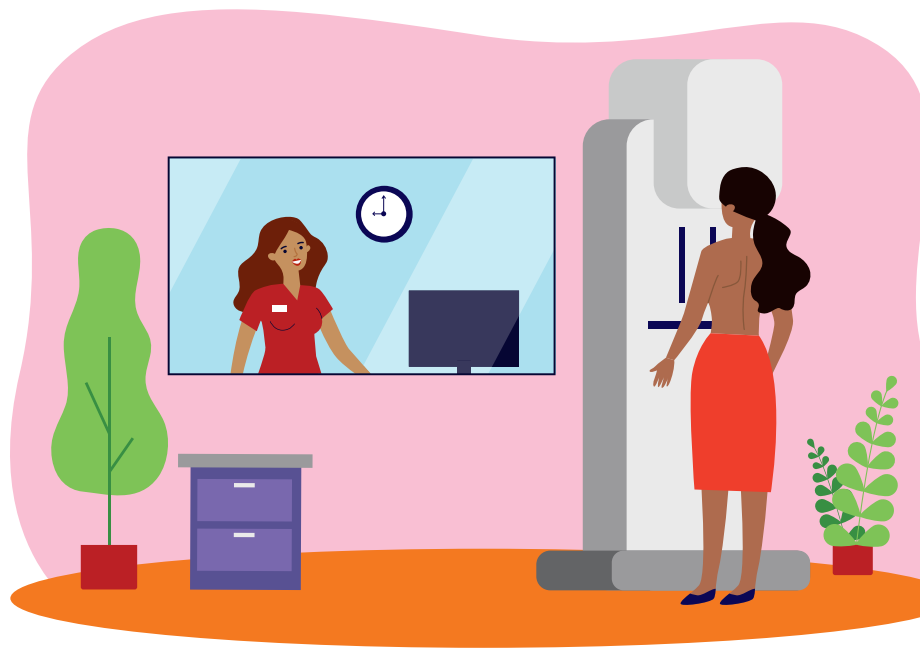
Key survey highlights include:

- **The cost of cancer loomed large for many respondents.** Four in 10 (41%) considered direct and indirect costs when they began treatment, and 60% found paying these costs stressful.

- **Discussing costs with healthcare providers often led to unlocking savings opportunities for those who did it.** Most respondents (77%) who discussed costs were able to get cost information, and 70% of those were offered lower-cost options.
- **Many respondents underestimated the costs of cancer.** Even after originally estimating their costs would be thousands of dollars, almost half (49%) of respondents reported their actual treatment costs were higher than they had expected, with as many as one in five (20%) reporting that they were significantly higher.
- **Financial impacts of cancer extended beyond treatment costs.** On top of direct costs, indirect costs from cancer treatment caused financial strain.
- **Many respondents who faced increased costs from cancer treatment simultaneously suffered economic setbacks because they were unable to work.** More than one-third (37%) experienced some change in their employment status — including nearly 50% of patients currently in treatment — and 6% lost or left their job altogether.
- **Nearly half of respondents (48%) took some sort of action to get help paying for direct or indirect costs of cancer.** Respondents reported getting financial assistance, borrowing money or even declaring bankruptcy.
- **The cost of cancer got in the way of other healthcare needs.** Nearly one in five (18%) respondents reported putting off preventive care, 16% reported putting off non-cancer-related care, and 10% put off elective surgeries due to cancer costs.
- **Costs were a factor in treatment decisions for many and a barrier to recommended treatment for some.** Forty-four percent of respondents considered the financial impacts of their treatment decisions, and 26% adjusted their treatment plans in some way, either changing or forgoing a treatment or medication, because of cost.
- **Financial burdens created emotional distress, depression, anxiety, exhaustion and a sense of powerlessness, among other negative emotions.** Caregivers were even more likely to suffer these psychological impacts than patients.
- **The financial burdens of cancer affected women, people of color and people with lower incomes disproportionately.** People in these groups suffered more financial hardship, took more actions to manage costs, and were more likely to make sacrifices or forego treatment in order to pay their bills.

Our results reveal the harsh reality that many patients and caregivers face financial hardships while fighting cancer. Unable to focus solely on fighting the disease, many patients experience stress, are forced to adjust their lives, and even put off the care they need to beat their disease simply because they cannot afford it.

Taken together with other research that shows cancer-related financial burden is associated with lower health-related quality of life and increased risk of depressed mood, our results point to an important opportunity to improve cancer care: financial relief for those who simultaneously face physical and financial vulnerabilities.⁴



Introduction

Nearly 40% of adults in the United States will be diagnosed with cancer in their lifetimes,⁵ and cancer is the second leading cause of death in the United States.⁶ As of January 2019, there were nearly 17 million cancer survivors living in the United States.⁷

The American Cancer Society estimates that, in the United States, 1.8 million people will be diagnosed with cancer, and more than 606,000 will die from cancer in 2020. Just over 50% of new cancers are diagnosed in women, and women represent 47% of deaths. Excluding skin cancer, breast cancer is the most commonly diagnosed cancer in women, followed by lung, uterine, and colorectal cancers. In 2020, more than 276,000 women will be diagnosed with breast cancer, and more than 42,170 women will die from the disease.⁸

The Costs of Cancer

The CDC projected that cancer-related health care would reach \$174 billion by 2020, an almost 50% increase from 2010, outpacing the growth of the U.S. gross domestic product.⁹ Cancer costs, which account for 5% of total U.S. healthcare expenditures, are projected to reach \$246 billion per year by 2030.¹⁰

In its 2020 report, "The Costs of Cancer: Accessing Patient Costs," the American Cancer Society analysis showed that U.S. cancer patients paid \$5.6 billion out of pocket in 2018 for cancer treatment, including surgery, radiation and chemotherapy medications.¹¹

Cancer is one of the most expensive illnesses to have. According to the American Society of Clinical Oncology, cancer patients with all types of insurance experience financial burdens at higher rates than people with other chronic conditions. On average, 43% of privately insured patients with cancer spend more than one-fifth of their income on health-related expenses, compared with 30% of those with other chronic conditions and 16% of those with no chronic conditions. Among people with public insurance, 24% of patients with cancer spend more than one-fifth of their income on healthcare expenses, compared with 19% of people with other chronic conditions and 6% of those with no chronic conditions.¹²

A Centers for Disease Control and Prevention (CDC) analysis of data between 2011 and 2016 showed that higher out-of-pocket costs persist into survivorship. In fact, the average cancer survivor paid \$1,000 out of pocket in a year compared to \$622 for people without a history of cancer. This study also showed that 25% of survivors reported financial hardships, such as trouble paying bills, and that number was even higher, around one-third (34%), for psychological hardships, such as worrying about medical bills.¹³

Financial Toxicity: The Burdens on Cancer Patients and Survivors

For individuals, the cost of cancer adds to cancer's physical toll, creating another kind of adverse side effect: financial toxicity. The financial burdens of the direct and indirect costs of cancer treatment lead to anxiety, financial difficulties and worse health and mental health status for cancer patients and survivors.

"It's better to NOT have to worry about the costs on top of worrying about the treatment. You shouldn't have to choose."

—Female patient



In a seminal study that helped introduce the concept of financial toxicity, 42% of cancer patients with insurance reported a significant or catastrophic financial burden from their treatment costs. The study also found that many participants had cut back on leisure activities, reduced spending on food and clothing, and used savings to cover out-of-pocket healthcare expenses. Even more alarming, due to cost, 20% reportedly took less medication than was prescribed, and 24% avoided filling prescriptions altogether.¹⁴ Our study similarly found that a meaningful number of cancer patients cannot strictly follow their treatment plans — 26% of respondents reported adjusting or avoiding treatment or medications because of cost.

In addition to direct costs to fight the disease or mitigate treatment side effects, cancer patients also face indirect costs such as for travel if they seek treatment away from home, caregiving support for help with activities of daily living, and basic living expenses such as housing, utilities and food.

Often, these costs hit when people are least able to afford them. Many cancer patients lose income because they can no longer work because of their disease, and when they lose their jobs, they often lose their health insurance, creating upheaval and potentially dire financial vulnerability.

In addition to financial burdens from the cost of care that patients experience during the course of their treatment, cancer survivors also suffer financial burdens into their recovery. One study analyzed the impact of financial burdens on long-term mental and physical health measures. Those who had borrowed money or declared bankruptcy, worried about large medical bills, couldn't cover medical visits, or had to make other financial sacrifices were more likely to report worse physical and mental health. They were also more likely to experience depressed moods and worry about cancer recurrence. Multiple financial problems seemed to compound the adverse physical and mental outcomes, as participants who experienced multiple financial problems had worse reported physical and mental health outcomes.¹⁵

In another study, within two years of a cancer diagnosis, 42% of people had depleted their life savings, an average loss of \$92,000.¹⁶ Still another analysis showed that one-third of cancer survivors had gone into debt, and 3% had filed for bankruptcy due to cancer costs. Of those who went into debt, more than half (55%) owed \$10,000 or more.¹⁷

The American Cancer Society's report, "The Costs of Cancer: Accessing Patient Costs," showed that certain groups are more likely to experience financial hardship due to cancer costs. These groups include lower- and middle-income people, as well as younger, less educated people, and people of color.

People on certain types of health insurance plans — or with no insurance at all — are also more vulnerable financially. For example, people with high deductibles may not be able to afford the out-of-pocket costs before they meet the deductible. This can cause them to postpone care until they can afford to pay for it or their health deteriorates to the point where they have no choice but to accept the financial burden. One 2019 study found that women on high-deductible health plans, defined as \$1,000 or more in this study, experienced delays in getting breast cancer diagnosis and treatment compared with women on health plans without high deductibles, presumably put off by the out-of-pocket costs.¹⁸

Understanding the Impact of Financial Toxicity on Patients, Survivors and Caregivers

To better understand the impact of direct and indirect costs of cancer on health and well-being, HealthyWomen partnered with CancerCare to conduct a nationally representative survey of cancer patients, survivors and caregivers. Support from Amgen and Daiichi Sankyo enabled this survey.

Our study aimed to assess consumer knowledge and perceptions of the costs of cancer care, quantify the financial burdens that cancer treatment creates, and understand the impact of those financial burdens on patients' ability to adhere to cancer treatment plans as well as on their overall financial, emotional and physical well-being. The survey also identified the most common sources of information about the cost of treatment and related expenses and gaps in resources about those costs for patients and caregivers.

Consistent with existing literature, our results confirm that costs are a major factor in the financial, emotional and physical health and well-being of cancer patients, survivors and caregivers. Both direct and indirect costs influence patients' decisions about what care to get or whether to get it at all. Some patients even reported changing or avoiding treatment and/or medication because of cost. In many cases, the cost of treatment itself can actually block patients' access to the treatment and, therefore, put their recovery in jeopardy.

Respondents also reported negative effects on their financial health and emotional well-being as a result of costs. Patients facing financial burdens reported anxiety, depression and distress as caused by these burdens. Unpaid caregivers in our survey reported even higher rates of emotional distress than patients with cancer, consistent with a study that showed that caregivers of cancer patients experience high rates of anxiety and depression and low quality of life.¹⁹

We investigated how factors such as gender, age, race, income, insurance type and geography affect financial burdens and related decision-making processes. In doing so, we found that women, people of color and people with lower incomes bore the most financial burdens. People in these groups were more likely to have experienced a change in their employment status or income, to have made lifestyle changes, to have adjusted their treatment plans because of cost, and to seek financial assistance to cope with the costs of cancer. These groups are also more likely to report feeling stressed about their ability to pay their out-of-pocket costs.

Between patients and caregivers, we found caregivers more likely to report emotional burdens such as stress, anxiety, worry and a feeling of powerlessness. Patients, conversely, were more likely to worry about cancer recurrence.

These survey results confirm the patient and caregiver experiences that social workers at CancerCare witness firsthand every day. Many clients come to CancerCare to access its financial assistance program, which offers grants to help cover expenses related to treatment, transportation, child care, home care and other services. CancerCare also provides clients with comprehensive emotional and practical support services to help offset the negative effects of financial toxicity, emotional distress, physical symptoms and side effects on their quality of life.

Statistical Methodology

Between September 4 and 18, 2020, HealthyWomen conducted an online survey lasting less than 15 minutes. We surveyed a nationally representative sample of 1,012 past or present cancer patients and caregivers of current or former cancer patients. The average age of respondents was 55 years old. Three-quarters of the respondents were female, and one-third (34%) were caregivers. The racial and ethnic composition of respondents was within 5% of the distribution of race and ethnicity in the U.S. population.

Statistical significance testing was performed at the 95% confidence level. It was not performed on open-ended/free-response questions.

Where this report compares responses of one group to another, we focus on comparisons with statistically significant differences found at the 95% confidence level.

We report percentages rounded to the nearest whole number, so some charts may not add to exactly 100%. For some questions, respondents were able to select all applicable answers, so totals will be greater than 100%.

Survey questions explored the impacts of financial burdens of cancer care on health and wellness decision-making. Most questions were multiple choice format, with a few open-ended, free-text response choices.



Demographics

Of the 1,012 participants in this survey, the majority (62%) were white, 16% were Hispanic/Latino, 13% were Black/African American, 6% were Asian/Asian American and the remaining 4% was composed of respondents who identified themselves as American Indian/Alaska Native, Native Hawaiian/Pacific Islander, multiracial and other. For purposes of this survey, respondents who identified as Hispanic/Latino were categorized only as Hispanic/Latino with no further categorization of race. Respondents identified as “white,” “Black/African American,” and “Asian/Asian American” in this report refer to people of non-Hispanic/Latino descent (Table 1).

The majority of respondents were women (75%), and two-thirds were ages 55 or older. The suburbs (47%) and the South (40%) had the most representation. More than one-half (54%) of respondents had an annual income between \$45,000 and \$149,999, nearly one-third (30%) earned less than \$44,999, and the remaining 16% earn more than \$150,000 annually.

The majority of respondents (76%) were current or former cancer patients, and nearly half (48%) were current or former primary unpaid caregivers for someone who currently or previously had cancer. The patients in our study tended to be older than the caregivers — with 45% of patients being ages 65 or more as opposed to 32% of caregivers — and were also less likely (35%) to have employment status changes than caregivers (42%).

Nearly one-quarter (24% or 486 respondents) had been both a patient and a caregiver at some point. For respondents who fell into both patient and caregiver groups, we categorized them by whichever role they had played more recently. A majority (59% or 141) had been patients more recently, so for the purposes of this analysis, we counted them as patients. In all, 34% of respondents (345 total) were categorized as caregivers.

Virtually all study participants were insured; the single largest group was covered by Medicare (38%) — consistent with an older set of respondents — followed by private, employer-sponsored coverage (32%) (Table 1).

Table 1. Respondent Characteristics

	Total (n=1012)*	White/ Caucasian	Hispanic/ Latino	Black/African American	Asian/Asian American
	100%	62%	16%	13%	6%
GENDER					
Female	75%	58%	18%	15%	5%
Male	25%	76%	9%	6%	7%
AGE					
18-34	12%	16%	57%	23%	2%
35-44	11%	39%	30%	18%	8%
45-54	10%	48%	14%	18%	13%
55-64	26%	72%	7%	11%	7%
65 or older	41%	80%	6%	8%	4%
RESIDENCE AREA					
A large city	19%	42%	25%	23%	7%
A suburb near a large city	47%	63%	16%	11%	7%
A small city or town	19%	67%	15%	12%	3%
A rural area	15%	80%	5%	5%	3%
REGION					
Northeast	17%	67%	12%	15%	4%
Midwest	18%	75%	10%	12%	2%
South	40%	60%	16%	18%	3%
West	25%	54%	23%	4%	14%
INCOME					
Less than \$20,000	7%	45%	18%	25%	1%
\$20,000 to \$44,999	23%	59%	24%	14%	2%
\$45,000 to \$149,999	54%	66%	13%	11%	6%
\$150,000 or more	12%	61%	13%	10%	12%
Prefer not to answer	4%	68%	8%	10%	10%
HEALTH INSURANCE					
Medicare	38%	74%	12%	10%	3%
Private insurance (employer)	32%	59%	14%	13%	9%
Medicaid	11%	31%	33%	27%	4%
Private insurance (not employer)	7%	63%	24%	6%	7%
VA or TRICARE	4%	73%	7%	14%	5%
Marketplace health plan	3%	55%	21%	10%	3%

Note: Due to rounding, some lines may add to slightly more or less than 100%.

*4% of respondents identified as something other than white, Hispanic/Latino, Black/African American, Asian/Asian American.

Table 2. Respondent Classification and Patient Treatment Status

	Respondents With a Cancer Diagnosis (Total)	Primary Unpaid Caregiver for Someone Who Is/Was Diagnosed With Cancer (Total)
Overall total	76%	48%
Most recent status (of respondents who were both patients and caregivers)	59%	41%
Category for survey	66%	34%
TREATMENT STATUS OF PATIENT		
Treatment has not started yet	6%	10%
Currently undergoing treatment	19%	17%
Cancer is in remission (reduction or disappearance of the signs and symptoms of a disease for less than five years)	26%	13%
Cancer survivor (complete remission for five or more years, up to ten years out from the end of cancer treatment)	25%	9%



Results

Knowledge and Perceptions of Cancer Care Costs

A cancer diagnosis can feel overwhelming, as patients often fear for their lives and don't know what to expect as they prepare to battle the disease. Our survey showed that, as patients embarked on their cancer treatment journey, costs were very much on their minds, with 37% of patients considering the direct and indirect costs of care upon diagnosis. The concern was even higher, at 49%, among caregivers. The consideration of costs at the time of diagnosis remained notable among all income levels — with 43% of those whose annual income is less than \$45,000 and 44% of those who earn between \$45,000 and \$149,999 a year considering the direct and indirect costs of care upon diagnosis. While two-thirds (67%) of people earning \$150,000 or more said they did not consider costs at the start of treatment, 33% of people in that higher income category still reported being concerned about costs.

In considering the costs of cancer treatment, participants took a broad view and considered many different types of expenses to be part of fighting the disease, as reflected in Table 3. As one female patient noted in an open-ended response, "Some of everything contributes."

A male patient also blamed "government and insurance industry red tape, delays and other hassles" for the costs of cancer care, and one female caregiver noted that "pet care cost when away from home for treatment" was one of the indirect costs of cancer.

"Some of everything contributes".

—Female patient



The most direct costs associated with cancer treatment are the out-of-pocket costs of medical care and medications, including copayments or deductibles for medications, doctor visits and tests. Most participants (77%) considered these direct costs when they thought about how much cancer treatment would cost them. Respondents also considered related healthcare costs associated with a cancer diagnosis, such as durable medical equipment, food and nutrition supplements, personal care expenses including over-the-counter remedies for medication side effects, long-term nursing care outside the home, and mental health counseling/therapy.

Cancer treatment disrupts patients' and caregivers' lives, and that includes their financial lives. Living with cancer can introduce a range of new expenses, which many participants in our survey recognized as part of the total cost of their cancer care. These costs included paid caregivers such as a home health aide or in-home nurse; transportation costs to and from treatment and associated expenses; caregiving assistance, such as help with household tasks; childcare; eldercare; and administrative tasks like income tax preparation and legal assistance.

Respondents also identified opportunity costs as contributing to the total cost of cancer, including lost income due to time away from work (56%), a change in employment status (57%), and loss of health insurance (37%), which is tied to employment for half the U.S. population.²⁰

Table 3. Contributors to the Total Cost of Cancer Care

	Percent of Respondents
DIRECT COSTS	
Direct, out-of-pocket medical costs (e.g., copayments, deductibles, or other medical expenses that are not reimbursed by insurance)	77%
Costs associated with durable medical equipment (e.g., medical equipment used in the home)	58%
Direct caregiver costs (e.g., professional caregiver such as a home health aide or in-home nursing care)	53%
Long-term nursing care outside the home	43%
INDIRECT COSTS	
Transportation to and from treatment	62%
Lodging if receiving treatment away from home	48%
Meal costs if receiving treatment away from home	42%
Food or nutrition supplements (e.g., food or supplements required as a result of cancer treatment)	54%
Personal care expenses like new clothing to accommodate weight loss or gain or over-the-counter products to combat treatment side effects	52%
Counseling/therapy	40%
Costs associated with fertility preservation	21%
Indirect costs for clinical trial participation	45%
Income tax preparation to include medical expenses	24%
Legal assistance (for example, writing a will or an advanced medical directive)	28%
CAREGIVER COSTS	
Childcare	23%
Eldercare	25%
Direct costs for household tasks/homemaker services (for example, cooking, shopping, cleaning, laundry, yard work)	48%
OPPORTUNITY COSTS	
Lost income of the patient due to the patient's time away from work	56%
Lost income of the unpaid caregiver due to the caregiver's time away from work	49%
Change in working or employment status of the patient (for example, decreased productivity, working fewer hours, not being able to keep a position, having to do different types of work)	57%
Change in working or employment status of the unpaid caregiver (for example, decreased productivity, working less hours, not being able to keep a position)	51%
Loss of health insurance	37%

Q9. Which of the following do you believe contributes to the total cost of cancer care? Select all that apply. (n=1012)

Regardless of how broadly respondents defined the total costs of cancer treatment, most researched or estimated their likely costs, but people with fewer financial resources were more likely to research the costs. Nearly two-thirds (63%) of people who earned less than \$45,000 researched costs, significantly more than their higher-earning counterparts (52%). Caregivers were significantly more likely than patients to research costs at the start of treatment, with 70% of caregivers researching costs compared with 55% of patients.

The most common sources of cost estimate information were healthcare providers (33%) or personal research with the insurance company (33%). Participants also turned to unofficial or informal sources such as the internet, cancer support networks and friends or family members. Just 16% reported researching costs from different healthcare providers and/or pharmacies, suggesting that once people get a cancer diagnosis, they are not “shopping around” for lower-cost alternatives, even if the costs they’re presented with pose financial barriers for them (Table 4).

“I would have loved one resource that provided answers to all the questions I had instead of needing to go to several different resources to try to find answers.”

–Female caregiver



Table 4. Resources Used to Estimate Costs

Type of Resource	Percent of Respondents
My healthcare provider gave medical and/or drug cost estimates	33%
I researched costs with my insurance company	33%
I researched costs on the internet	21%
I researched costs through cancer support networks	19%
I researched costs from different healthcare providers and/or pharmacies	16%
I researched costs by speaking with friends and family	15%
I didn't estimate costs	40%

Q10. When you, or the person you are a caregiver for, were diagnosed and began the path of treatment, what resources did you use to estimate cost? Select all that apply. (n=1012)

STICKER SHOCK

People expected cancer treatment to be expensive, yet many still underestimated their costs, with 49% of respondents saying costs wound up higher than they expected and as many as 20% indicating that they were significantly higher.

When estimating likely costs, a majority (61%) of participants expected direct costs of treatment to be \$5,000 or more, with nearly one-quarter (22%) estimating treatment costs would be \$25,000 or more. Just over half (53%) expected the same for their direct medication costs, with nearly one in five (18%) assuming medications would cost \$25,000 or more. Respondents made similar assumptions about indirect costs (Table 5).

Table 5. Expectations of Direct and Indirect Costs

	Less Than \$1,000	\$1,000-\$4,999	\$5,000-\$9,999	\$10,000-\$24,999	\$25,000+	Do Not Know
Expected total direct treatment cost over the span of treatment	9%	20%	19%	20%	22%	10%
Expected total medication cost over the span of treatment	16%	18%	20%	15%	18%	13%
Expected total indirect costs over the span of treatment	16%	19%	19%	16%	17%	13%

Q12. How much did you perceive the costs would be for direct treatment (for example, out-of-pocket medical costs, caregiver costs), medication and indirect costs (for example, transportation, meals, lodging, childcare, time away from work)? (n=415)

In reality, costs were higher than expected for a substantial portion of respondents. Nearly half found their actual treatment costs (49%), medication costs (42%) and indirect costs (47%) were more than they had expected, with at least 20% reporting these costs were significantly more than expected (Table 6).

In an open-ended response about the experience of having cancer, one participant described their ability to estimate costs, which unfortunately came from experience:

"I've had cancer twice. The first time, I was too shocked to research anything. The second time, I estimated the cost as close to what I had paid the first time. It came to more, of course, but not much more."

Table 6. Actual Direct and Indirect Costs

	Significantly Less Than What You Thought It Would Be	A Little Less Than What You Thought It Would Be	Neither More nor Less Than What You Thought It Would Be	A Little More Than What You Thought It Would Be	Significantly More Than What You Thought It Would Be	Don't Know
Total direct treatment cost so far	13%	11%	25%	29%	20%	2%
Total medication cost so far	14%	13%	29%	20%	22%	2%
Total indirect costs so far	9%	16%	26%	24%	23%	2%

Q13. How much has what you actually spent on treatment differed from how you, or the person you are a caregiver for, thought or perceived it would be? (n=363)

The Financial and Emotional Burdens of Cancer Costs

Our survey explored both the financial and emotional burdens for cancer patients, survivors and caregivers.

FINANCIAL IMPACTS

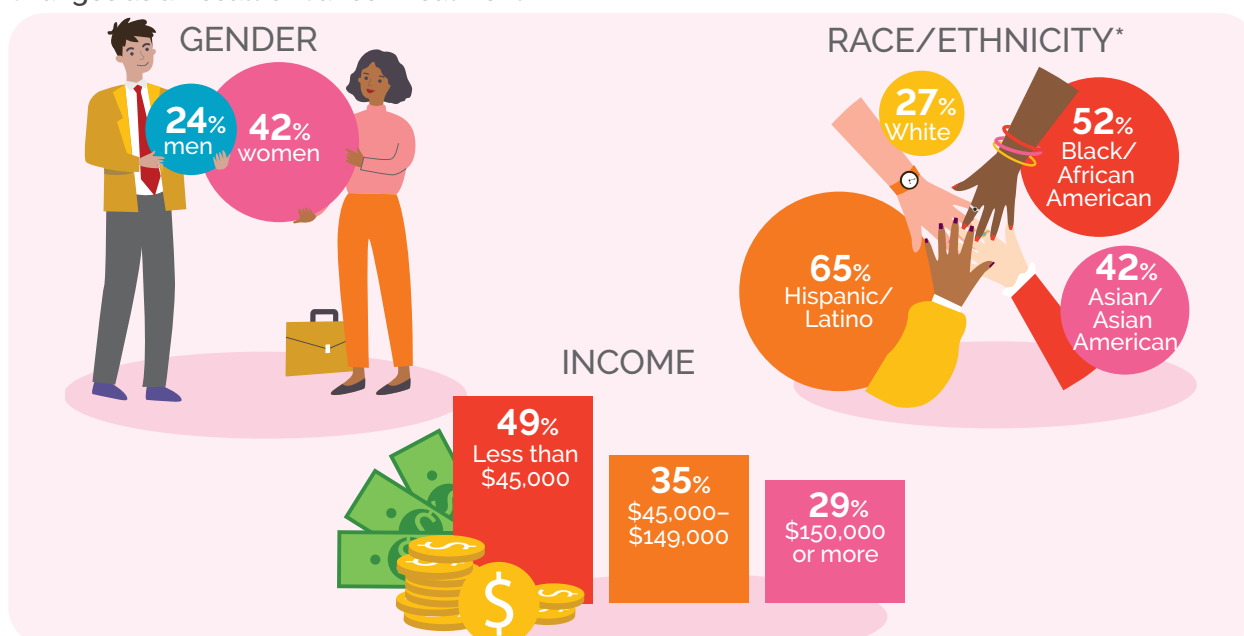
The cost of cancer takes a heavy financial toll on patients and primary caregivers.

Many respondents in our study reported employment and income changes during their cancer treatment. Fifty-seven percent of patients and 51% of unpaid caregivers reported that a change in their work or employment status during cancer treatment contributed to the total cost of cancer care, and 56% of patients and 49% of unpaid caregivers attributed lost income due to time away from work as a contributing factor.

Women and people of color were more likely to report employment changes and lost income due to cancer than other groups. Only one-quarter (24%) of male respondents reported employment changes, compared with 42% of women. More than half of Black/African American (52%) and Hispanic/Latino (65%) respondents reported a change in employment status as a result of cancer treatment (Figure 1).

Employment changes correlated to income levels, suggesting people on the lower end of the income scale faced more professional disruption due to cancer. Nearly half (49%) of people who earned less than \$45,000 reported a change in employment due to cancer, a statistically significant difference compared with higher-earning groups.

Figure 1. Respondents Who Had Employment or Income Status Changes as a Result of Cancer Treatment



Q37. Has or did your employment status or income change as a result of cancer treatment?

*4% of respondents identified as something other than white, Hispanic/Latino, Black/African American, Asian/Asian American.

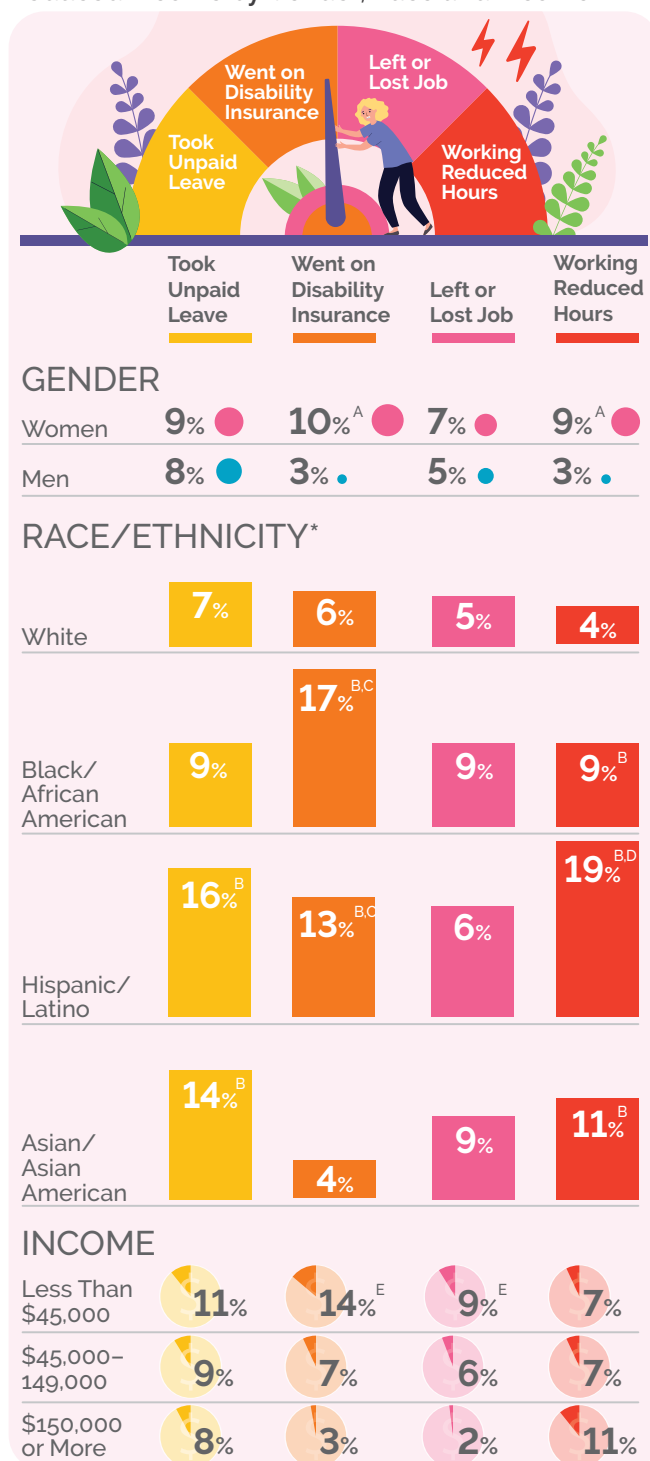
The costs of cancer hit when many people's income is already reduced because they are less able to work. A majority (59%) of women compared to less than half (47%) of men believed a loss of income contributed to the cost of care. Women, people of color, and people with lower incomes were more likely to report having experienced certain types of employment changes associated with reduced income (Figure 2).

TAKING ACTION TO PAY FOR CANCER CARE

In response to difficulties paying cancer-related bills, nearly half (48%) of respondents reported taking action of some sort to get help. For example, some had to borrow money from a friend or family member to pay for cancer-related care, drugs or services. Others borrowed money for non-cancer-related bills such as their mortgage, utilities or car payments. Some had received financial assistance from a nonprofit organization, often called a patient assistance program, for direct or indirect costs, and 14% had received financial assistance (for example, copayment coupon or discount card) from a drug maker.

Though less common, some respondents had taken more extreme actions as a result of not being able to afford cancer bills, such as taking out private loans, refinancing or selling homes or other property, and declaring bankruptcy. Three percent had to let a pet go, and perhaps most tragically, 8% had delayed, changed or gone without treatment and 8% had gone without groceries (Table 7).

Figure 2. Employment Changes Associated With Reduced Income by Gender, Race and Income



*4% of respondents identified as something other than white, Hispanic/Latino, Black/African American, Asian/Asian American.

A-statistically significant difference vs. male respondents

B-statistically significant difference vs. white respondents

C-statistically significant difference vs. Asian/Asian American respondents

D-statistically significant difference vs. Black/African American respondents

E-statistically significant difference vs. both other income groups

Table 7. Actions Taken to Manage Cancer-Related Bills

	Percent of Respondents
BORROWED MONEY FROM FRIENDS OR FAMILY	
Had to borrow money from a family member or friend to pay for cancer-related care (surgery, chemotherapy, therapy, etc.)	11%
Had to borrow money from a family member or friend to pay for cancer medication	11%
Had to borrow money from a family member or friend to pay for cancer-related durable medical equipment for home care (hospital bed, bedside commode, home health care aide, etc.)	9%
Had to borrow money from a family member or friend to pay non-cancer-related bills (utilities, mortgage, car payments, etc.)	14%
RECEIVED FINANCIAL ASSISTANCE	
Received financial assistance from a nonprofit organization (referred to as a patient assistance program) to pay for cancer-related care (surgery, chemotherapy, therapy, etc.)	13%
Received financial assistance from a nonprofit organization (referred to as a patient assistance program) to pay for cancer medication	12%
Received financial assistance from a nonprofit organization (referred to as a patient assistance program) to pay for cancer-related durable medical equipment for home care (hospital bed, bedside commode, home health care aide, etc.)	9%
Received financial assistance from a nonprofit organization (referred to as a patient assistance program) to pay non-cancer-related bills (utilities, mortgage, car payments, etc.)	9%
Received financial assistance from the drug maker (copayment coupon, discount card) for cancer medications	14%
OTHER ACTIONS	
Had to delay, change or forgo treatment	8%
Had to forgo groceries	8%
Had to take out a private loan	8%
Had to mortgage, refinance or sell your house or other property	6%
Had to declare bankruptcy	4%
Had to let pet go	3%
Other	5%
None of the above	52%

Q14. Which of the following actions have you, or the person you are a caregiver for, had to take because you, or the person you are a caregiver for, could not afford to pay bills due to the cost of cancer treatment? Select all that apply. (n=1012)

Communities of color seemed to be more adversely affected by the cost of cancer treatment, as white people were less likely than all other races/ethnicities to have taken an action to afford bills. Women were also more likely to have taken actions than men (54%

compared with 30%). People in the lowest income groups, those earning less than \$45,000 a year, were more than twice as likely as people earning more than \$150,000 to have taken some action to be able to afford their care. These actions included borrowing money to pay for cancer care or medications, getting financial assistance from a nonprofit organization or drug maker, and forgoing groceries.

In open-ended responses, respondents described taking money out of retirement or other savings, using credit cards — sometimes at very high interest rates — and spending their life savings on direct and indirect costs. Several respondents said friends had created fundraisers, such as online GoFundMe campaigns, to help them pay medical bills. Others reported setting up payment plans with their healthcare providers — sometimes lasting several years — and in one case, the healthcare provider had lowered the total amount the respondent owed. One respondent sold their car, another sold jewelry, and one moved in with family to cut costs.

LASTING BURDENS

Financial burdens linger even after cancer treatment ends. Among those respondents who had finished paying their cancer-related medical bills, almost one-third had taken more than a year to pay those bills, including 10% for whom it took between three and five years.

These lingering medical bill balances were not equitably distributed. Nearly half of female respondents (46%) had taken more than a year to pay off their cancer bills, compared with 71% of men who paid their bills within a year.

Lower-income respondents struggled to pay cancer-related bills quickly; more than half (56%) of respondents earning less than \$45,000 annually took more than a year to pay off their bills, and nearly one in 10 respondents (8.3%) reported taking five years to do so.

White respondents were the most likely to have paid their bills off within one year — 63% compared with 46% of Black/African American respondents and 40% of Hispanic/Latino respondents.

Even though many respondents had paid off cancer-related medical bills in under a year, 70% of those who had not yet finished paying their bills expected it would take more than a year to pay them off. That includes 46% who estimated it will take them three to five years to finish paying. Around one in five (22%) respondents expected to need five years to pay off their bills.

The lingering financial impacts of cancer treatment were revealed in some of the open-ended responses we received. One female patient responded, “I put medical payments on credit cards and now have huge credit card debt.” Another said, “I drained my savings. Put the rest on a credit card, which I am paying monthly.”

“I put medical payments on credit cards and now have huge credit card debt.”

—Female patient



ADJUSTING TO CANCER COSTS

Most respondents (62%) reported having to make some changes in their spending habits to be able to pay for cancer care. The biggest adjustment was changes to travel, which 38% reported making. More than one-third (34%) reported changing their personal priorities and goals, and 32% changed their practices regarding going out to eat.

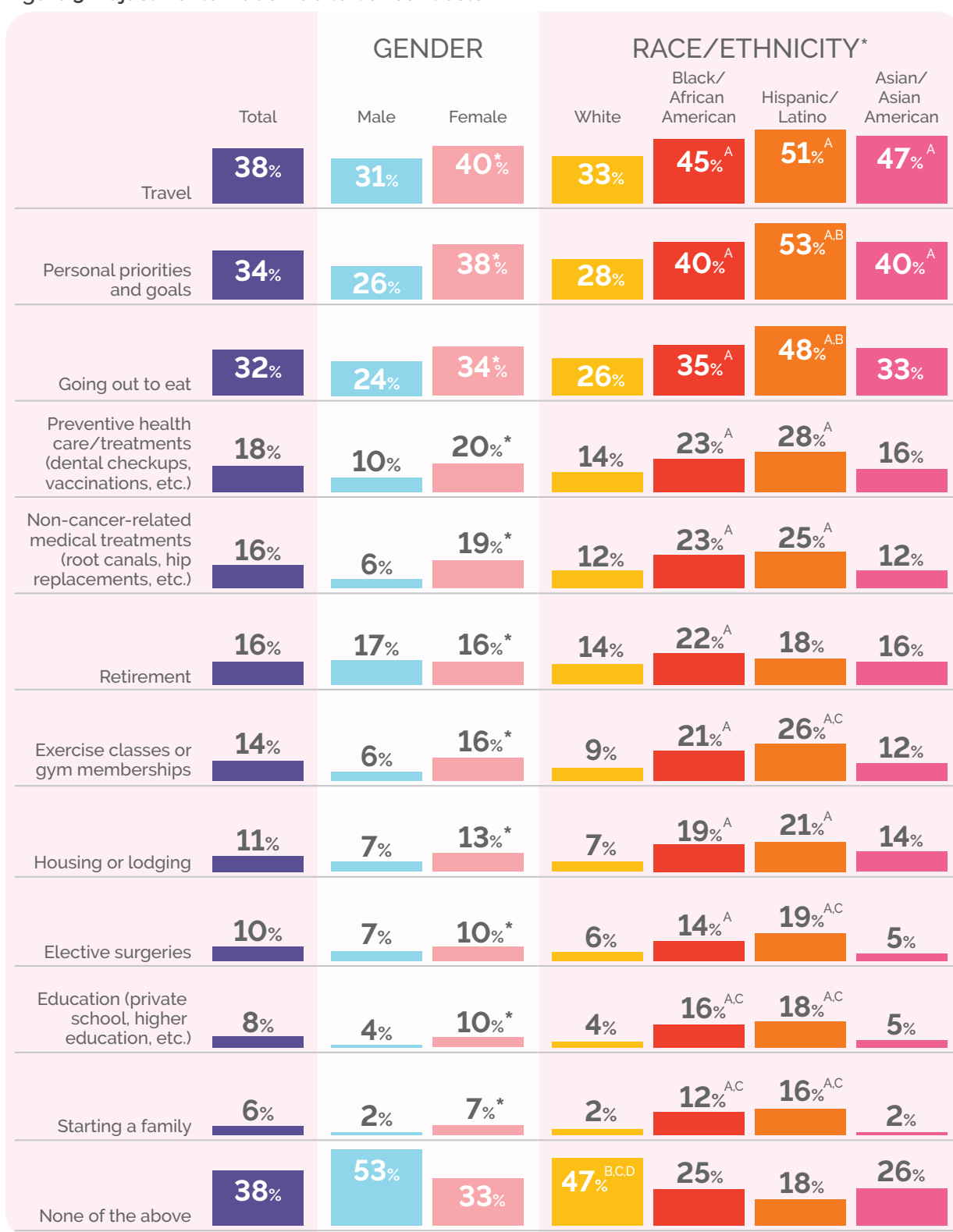
Women were more likely than men to have made lifestyle changes to afford their cancer treatment bills; 38% of women had adjusted their personal goals and priorities compared with 23% of men. Women also made greater changes to going out to eat, with 34% of women reporting that they had scaled back, compared to 24% of men.

Hispanic/Latino respondents were most likely to have made lifestyle or household adjustments due to cancer treatment costs, more than twice as likely (63%) as white respondents (27%). Black/African American (38%) and Asian/Asian American (37%) respondents were also significantly more likely to have adjusted their lifestyles because of cancer costs.

Respondents also reported making trade-offs regarding their long-term physical and financial health, with 18% reporting changing their preventive health care and treatments, 16% changing their non-cancer medical care, and 16% changing plans with regard to their retirement savings. Women were twice as likely as men to put off preventive healthcare services and three times more likely than men to defer non-cancer-related treatments. Female patients were more likely to change their preventive care (17%) compared with male patients (11%).

Race/ethnicity and socioeconomic status appear to play a role in these decisions. Black/African American (23%) and Hispanic/Latino (25%) respondents were more likely than white (12%) and Asian/Asian American (12%) respondents to put off non-cancer-related medical care, and people who earn \$45,000 or less annually were more likely to put off both preventive and non-cancer-related care than people who earn more.

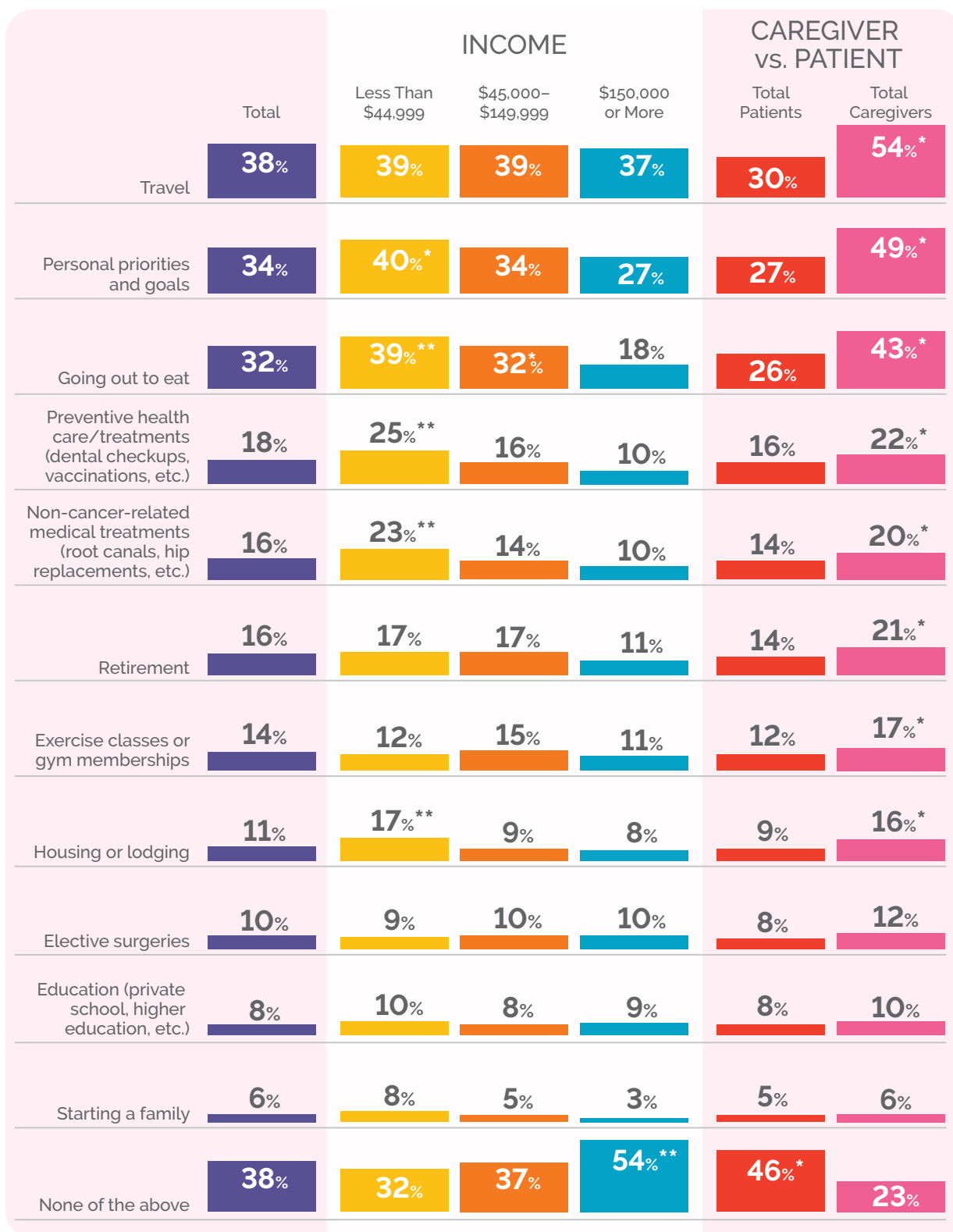
Figure 3. Adjustments Made Due to Cancer Costs



*=Statistically significant difference

*4% of respondents identified as something other than white, Hispanic/Latino, Black/African American, Asian/Asian American.

A=Statistically significant difference vs. white group
 B=Statistically significant vs. Black/African American group
 C=Statistically significant vs. Asian/Asian American group
 D=Statistically significant vs. Hispanic/Latino group



*-Statistically significant difference vs. \$150k group
 **-Statistically significant vs. both other income groups

*-Statistically significant

EMOTIONAL IMPACTS

The emotional impacts of cancer treatment costs were significant. More than half of respondents expressed negative emotions as a specific result of cancer costs. The most common feelings triggered by costs included depression, frustration, worry, stress or tension, feeling overwhelmed, anxiety, distress, helplessness or hopelessness, and anger. There were noteworthy gender differences, with female patients and caregivers being more likely than their male counterparts to experience most of these emotions regarding their overall experience with cancer. People currently undergoing treatment were more likely to experience certain emotions related to cost, such as depression and anxiety, than people who were in remission.

Interestingly, caregivers were significantly more likely to report feeling worry, anxiety and exhaustion than patients themselves. For example, 59% of caregivers reported feelings of frustration, 58% reported anxiety, and 56% reported feeling overwhelmed, compared with 33%, 46% and 39% of patients, respectively. Caregivers also reported insomnia, helplessness or powerlessness, panic or fear, distress, anger, or restlessness more often than patients, as well as a feeling of being overly protective or role reversal, such as when a caregiver was previously a dependent but then must step into a caregiving role because of the cancer diagnosis.

Patients, on the other hand, were more likely to report fear of a cancer recurrence (56%) than caregivers (44%).

Notably, respondents were more likely to identify negative feelings associated with the costs of cancer than with their overall cancer experience. Just as caregivers were more likely than patients to experience negative feelings due to cancer, they were also more likely to experience negative emotions as a result of the costs of cancer (Table 8).



Table 8. Feelings and Behaviors Associated with Cancer and with the Costs of Cancer

	Experienced Over the Course of Cancer		Experienced Due to Direct or Indirect Costs of Cancer	
	Patient n=671	Caregiver n=341	Patient n=671	Caregiver n=341
STRESS/ANXIETY/FEAR				
Stress/tension	50%	71%*	48%	72%*
Anxiety or nervousness	46%	58%*	44%	71%*
Panic or feeling scared or fearful	28%	40%*	34%	66%*
Distress	25%	39%*	39%	68%*
Worry	53%	74%*	46%	74%*
Overwhelmed	39%	56%*	46%	70%*
SADNESS/DEPRESSION				
Depression	36%	37%	55%	76%*
Grief/feelings of loss	22%	41%*	27%	46%*
Isolation or loneliness, cut social ties, lessened social contact with friends and family, inability to connect with others or exclusion	23%	32%*	34%	55%*
Helplessness, hopelessness or powerlessness	27%	43%*	40%	66%*
ANGER/FRUSTRATION				
Anger	23%	31%*	45%	63%*
Resentment (feel bitterness or indignation at a circumstance, action or person)	12%	21%*	35%	49%*
Feelings of guilt	13%	27%*	47%	48%
Frustration	33%	58%*	49%	74%*
EXHAUSTION				
Exhaustion or tiredness	50%	62%*	32%	70%*
Insomnia/sleeplessness	36%	45%*	42%	57%*
FEAR OF ILLNESS				
Fear of having another chronic disease while having cancer (fear of comorbidities)	23%	21%*	33%	58%*
Fear of co-infection (for example, an infection in addition to the cancer)	16%	19%	29%	58%*
Fear of recurrence of cancer	56%*	44%	31%	71%*

	Experienced Over the Course of Cancer		Experienced Due to Direct or Indirect Costs of Cancer	
	Patient n=671	Caregiver n=341	Patient n=671	Caregiver n=341
Hypochondria (for example, living in fear that you have a serious, undiagnosed medical condition)	11%	11%	20%	57%*
BEHAVIOR CHANGE				
Become controlling and/or overbearing (tending to overwhelm, unpleasantly domineering)	7%	11%*	26%	39%*
Become secretive	9%	9%	36%	50%*
Substance abuse (tobacco, alcohol, drugs)	7%	7%	41%	33%
Being withdrawn (not wanting to communicate with other people)	21%	27%	32%	57%*
Impulsiveness (characterized by actions based on sudden desires, whims or inclinations rather than careful thought)	7%	11%	40%	39%
Become overly protective (for example, to protect someone more than necessary)	10%	38%*	24%	21%
Role reversal (for example, the caregiver becomes the dependent or the dependent becomes the caregiver)	9%	24%*	25%	48%*
Inability to perform specific chores (yard work, cleaning, cooking, paying bills, etc.)	32%*	21%	30%	68%*
Restlessness (the inability to rest or relax as a result of anxiety or boredom)	21%	36%*	41%	60%*
RELATIONSHIP CHANGES				
Strengthened relationships	25%	33%*	28%	56%*
New problems or worsened problems in relationships	11%	18%*	47%	52%

Q17. Which of the following have you, as a patient, you, as a caregiver experienced over the course of the cancer? Select all that apply.
Q18. Which of the following do you believe you have experienced due to the direct (out-of-pocket medical costs, caregiver costs, etc.) or indirect (transportation, meals, lodging, childcare, time away from work, etc.) costs of cancer? Select all that apply.
*Statistically significant difference

When asked about their level of concern regarding the ability to pay for various aspects of care, respondents expressed the greatest concern about their ability to pay for medical care, including concern about paying for medical treatment (47%), medication (45%), a hospital visit (42%), a doctor's visit (38%) or physical aids and equipment to help cope with physical effects of cancer treatment (34%). More than one-third (34%) also expressed concern about losing their job and their ability to pay rent or mortgage. One in three (30%) expressed concern about being able to pay for food because of the cost of cancer treatment (Figure 4).

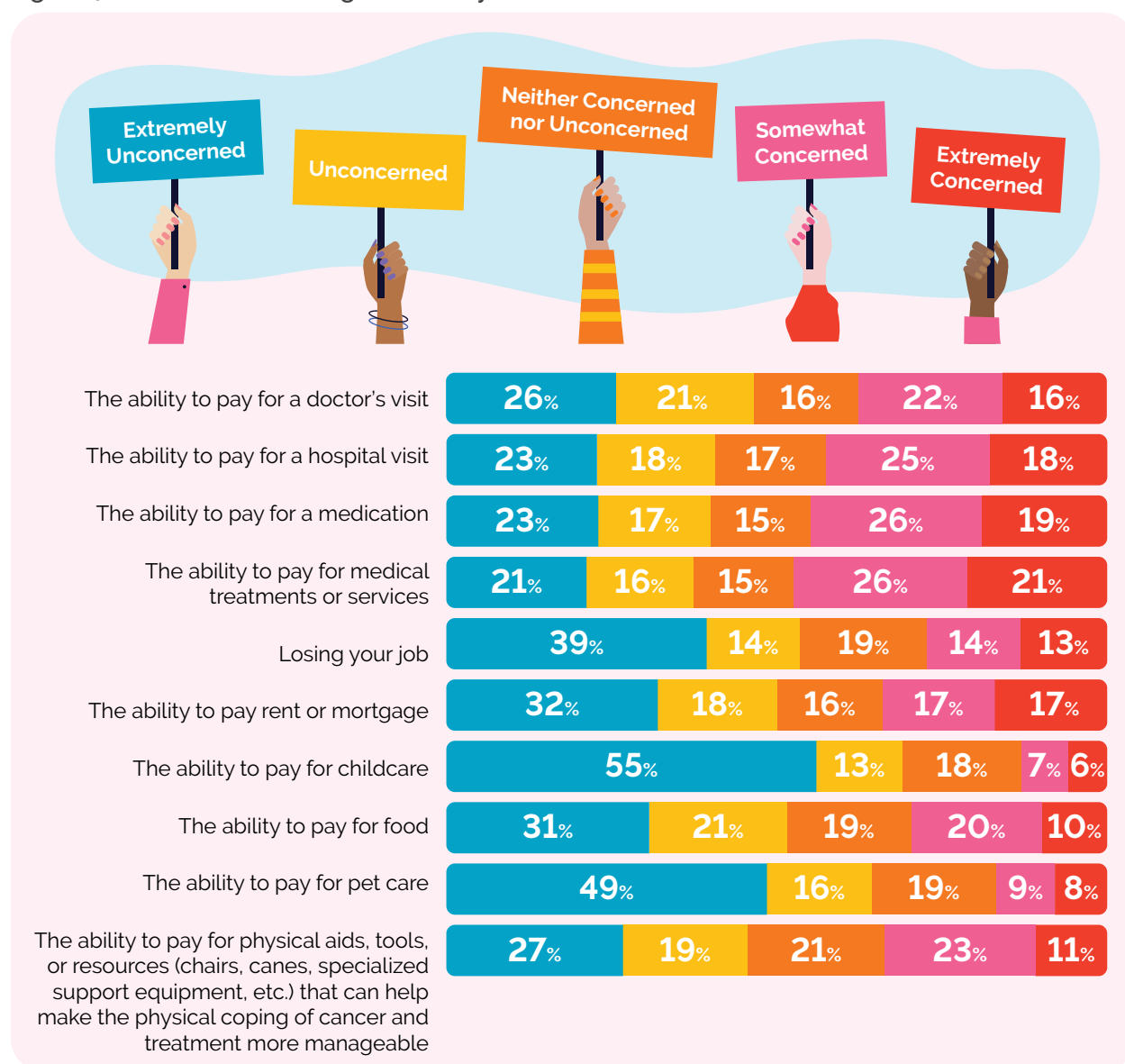
Caregivers were more likely to express concern about these costs than patients. For example, 44% of patients and 55% of caregivers were somewhat or extremely concerned about the patient's ability to pay for medical treatment. Similarly, 40% of patients were concerned about paying for medications and 39% for hospital visits, compared with 55% and 50% of caregivers, respectively. Forty percent of caregivers and 31% of patients were concerned about paying rent or mortgage.

Women were more likely than men to be somewhat or extremely concerned about their ability to pay for all types of treatment-related costs; women were almost twice as likely as men to worry about paying rent or mortgage and food, and to fear losing their job.

Lower-income respondents were significantly more likely to be somewhat or extremely concerned about paying for all types of cancer-related care and medication than higher income respondents, and significantly more likely to express concern about paying rent or mortgage, paying for pet care, or paying for food.



Figure 4. Concern About Being Able to Pay for Cancer-Related Costs



Q19. On a scale from 1 to 5 (where 1 is extremely unconcerned and 5 is extremely concerned), how concerned have you been about: (n=1012)

More than half (60%) of respondents reported finding paying for direct and indirect costs of cancer to be stressful, including more than one-third (35%) who said these costs are very or extremely stressful. Once again, caregivers were more likely than patients to report high levels of stress related to paying for cancer costs.

Women were also significantly more likely than men to say paying for care was stressful, as were most groups of respondents of color compared with white respondents and lower income earners compared with higher income earners (Figure 5).

CANCER COSTS AFFECT PATIENTS' TREATMENT DECISIONS

Despite the stress and anxiety respondents reported related to the costs of cancer care, few (30%) had spoken to a professional, such as a social worker, about the impact of those costs. Even fewer (23%) reported that their family members had done so. People with lower incomes were twice as likely as the highest income respondents to speak or consider speaking with a social worker about the financial impact of their care.

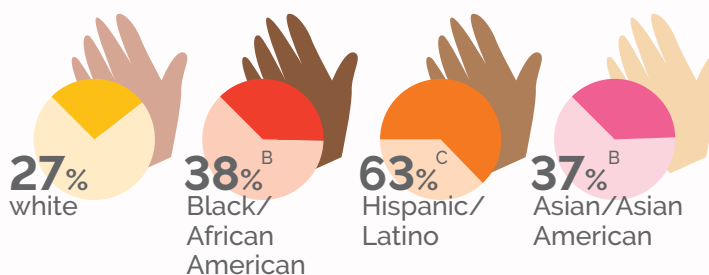
Slightly more than half of respondents (54%) reported discussing costs of treatment and/or medication with their healthcare provider, and just 28% had discussed both treatment and medication costs. Given the concerns patients reported about the cost of care, and how much most people now have to pay for health care even if they are insured, it is noteworthy that nearly half (46%) did not report discussing any costs at all with their healthcare provider.

White and Asian/Asian American respondents were significantly more likely to discuss costs with a healthcare provider than Black/African American and Hispanic/Latino respondents. Ironically, those earning \$150,000 or more were

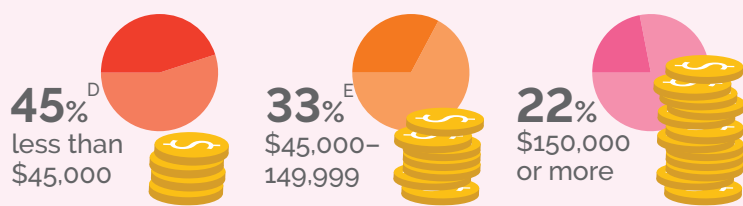
Figure 5. Respondents Who Reported Paying for Cancer Costs as Extremely or Very Stressful



RACE/ETHNICITY*



INCOME



Q20. On a scale from 1 to 5 (where 1 is not at all stressful and 5 is extremely stressful), how stressful have you found the ability to pay both the direct (out-of-pocket medical costs, caregiver costs, etc.) and/or indirect (transportation, meals, lodging, childcare, time away from work, etc.) costs of cancer treatment? (n=1012)

*4% of respondents identified as something other than white, Hispanic/Latino, Black/African American, Asian/Asian American.

A-Statistically significant difference

B-Statistically significant vs. white group

C-Statistically significant vs. all other groups

D-Statistically significant vs. both other income groups

E-Statistically significant vs. the highest income group

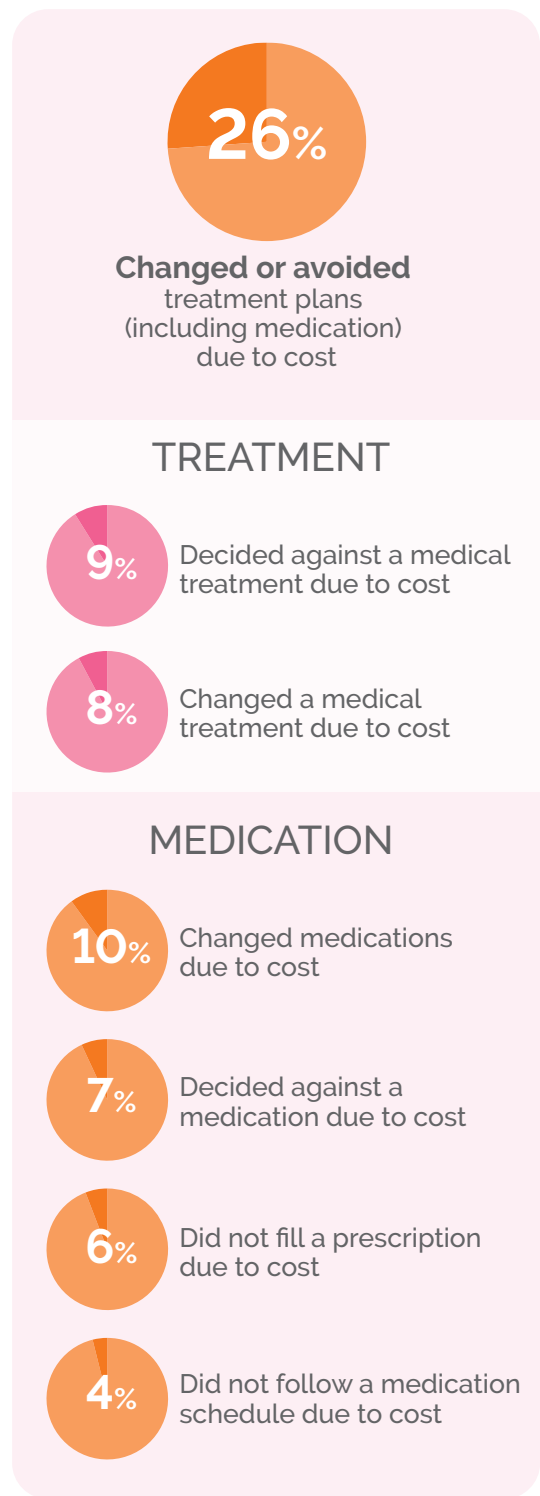
significantly more likely to discuss costs than people earning less than \$45,000 even though they are more likely to be able to absorb the costs than their lower-income counterparts.

Discussing costs turned out to be helpful for patients looking for ways to save money. When patients were able to find out how much treatments and/or medications would cost, in most cases (70%), respondents received lower-cost options for healthcare services and/or medications. Though people with lower incomes were significantly less likely to discuss costs, when they did, they were significantly more likely to be provided with lower-cost options.

Costs were a factor in treatment decisions and treatment-plan adherence for almost half of respondents. More than four in 10 (44%) took the financial impact of treatment into consideration when making decisions about their care, and nearly one-third (32%) would have made different treatment decisions had they known about more affordable options. Respondents earning below \$150,000 were significantly more likely than those earning more to factor costs into their decisions, and 42% of those earning less than \$45,000 would have made different decisions if it would have made treatment more affordable.

Though almost three-quarters (74%) of respondents strictly followed their cancer treatment plan regardless of cost, more than a quarter of respondents (26%) reported adjusting or avoiding treatment because of cost. Women were significantly more likely than men to change their treatment plan because of cost (29% compared with 17%). Among racial and ethnic groups, Black/African American respondents were most likely to report changing their treatment because of cost (54%), followed by Hispanic/Latino respondents (47%) (Figure 6).

Figure 6. Changing or Avoiding Treatment Due to Cost



Q28. How did you or the person you are a caregiver for follow the treatment plans? Select all that apply. (n=1012)

RESOURCES AND TOOLS FOR MANAGING FINANCIAL BURDENS OF COMPREHENSIVE CANCER CARE

We asked respondents about their experience with various tools and resources to manage the cost of cancer care, such as bill and payment trackers, cost estimators, financial planning tools, question lists, payment plans, and resources to help pay for the direct or indirect costs of cancer treatment.

Respondents were more likely to have found various resources on their own than to have a health-care team, insurer, or employer provide such resources. Nearly one-third (31%) of respondents were not provided with any tools or resources to help with the costs of cancer treatment. Women were more likely than men to have been provided and to have sought out tools and resources to help manage cancer-related costs.

The most common resources that respondents found on their own were question lists for their healthcare team (39%) and for their insurance company (32%), explanation of health insurance benefits (32%), financial planning tools (32%), direct and indirect cost estimation (31%) and resources for help with food (30%).

Respondents more often reported having been presented with information than seeking information on their own with regard to payment plans and resources to help pay for cancer treatment and durable medical equipment (Table 9).

Because consumer preferences in communications can influence how effective those communications are, we sought to understand how respondents prefer to get information. Most (61%) prefer face-to-face communication, though approximately half prefer to read printed material or to get their information on the internet. Respondents under age 55 were more likely than older respondents to prefer online text or video chats with experts, and respondents ages 65 and older prefer speaking with someone face to face.

Figure 7. Preferred Methods for
Receiving Cancer-Related Information



Q31. What are your preferred methods of receiving information about cancer treatment, cancer-related costs and other resources?

Table 9. Tools and Resources for Managing Cost Impacts

	I Was Provided With	I Found on My Own	Both
COST ESTIMATORS			
Cost estimate tools/worksheets	19%	26%	3%
Cost comparisons for direct (out of pocket medical costs, caregiver costs, etc.) and indirect (transportation, meals, lodging, childcare, time away from work, etc.) for medical treatment	19%	27%	3%
Direct (out of pocket medical costs, caregiver costs, etc.) and indirect (transportation, meals, lodging, childcare, time away from work, etc.) cost estimation	22%	31%	5%
FINANCIAL PLANNING AND PAYMENT TOOLS			
Bill and payment trackers	16%	28%	3%
Estate or financial planning tools/worksheets (wills, etc.)	14%	32%	2%
Payment plans	29%	23%	4%
QUESTION LISTS			
List of questions for the employer	13%	28%	3%
List of questions for insurance companies	21%	32%	4%
List of questions for the healthcare team	27%	39%	6%
RESOURCES TO HELP PAY BILLS			
Resources to help with payment of cancer treatment	28%	24%	4%
Resources to help with rent, utilities, and/or student loans	13%	29%	3%
Resources to help with home healthcare expenses	20%	25%	4%
Resources to help with lodging costs if traveling for treatment	19%	25%	3%
Resources to help with payment of prescriptions	25%	27%	5%
Resources to help with food	16%	30%	3%
Resources to help with travel for treatment and/or post-treatment procedures	20%	25%	3%
Resources to help with durable medical equipment (for example, medical equipment used in the home, including canes, in-home hospital beds, lymphedema sleeve, etc.)	27%	23%	5%
OTHER INFORMATION/RESOURCES			
Explanation of health benefits under insurance plan	34%	32%	6%
Resources on how to return to work	15%	27%	3%
None	31%	27%	21%

Q29. What resources and tools focused on costs for cancer treatment and care have you been provided or did you find on your own? Select all that apply under "I was provided with," "I found on my own"; you may mark both. (n=1012)



Conclusion

Healthcare costs in the U.S. increasingly fall to consumers to pay out of pocket. These costs weigh on consumers and often stand in the way of the care people need. A 2019 Gallup survey showed that one-third of U.S. adults could not afford health care in the past year, and as many as one in four deferred care for a serious medical condition because of cost.²¹ A subsequent survey found that half of Americans fear bankruptcy due to a major health event, with higher levels of concern among women and people of color.²²

Our study further highlights that cancer patients are not immune from these financial burdens. One-quarter of respondents were unable to follow their treatment plan — a meaningful number when the stakes are as high as fighting cancer. Many more described feeling significant stress over the cost of their care. Even if costs did not directly interfere with their ability to get recommended treatment, costs are clearly taking a broader toll than evidenced by treatment changes alone. Cancer patients and survivors bear high levels of stress and emotional strain, fed in part by the treatment-related costs that burden them.

These burdens are not evenly distributed. Our study confirms that the negative effects of cancer-related costs disproportionately affect women, people of color, and people on the lower end of the income spectrum. While experiencing greater stress and more tangible negative effects of cancer treatment on income and employment, these groups were more likely to research costs and take actions to get help or find ways to afford their bills.

Our results also paint a picture of patients who are left alone to figure out how to pay their bills. They're more likely to research solutions or resources on their own than to get help from their healthcare providers or other organizations.

When participants sought information and assistance, many were able to find help from family and friends or nonprofit organizations and drug manufacturers. Notably, those who researched and openly discussed costs with their healthcare providers were often able to access lower-cost options. One female patient told us, "My oncologist found a program that would cover my cost as a clinical trial." This type of help from healthcare providers didn't get reported often,

but it illustrates the value of provider partnership in managing costs and points to the power of honest communications, not just about physical symptoms but financial hardships as well.

The data also suggest that consumers must be proactive in managing their costs. One respondent mentioned that she felt “on my own completely” and another reflected in an open-ended comment:

“Had I not scrutinized each bill carefully, I would have paid an extra \$3,800. Those are the ones I’ve found so far. There may be more ... Patients need to be told to proofread the bill themselves, or, if unable, have someone else do it.”

Another respondent shared their approach: “I’ll asked a lot of questions wherever I went.”

“My oncologist found a program that would cover my cost as a clinical trial.”

–Female patient



A PATH FORWARD TO EASE CANCER-RELATED FINANCIAL STRESS

To ease the burdens that costs impose on cancer patients and caregivers, healthcare organizations and others who support cancer patients should seek opportunities to provide tangible financial support as well as emotional and mental health support for cancer patients, survivors and caregivers.

As a first step, healthcare providers and staff should be proactive in opening conversations about costs and financial worries. Even patients who are able to pay for care are likely to experience a level of stress that could interfere with optimal health and well-being. They may not feel comfortable sharing those concerns in the midst of cancer treatment, which may hinder their capacity to be proactive. Inviting open conversations about costs and helping patients find more affordable solutions may help reduce cancer-related financial stress for consumers.

Additionally, insurers, employers and nonprofit patient assistance programs or patient navigators can all contribute to more open and transparent information about the true costs of cancer.

Across the healthcare ecosystem, many organizations could play a role in helping consumers find the information and alternatives they need to reduce cost barriers to essential cancer treatment and related services. Advocacy organizations have and will continue to play a key role in amplifying patient voices, identifying patient needs and creating programs to fill those gaps. The CancerCare case management program, for instance, helps clients overcome barriers to care. A core component of this program is providing clients the guidance and skills they need to confidently participate in decisions related to their care. Efforts such as these need support to reach more patients who are struggling with the financial burdens of cancer care.

Policymakers and insurers should examine the out-of-pocket costs cancer patients pay as well as all the other indirect costs that go along with a cancer diagnosis. Implementing policies such as caps or limits on what cancer patients are forced to pay; providing incentives for providers and drug makers to lower consumers' costs; requiring insurers to cover cancer care without making it subject to deductibles so patients with high deductibles don't have to spend large amounts before insurance coverage begins; or including more indirect costs in insurance coverage could help consumers afford their cancer treatment, which could in turn improve their overall health and well-being.

Until such policy changes occur, patients may be left to advocate for themselves financially as well as clinically. Our research suggests that being proactive can help patients manage financial burdens, which highlights the need to educate patients and caregivers to advocate for themselves.

No one should be forced to put off or decline cancer treatment because of cost, and no one fighting cancer should go without food. Our study found that these are real trade-offs people are forced to make, and that women, people of color and people with lower incomes are forced to make these heartbreaking trade-offs at disproportionately high rates.

To improve access to quality cancer care for more Americans, policymakers, healthcare providers and insurers should acknowledge and take steps to mitigate the harmful effects of direct and indirect costs. Only with an honest assessment of the role cost plays in preventing optimal cancer care and outcomes can the United States achieve a more just, fair, and effective approach to cancer.

At HealthyWomen and CancerCare, we are committed to empowering all women, including current and former cancer patients and caregivers. We will continue to educate people about cancer diagnosis and treatment as well as provide resources to help people discuss and manage the direct and indirect costs of cancer.

We are committed to arming women — and the people who love them — with information and tools, so they are better positioned to address the difficulties and reduce the barriers to necessary care that arise from those costs.



About HealthyWomen

HealthyWomen is a unique and progressive not-for-profit organization that has inspired and empowered millions of women to take a proactive role in their health and the health of their families for 30 years. Over the years, HealthyWomen has developed an extensive library of information on topics ranging from heart disease and breast cancer to sexuality and wellness — with hundreds of lifestyle and condition-oriented topics in between. With clinical information that is reviewed by leading health experts to ensure that accurate and reflects the latest scientific advances, HealthyWomen is a proven and trusted resource for consumers. Notably, HealthyWomen prides itself on its 24/7 multichannel media platform with award-winning educational content as well as advocacy, awareness campaigns. HealthyWomen delivers information that women can learn from and act upon via informative, motivating and shareable content. HealthyWomen continues to be a rich resource with a broad reach among a highly engaged community, reaching over 1.5 million women each month; engaging over 60,000 healthcare providers (60% RNs and NPs, 40% OB-GYNs, general practitioners and MDs); and proudly partnering with dozens of local and national organizations.

About CancerCare

Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include case management, counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

This report was made possible with the support of Amgen and Daiichi Sankyo.

Endnotes

- 1 "Facts & Figures 2020 Reports Largest One-year Drop in Cancer Mortality, American Cancer Society," January 8, 2020, <https://www.cancer.org/latest-news/facts-and-figures-2020.html>.
- 2 "Financial toxicity," National Cancer Institute, last accessed January 10, 2021, <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/financial-toxicity>.
- 3 National Cancer Institute, "Financial toxicity."
- 4 Hrishikesh Kale and Norman Carroll, "Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors," *Cancer* 122, no. 8 (2016): 283-89. doi:10.1002/cncr.29808.
- 5 "Cancer Statistics," National Cancer Institute, last updated September 25, 2020, <https://www.cancer.gov/about-cancer/understanding/statistics>.
- 6 CDC's National Center for Chronic Disease Prevention and Health Promotion: Division of Cancer Prevention and Control, "Cancer is the second leading cause of death in the United States," https://www.cdc.gov/chronicdisease/pdf/aag/DivisionElevator_DCPC-508.pdf.
- 7 "U.S. Cancer Survivors Numbered Nearly 17 Million at the Start of 2019," *The Asco Post*, last updated June 17, 2019, <https://ascopost.com/News/60154>.
- 8 American Cancer Society, *Cancer Facts & Figures 2020*, <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf>.
- 9 "Cancer: CDC works to prevent cancer and improve the health of people with cancer," Advanced Search National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention, last reviewed December 16, 2020, <https://www.cdc.gov/chronicdisease/resources/publications/factsheets/cancer.htm>; actual 2020 numbers are not yet available.
- 10 Jo Cavallo, "National Cost of Cancer Care in the United States Expected to Rise to \$246 Billion by 2030," *The Asco Post*, last updated June 30, 2020, <https://ascopost.com/news/june-2020/national-cost-of-cancer-care-in-the-united-states-expected-to-rise-to-over-246-billion-by-2030/>.
- 11 American Cancer Society Cancer Action Network, *The Costs of Cancer 2020*, <https://www.fightcancer.org/sites/default/files/National%20Documents/Costs-of-Cancer-2020-10222020.pdf>.
- 12 Jaime Rosenberg, "Discussing the Cost Burden of Cancer With Patients," *AJMC*, June 6, 2108. <https://www.ajmc.com/view/discussing-the-cost-burden-of-cancer-with-patients>.
- 13 DU Ekwueme et al., "Annual Out-of-Pocket Expenditures and Financial Hardship Among Cancer Survivors Aged 18–64 Years — United States, 2011–2016," *MMWR Morb Mortal Wkly Rep*, 68 (2019): 494–99, <http://dx.doi.org/10.15585/mmwr.mm6822a2>.
- 14 S. Zafar et al., "The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience." *The Oncologist* 18, no. 4 (2013): 381, <https://theoncologist.onlinelibrary.wiley.com/doi/full/10.1634/theoncologist.2012-0279>
- 15 Kale and Carroll, "Self-reported financial burden."

- 16 Adrienne M. Gilligan et al., "Death or debt? National estimates of financial toxicity in persons with newly-diagnosed cancer." *The American Journal of Medicine* 131, no. 10 (2018): 1187-99, [https://www.amjmed.com/article/S0002-9343\(18\)30509-6/fulltext](https://www.amjmed.com/article/S0002-9343(18)30509-6/fulltext).
- 17 Matthew P. Banegas et al., "For working-age cancer survivors, medical debt and bankruptcy create financial hardships," *Health Affairs* 35, no. 1 (2016): 54-61, <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2015.0830>.
- 18 Frank J. Wharam et al., "Vulnerable and less vulnerable women in high-deductible health plans experienced delayed breast cancer care," *Health Affairs* 38, no. 3 (2019): 408-15, <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2018.05026>.
- 19 Hai-mei Geng et al., "Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis." *Medicine* 97, no. 39 (2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6181540/>.
- 20 "Health Insurance Coverage of the Total Population: Timeframe 2019," State Health Facts, Kaiser Family Foundation, last accessed January 10, 2021, <https://www.kff.org/other/state-indicator/total-population/?currentTimeframe=true>.
- 21 Lydia Saad, "More Americans Delaying Medical Treatment Due to Cost," Wellbeing, Gallup, December 9, 2019, <https://news.gallup.com/poll/269138/americans-delaying-medical-treatment-due-cost.aspx>.
- 22 Dan Witters, "50% in U.S. Fear Bankruptcy Due to Major Health Event," Wellbeing, Gallup, September 1, 2020, <https://news.gallup.com/poll/317948/fear-bankruptcy-due-major-health-event.aspx>.

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