



CANCERcare®

# Patient Access & Engagement Report



2016



CANCER*care*<sup>®</sup>

## About CancerCare<sup>®</sup>

Founded in 1944, CancerCare<sup>®</sup> 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 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.

CancerCare programs and services help 180,000 people each year. We distribute 350,000 publications and welcome 2.2 million website visits annually. In the past year, CancerCare provided nearly \$13 million in financial assistance. The size and scope of CancerCare has grown tremendously since 1944, but it has never wavered from its mission of providing help and hope to people affected by cancer.

To learn more, visit [www.cancercare.org](http://www.cancercare.org) or call 800-813-HOPE (4673).

## Our Mission

CancerCare<sup>®</sup> is the leading national organization dedicated to providing free, professional support services including counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

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# 2016

## Patient Access & Engagement Report



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## Sponsor Acknowledgment

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**AbbVie; Amgen; AstraZeneca; Bristol-Myers Squibb; Genentech; Helsinn Therapeutics, US; Gilead Sciences; Incyte Corporation; Janssen; Lilly; Merck; PhRMA; and Pfizer.**



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### Collaboration with Harborside Press

In 2015, CancerCare contracted with Harborside Press to manage the survey process and overall development of this report. Harborside Press aided in the development of the survey questions, managed the survey panel vendor as well as the data analysis, provided editorial support and guidance, and produced the publication. In addition, Harborside Press provided overall strategic consultation on the report. CancerCare would like to thank Harborside Press for the care and dedication given to this project.

### About Harborside Press

Harborside Press is a medical information, publishing, and health-care communications company based in Huntington, New York. Harborside Press is the publisher of *The ASCO Post*, *JNCCN—Journal of the National Comprehensive Cancer Network*, the *Journal of the Advanced Practitioner in Oncology*, and the *Journal of Oncology Practice*. Harborside Press also provides the management services for the Advanced Practitioner Society for Hematology and Oncology. For more information on Harborside Press, please visit [www.HarborsidePress.com](http://www.HarborsidePress.com).

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## A Message to Our Colleagues and Friends

**O**n behalf of CancerCare, we are delighted to provide you with this landmark look into the lives of people who have been diagnosed with cancer. The **2016 CancerCare Patient Access and Engagement Report** presents the perspectives of thousands of Americans, broadly diverse in geography, age, education, income, ethnicity, and type and stage of cancer.

CancerCare initiated this project because, although we touch nearly 200,000 clients annually, there is much we want to know about how people experience life with and beyond cancer. We needed a better understanding of the specific needs of a broad range of cancer patients throughout their continuum of care.

The report is based on the results of six distinctly focused surveys, each with at least 500 respondents. The questionnaires probed patients' access to care as well as their experiences and engagement related to their diagnosis, treatment, communication with the clinical care team, financial and insurance issues, quality of life and symptom management, and survivorship.

Through this research, we learned that many patients experience cancer with far fewer resources than they need to make informed treatment decisions; manage their practical, emotional, and financial lives; and get the comprehensive care they need. We hope that our colleagues from other industries who care for people with cancer—clinicians, insurers, manufacturers, advocates—will consider these findings as they develop new and better ways to support patients. It is our intention to field special projects like this on a regular basis to help inform our programs as treatments, provider services, and payment systems evolve.

CancerCare and its Board of Trustees would like to thank the thousands of patients who shared their opinions and experiences with us. We also extend heartfelt appreciation to the members of our Advisory Board for their expert guidance through the research and report development. And to the many dedicated social workers at CancerCare, our devoted partner Harborside Press, as well as a cadre of dedicated volunteers, we are grateful for your hard work, professional judgment, and day-to-day management of the many details that a large project like this entails.

Sincerely,



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## *Executive Summary*

# Understanding the Experience of Cancer

When the National Cancer Act became law in 1971, cancer was considered largely untreatable, and the number of survivors in the United States hovered around a dismal 3 million.<sup>1</sup> Since then, significant progress in the biologic understanding of cancer, earlier detection, new diagnostic tools, advances in more effective therapies, and improvements in the management of cancer have made possible a record 14.5 million cancer survivors. And that number is expected to grow to 19 million by 2024.<sup>2</sup>

However, for many survivors, cancer and its treatment leave long-lasting—and even permanent—physical, psychosocial, and financial consequences in their wake. And although some survivors require no further intervention after their initial treatment, others face years of maintenance therapy to reduce the risk of cancer recurrence or need ongoing treatment to slow progression of advanced or metastatic disease. For survivors and their families, a cancer diagnosis can be life defining.

For more than 70 years, CancerCare has been providing support services and educational programs to help people affected by cancer manage the emotional, practical, and financial challenges of the disease. Yet, we know there is much to learn about how people

experience life with and beyond cancer, especially in the context of rapidly changing treatment options, care delivery systems, and payment models.

To gain a better understanding of and appreciation for the needs of survivors, their families, and caregivers—and how best to serve and engage them—we commissioned 6 nationwide online surveys (see page 10 for the study methodology). With sample sizes of at least 500 respondents each, diverse in age, gender, ethnicity, education, income, geography, cancer type and stage, more than 3,000 unique adults shared their experiences and perceptions on a wide range of topics that span from diagnosis to survivorship. The findings constitute the **2016 CancerCare Patient Access and Engagement Report**.

The report provides insight and context regarding a great many aspects of patients' cancer experiences, illuminating the gaps in care, identifying barriers to their engagement with care providers, and highlighting the physical, emotional, and financial toll of the illness on survivors. The results from our survey will help CancerCare and others to more effectively represent the concerns of survivors, advocate for better access to the most advanced care, and define and promote patient engagement to improve survivors' quality of life and optimize their disease outcomes.



## Survey 1: Understanding the Diagnosis of Cancer

This survey examined how well patients with cancer understood their diagnosis and the ways in which they responded. We probed how they sought information, the follow-up conversations they had with their medical team, their access to diagnostic testing, the role that insurance concerns played in their decisions, whether they had sufficient information about their cancer diagnosis, and where they found emotional and practical support to help them cope with the news of their diagnosis and identify next steps.

### *Survey 1: Key Findings*

- Most patients diagnosed with cancer followed their physicians' recommendations for diagnostic tests and said they understand the purpose and risks of those tests.
- Nearly all respondents could access diagnostic testing quickly and conveniently and had confidence in the expertise of the medical professionals who diagnosed them.
- One-quarter of respondents ages 25 to 54 disagreed with some of their doctors' recommendations for diagnostic testing and did not follow them.
- Fewer than half of the total respondents discussed



the cost of follow-up testing with their physician. Among 25 to 54 year olds, one-quarter of white patients and two-thirds of African American and Hispanic patients talked with their physicians about this issue.

- Patients ages 25 to 54 had more post-diagnosis conversations about their cancer with nurses, religious leaders, social workers, physician assistants, or nurse practitioners as did patients 55 and older. African American and Hispanic patients in this age group had 35% more conversations with their medical team than their white counterparts.

## Survey 2: Treatment Planning

At the heart of patient-centered care is effective communication and shared decision-making. In this survey, we examined how well patients were able to engage with their clinical care team during the planning of their cancer treatment and the extent to which they participated in the decision-making. We queried whether respondents had enough information about treatment options to make informed decisions, including treatment benefits and risks, clinical trial opportunities, the impact of their cancer and treatment on their ability to work and manage their lives and relationships, and how much of the cost of therapy



would be their responsibility. Other topics in this survey included opinions about their care teams, adherence to treatment and the roles of caregivers.

### ***Survey 2: Key Findings***

- Only about two-thirds of respondents reported having adequate information about the benefits of their treatment plan, its potential side effects, or the reasons the treatment was recommended.
- Only 13% of overall respondents felt adequately informed about clinical trial opportunities.
- Less than half of respondents said they had adequate information on a variety of concerns, including whether they would be able to continue working during treatment, how much home care was required, the emotional impact of having cancer and its treatment, and how much of the cost of care was their personal responsibility.
- Fewer than half of respondents obtained a second opinion about their treatment plan.
- The majority of respondents said they trusted their physicians, understood the reason for their medications, and believed they were getting the best care. One-quarter of respondents said they were not getting the most advanced care available. Only about half reported their care team regularly inquired about their level of distress.
- Patient satisfaction levels were low regarding their medical team's attention to clinical trial opportunities and new treatment options.

### **Survey 3: Communication With the Care Team**

Here we investigated patients' perceptions of their relationships with their physicians, how well respon-

dents understood discussions with their clinical care team, how accessible providers were for follow-up discussion, with whom they preferred to consult, and how medical care teams responded to patients' emotional, physical, and financial distress. Other areas of inquiry included adherence to the treatment plan and preferred channels of communication.

### ***Survey 3: Key Findings***

- Most respondents were satisfied with their clinical care coordination, understood discussions with their providers about their cancer and its treatment, and were able to connect with members of their health-care team in a reasonable amount of time.
- Among patients ages 25 to 54, white patients were significantly more likely than African American and Hispanic patients to report that they had confidence in their ability to talk to their physicians about their concerns and that their physicians spoke to them in understandable language. Conversely, African American respondents in this age segment were significantly more likely to report that their physicians listened to their concerns and asked for their opinions.
- About 20% of African American and Hispanic respondents reported that they experienced serious communication problems with their clinical care team, including a lack of translation services, difficulty understanding what their doctors said about their treatment, and discomfort talking about how cultural, religious, and personal values affected their treatment.
- Most patients considered their oncologists and primary care physicians to be part of their cancer care



team. Nearly half of the respondents also included nurses on their care team.

- Respondents generally chose to discuss treatment-related issues with their oncologists. For lifestyle concerns, such as diet and exercise, sexuality and intimacy, work, emotional distress, and questions about end-of-life issues, they preferred talking with their primary care physicians.
- Fewer than half of the respondents were asked by a member of their care team if they were feeling distressed by their cancer or its treatment.
- Despite the prevalence of emotional and financial distress among cancer patients, survey respondents reported few referrals by members of their care team to counseling services or other professionals for support.

#### **Survey 4: Financial and Insurance Issues**

In this survey, we assessed how well patients understood their insurance coverage out-of-pocket costs; awareness of clinical pathways, guidelines, and step therapy; impact of insurance on access; monthly spending during treatment; its impact on patients' finances, care team involvement, and support; and the steps patients took to reduce expenses.

##### ***Survey 4: Key Findings***

- Only about one-half of respondents reported understanding their health insurance coverage for their cancer care “completely” or “very well.”
- Twenty-five percent of patients between the ages of 25 and 64 stopped working during active treatment, and 13% switched from full-time to part-time employment. Only one-third continued working full-time during treatment.

- Despite the 58% of respondents reporting being distressed about their finances during treatment, 25% of those ages 25 to 64 said their medical care team never considered their financial situation during treatment planning, and 34% said it was only “sometimes” considered.
- Many patients used care-altering strategies to reduce their expenses, some of which may have compromised their cancer treatment.
- To afford treatment, one-third of respondents ages 25 to 54 reported cutting back on daily essentials, such as groceries and transportation, and/or borrowing from family members and friends; 21% missed a utility bill payment; and 17% missed a rent or mortgage payment.
- When asked to tabulate their average monthly out-of-pocket spending for treatment-related expenses, non-elderly respondents reported spending \$1,112, nearly twice as much as those 65 and older.
- Among those ages 25 to 64, 44% were concerned that they would lose their insurance if they were unable to work.

#### **Survey 5: Symptoms, Side Effects, and Quality of Life**

This survey explored how patients experienced cancer and its treatment in the context of day-to-day living. Questions focused on quality-of-life priorities, how well patients were prepared for various symptoms and side effects, the impact of those adverse events on their lives, where and how they sought advice, the responsiveness of their care teams, their experiences with pain and concerns about treating it, and their use of various support therapies.

# 2016 Patient Access & Engagement Report



## ***Survey 5: Key Findings***

- Moderate to severe fatigue was the most common symptom reported, with nearly half of women reporting that it interfered with their day-to-day activities. Women were more likely than men to report experiencing anxiety, having difficulty exercising and staying physically active, and suffering from nausea or vomiting.
- Although the majority of total respondents reported feeling satisfied with how well their clinical care team prepared them for cancer-related symptoms and side effects, 35% of those ages 25 to 44 reported feeling “very” or “somewhat dissatisfied.”
- Respondents most often discussed cancer-related symptoms and side effects with their physicians and to a lesser extent with a physician assistant, nurse practitioner, or nurse. In these discussions, nearly 40% did not report symptoms or side effects because they did not want to “bother” their doctors.
- Nearly 40% of respondents ages 25 to 64 were required by their insurers to follow a “fail-first” regimen in treating symptoms and side effects. For most of them, this required that they use a non-preferred medicine for 2 to 3 months.
- One-quarter of respondents used cancer-specific



counseling or support services to help them cope with their cancer. Those between the ages of 25 and 44 and in active treatment were twice as likely to have used these services.

- One-quarter to more than one-third of respondents said their ability to perform day-to-day activities—such as working, exercising, entertaining friends and family, caring for children, and preparing meals—was dramatically compromised.
- One-third of respondents reported that they did not have a caregiver to support them through treatment and help with their activities of daily living and household responsibilities.

### **Survey 6: Survivorship**

In this survey, we wanted a better understanding of how cancer changes survivors' lives, especially younger survivors. Questions focused on the ways in which having cancer affected their quality of life, relationships, and perspectives, and how their lives have changed since their diagnosis. We also asked them about their knowledge and use of advance directives, living wills, and health-care proxies as well as their familiarity with and perceptions regarding palliative care and hospice.

#### ***Survey 6: Key Findings***

- Living with cancer brings about profound physical,



# Executive Summary

emotional, financial, social, and spiritual changes for most patients, but this is especially true for younger patients between the ages of 25 and 54.

- Women were much more likely than men to report that cancer had a positive effect on at least some part of their lives, including relationships with family members and friends.
- Cancer caused significant stress for most respondents; they reported the impact the disease had on their family members to be the most stressful element. In all aspects of life mentioned in this survey, respondents ages 25 to 54 were significantly more likely than those ages 55 and older to report being “highly” or “extremely distressed.”
- Receiving a cancer diagnosis prompted a considerable proportion of respondents under age 45 to have end-of-life discussions with family members, including where they would like to spend their final days, when life-prolonging medical care should be used, their expressions of fears and concerns about dying, who they wanted to make medical decisions if they were unable, their beliefs about preserving life as long as possible, and their hopes

for their end-of-life care. However, a significant proportion of respondents ages 45 and older had not communicated their wishes about these topics to family members or friends.

- After being diagnosed with cancer, about one-third of respondents younger than age 45 had some form of legal document in place that detailed their end-of-life wishes: health-care power of attorney, health-care proxy, living will, or last will and testament. Among respondents older than 45, between 29% and 46% had not taken steps to complete at least one of these legal documents.
- Respondents from all age groups had widespread misconceptions about palliative and hospice care. ■

## References

1. American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2014–2015. Atlanta: American Cancer Society; 2014.
2. Cancer.Net, a website of the American Society of Clinical Oncology: About Clinical Trials. Available at [cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/about-clinical-trials](http://cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/about-clinical-trials). Accessed March 18, 2016.



# Methodology

In 2015, CancerCare initiated a research project to define engagement according to people diagnosed with cancer; identify barriers to their engagement with care providers; and characterize the financial, emotional, social, and quality-of-life costs of cancer to patients and families. The **2016 CancerCare Patient Access and Engagement Report** is a summary and analysis of the data collected through this project.

## Survey Development

Surveys were developed to focus on six separate components of the patient experience:

1. Understanding the diagnosis of cancer
2. Participation in treatment decisions and planning
3. Communication with the care team
4. Financial and insurance issues
5. Symptoms, side effects, and quality of life
6. Survivorship

The multitude of diverse patient experiences shared with CancerCare social workers and counselors guided the development of our survey questions. We asked our advisory board, a group that includes renowned experts in survey development, patient engagement, and care of cancer patients, to review and comment on the questionnaires. We then piloted the surveys with CancerCare clients to ensure the questions were clear and the surveys could be completed in a reasonable amount of time.

The six surveys averaged 41 questions and took 20 minutes to complete. At the beginning of each, respondents were asked to complete the 11-question Patient Activation Measure® (PAM®), a validated survey tool developed in 2004 by Judith H. Hibbard, PhD, MPH, at the University of Oregon. Patient activation refers to an individual's knowledge, skills, and confidence for managing one's own health and health care.<sup>1</sup> Although not discussed in this report, the PAM results combined with the cancer-specific findings are being studied to inform recommendations on how proven strategies promoting activation may be applied to help cancer patients more effectively engage with their health care.

**This study was conceived to better understand the unmet needs of cancer patients across the United States.**

## Patient Recruitment and Survey Deployment

We sought to create respondent samples that represented the national population of cancer patients by gender, age, ethnicity, income, education, and cancer type. Because the surveys were to be administered on-line, we were able to recruit participants through consumer panels. All survey respondents were at least 25 years old and had received a defin-

itive diagnosis of cancer from a physician or other health-care practitioner.

Through filters, the research vendors used specific criteria so that each survey sample had approximately 25% coverage in the Northeast, Midwest, Southeast, and Southwest/West. To reflect the experiences of people with many types of cancer, we targeted an approximate split into one 50% subgroup of the most common cancers (lung, breast, colorectal, and prostate) and another 50% subgroup of all other cancers, excluding non-melanoma skin cancer. The target number of valid responses for each survey was 500 or more; the research vendors sent approximately 3,000 e-mails per survey to reach this goal. Respondents who accepted the invitation to participate were randomly assigned to one of the six surveys to complete.

CancerCare made a deliberate decision not to ask patients in its own client database to complete these surveys. The intent was to gather data on the experiences of a broad and diverse group of people with cancer, and not bias the results by enlisting those who have used our services and therefore are at least somewhat engaged in their own care. For that same reason, we did not solicit participation through on-line communities or chat rooms.

The six surveys were administered from July through December 2015.

## Data Analysis and Reporting

Researchers collected, sorted, validated, and aggregated the data, producing cross-tab reports of the results. CancerCare and Harborside Press then analyzed the data and examined the cross-tab reports for any sig-

nificant differences among the profile characteristics. Differences between responses across groups of respondents were tested statistically at a confidence level of 0.90, meaning that there is a 90% probability the differences between any two groups of patients are meaningful, rather than random.

**The multitude of diverse patient experiences shared with CancerCare social workers and counselors guided the development of our survey questions.**

Harborside Press created the final report, with stages of review and approval from CancerCare. The advisory board of the **2016 CancerCare Patient Access and Engagement Report** reviewed the survey methodology, the data analyses, and the final report before publication.

This report represents a first examination of the survey data. Plans for further work with these data include deep analyses of the responses within each profile characteristic.

## Study Limitations

This study was conceived to better understand the unmet needs of cancer patients across the United States. Although the findings of this study may in fact be representative of cancer patients overall, we are only claiming with confidence that the results reflect the populations as defined within each survey.



To be truly representative:

- Every member of the population should be eligible to participate in the study
- Every member of the population should be equally likely to participate in the study
- Participants should be randomly selected
- A sufficient number of participants need to participate in the study

**We have a high degree of confidence that the results reflect the experiences, perceptions, and opinions of a significant proportion of the people across the US who have been diagnosed with cancer.**

The chief constraints to capturing truly representative samples for each survey were availability of appropriate respondents and funding. To the best of our knowledge, no one sample exists that includes every cancer patient in the United States. Our approach to

be as representative as possible and to reduce bias was to recruit participants for this study from reputable national panels of consumers. These panels include millions of US consumers who are profiled on a broad range of characteristics.

Since the studies were conducted via online surveys, our samples skew toward more educated, affluent, and engaged respondents. This was especially evident in the profile characteristics of nonwhite respondents.

The funding available for this project limited us to obtaining 500 respondents per survey. Considering our interest in identifying differences based on profile characteristics, we applied recruitment quotas on education, age, income, and type of cancer, while also prioritizing diverse respondents.

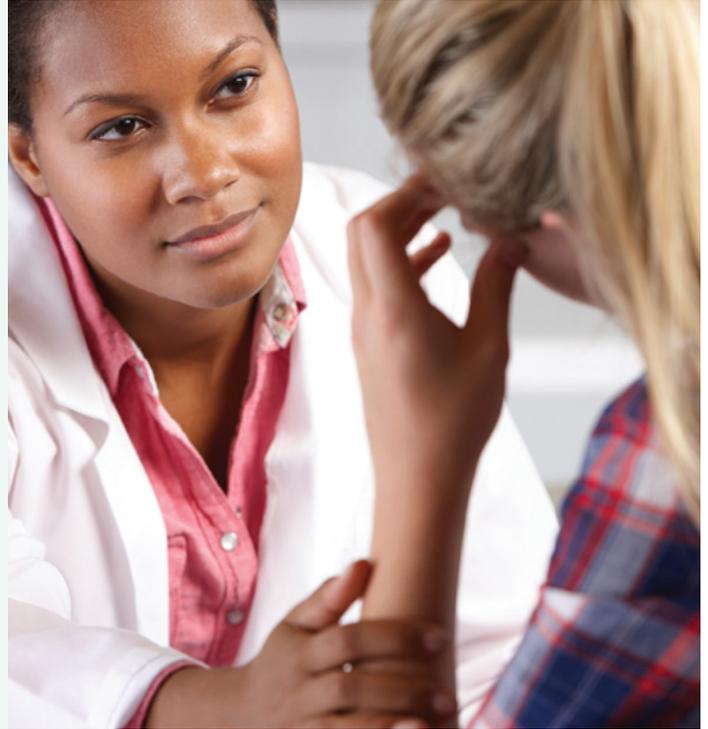
In summary, although we do not claim our report findings to be precisely representative of the US population, we have a high degree of confidence that the results reflect the experiences, perceptions, and opinions of a significant proportion of the people across the US who have been diagnosed with cancer and that the report is a valuable addition to existing knowledge.

## Reference

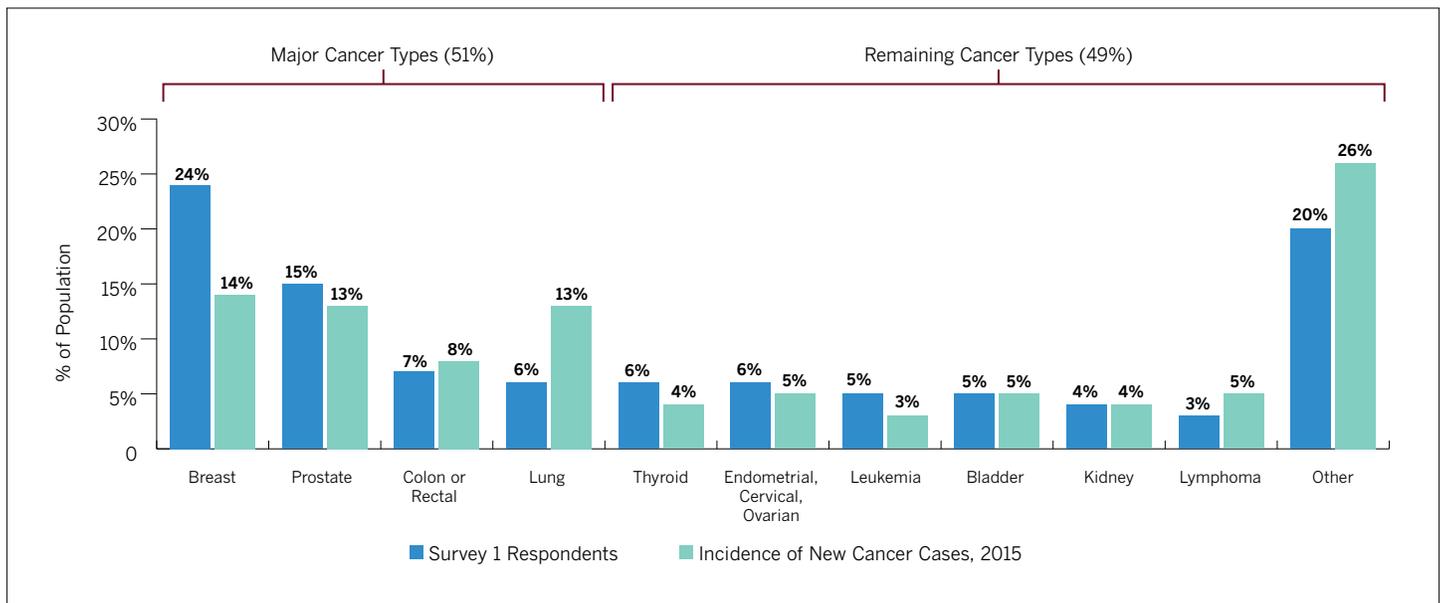
1. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res* 2005;40:1918–1930. doi:10.1111/j.1475-6773.2005.00438.x. ■

**F**or *Survey 1: Understanding the Diagnosis of Cancer*, CancerCare set out to understand how patients responded to being diagnosed with cancer, what access they had to diagnostic testing, how they complied with follow-up recommendations, how they gathered information, who they consulted regarding their diagnosis, and what support was available during this anxious time.

See Figure 1 for a distribution of the respondents by cancer type.<sup>1</sup>

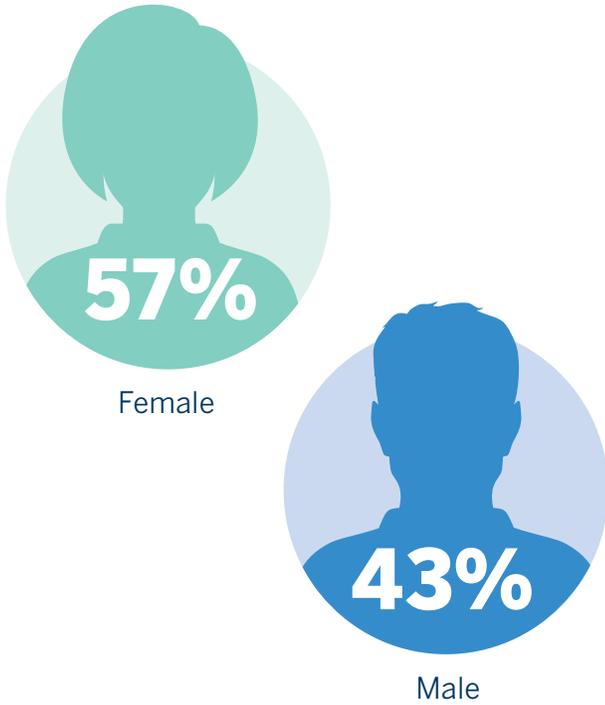


**Figure 1: Distribution of Respondents by Cancer Type (N=500)**

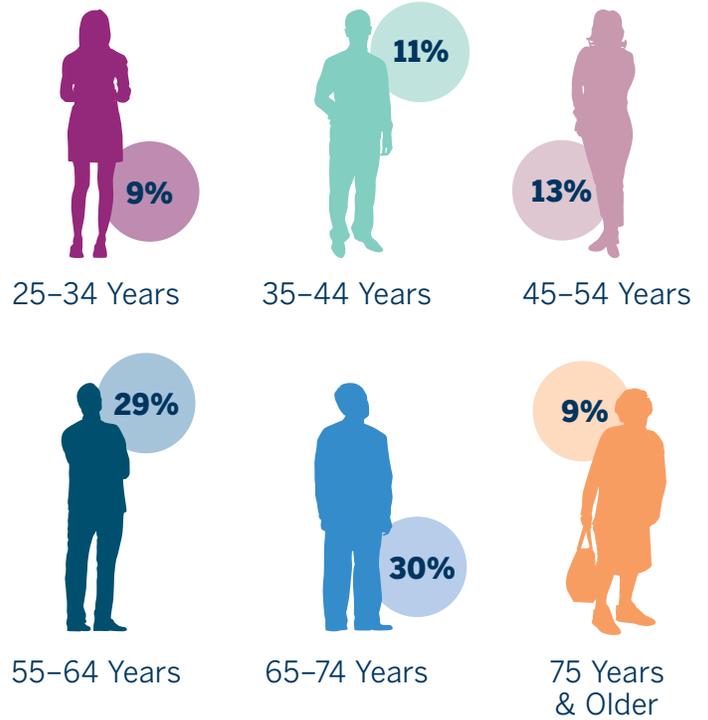


# Survey 1: Respondent Demographics (N=500)

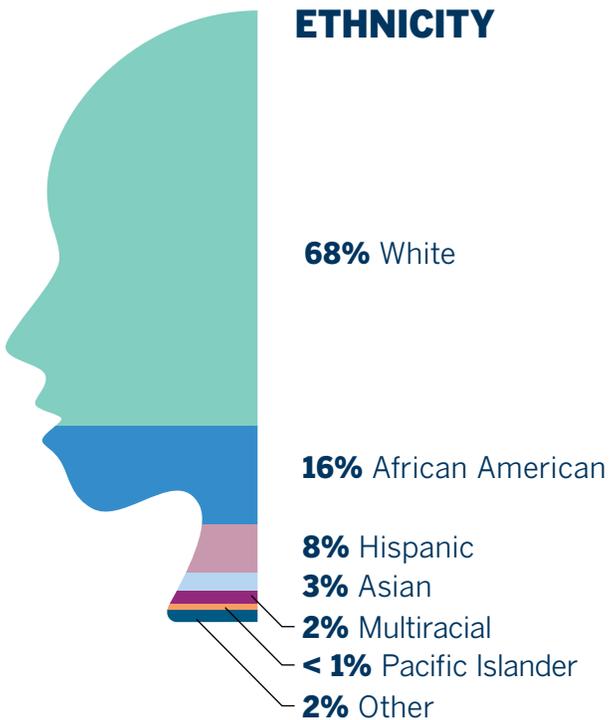
## GENDER



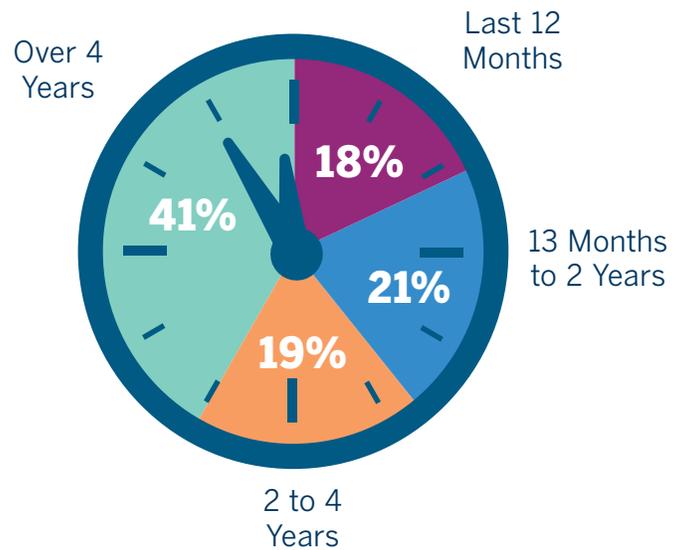
## AGE



## ETHNICITY

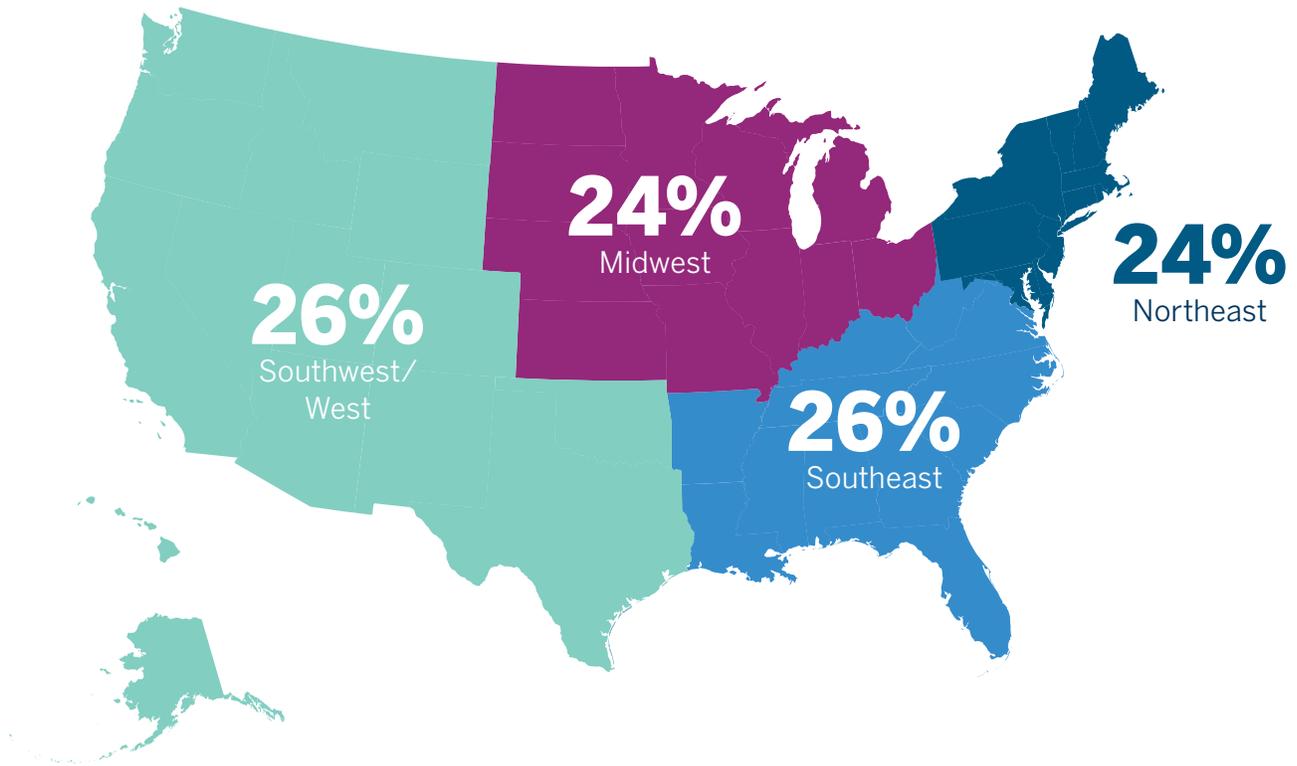


## TIME SINCE FIRST DIAGNOSED

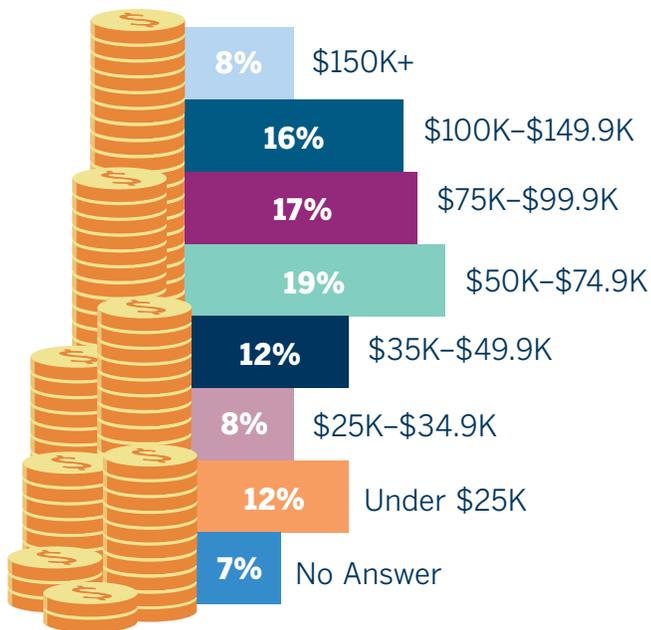


# Survey 1: Respondent Demographics (N=500)

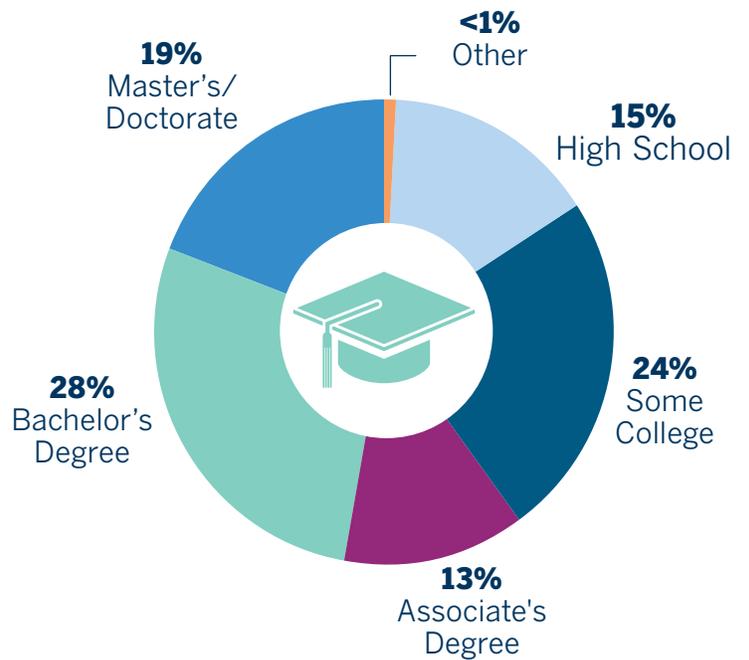
## REGION



## INCOME



## EDUCATION





### Observations

According to our survey findings, about one-half of patients with the most common cancers discovered them through screening, while one-third noticed a change in their health and consulted their physician. Among those with less common cancers, 42% had consulted a doctor after noticing a change in their health and 24% said their cancer was detected through screening. Within both groups, 15% indicated they mentioned symptoms during their regular health check-up, prompting their doctor to order tests.

### Financial Concerns

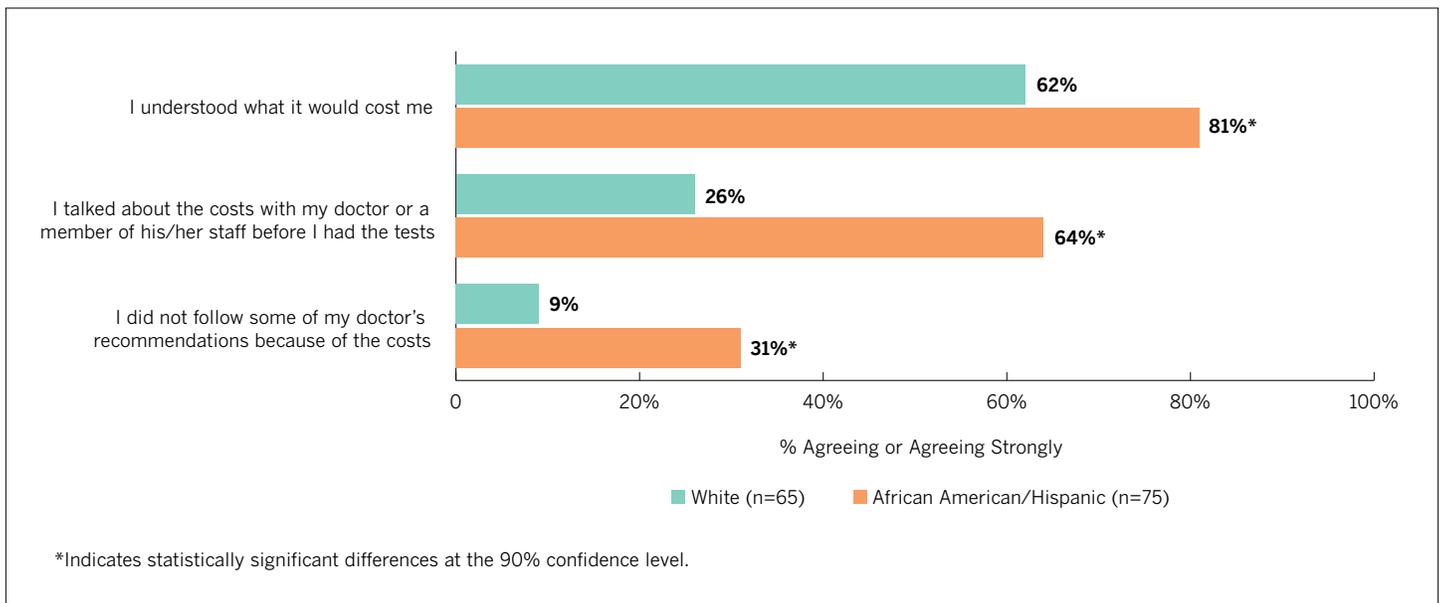
Once cancer was suspected, nearly all of the respondents said they understood the purpose and risks of undergoing further diagnostic testing, and most followed their physicians' recommendations for additional tests. One-quarter to

more than one-half of those between the ages of 25 and 54 years discussed test costs with their doctor as compared to 25% of older patients. More than one-fifth of the younger age group did not follow some of their doctors' recommendations because of cost. African American and Hispanic respondents ages 25 to 54 years were significantly more aware of and concerned about costs of diagnostic tests than their white counterparts. Nearly one-third of younger African American and Hispanic patients did not follow some of their doctors' recommendations because of cost (Figure 2).

These findings are particularly concerning, since nearly all patients in our survey had either public or private health insurance. Although some or most of the direct medical costs to confirm a cancer diagnosis are typically covered, out-of-pocket costs such as co-pays can still be quite high. Financial concerns may be hindering some patients from getting the diagnostic care needed to identify their cancer.

*Continued on page 18*

**Figure 2: Testing Costs and Younger Patients (Ages 25 to 54)**





CANCERcare®

# Vera S.

## How I Partnered With My Oncologist

**W**hen Vera S. was diagnosed with breast cancer at age 72, she knew she needed to learn as much as possible about her disease and the steps she would need to take to ensure a positive outcome.

“Coping with such a serious diagnosis was all new to me,” says Vera. “I had to figure out what to do with all the information I was accumulating. It was like learning a new language. I was afraid, but I did not let my fear control me. My need for organization and clarity and getting myself out of chaos is what motivated me.”

Vera was determined to assemble a top-notch medical team and partner with each member of that team during every step of her care. Before her first meeting with her surgical oncologist, Vera read his profile on his hospital’s website to learn about his background and get a sense of whether he would be a good match for her. He was. When Vera walked into his office, she was greeted with a warm smile and presented with a complete assessment of her breast cancer and the course of treatment he recommended. Vera then met with her medical oncologist who, after discussing her treatment plan with the hospital’s tumor board, agreed with her surgeon’s recommendations, and outlined the side effects she could expect.

The more Vera learned about her disease, the more proactive she became. She made lists of questions to ask her oncologists at every office visit and took notes, which

later helped her prevent a serious mix-up when she was nearly given the wrong drug.

“All of my doctors told me I had to be my own best advocate, and because I became so educated about my care and kept reading over my notes, I knew I wasn’t supposed to get that particular drug,” says Vera.

**“My need for organization and clarity and getting myself out of chaos is what motivated me.”**

Vera continued to gather information about adopting healthy habits, revising her diet and exercise routine, and making sure she stayed connected to her circle of friends who took turns accompanying her to every medical appointment. Vera also continued to learn about her cancer from brochures she picked up during hospital visits and counselors she met at *CancerCare*.

Looking back on her treatment, Vera says her strong relationship with her medical team stemmed from a place of mutual respect. “I felt like I was a partner with my doctors because they were so respectful of my questions, being careful to answer all of them, and never showing any impatience. I established a good rapport with my oncologists and nurses. I was taken care of very well.” ■



Continued from page 16

We examine in greater detail the financial distress many cancer patients face in Survey 4, which focuses on financial and insurance issues.

### Access to Diagnostic Tests

Nearly all respondents said they had convenient and timely access to diagnostic testing and confidence in the expertise of those evaluating the results. However, more than one-quarter of patients ages 25 to 54 did not agree with their providers' testing recommendations and did not follow them (Figure 3).

### Understanding the Diagnosis

The majority of survey respondents learned they had cancer from a physician (89%), with just a minimal percentage (5%) receiving the diagnosis from a physician assistant (PA) or nurse practitioner (NP). More African Americans

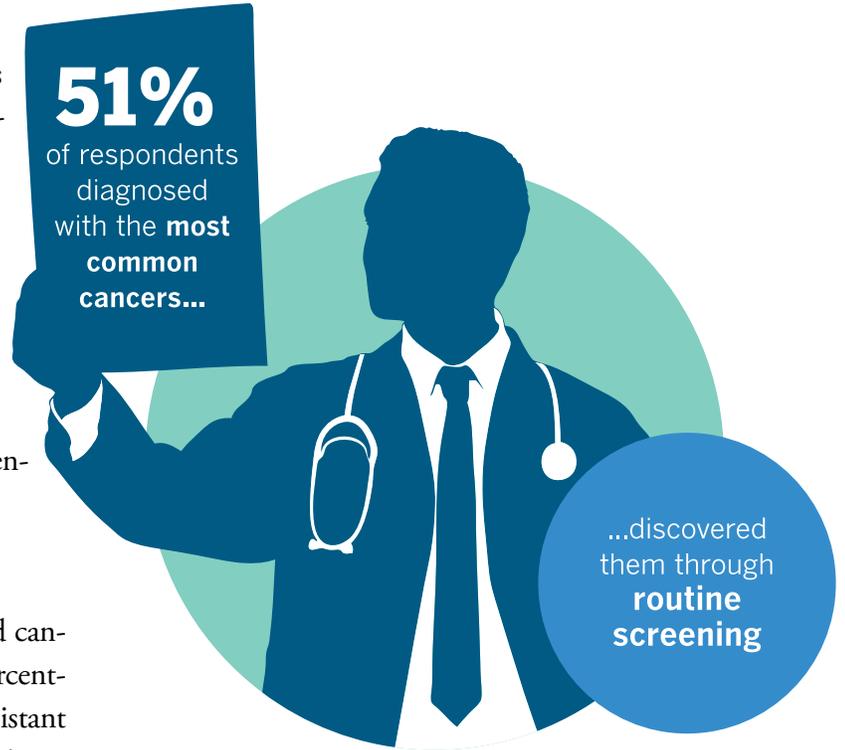
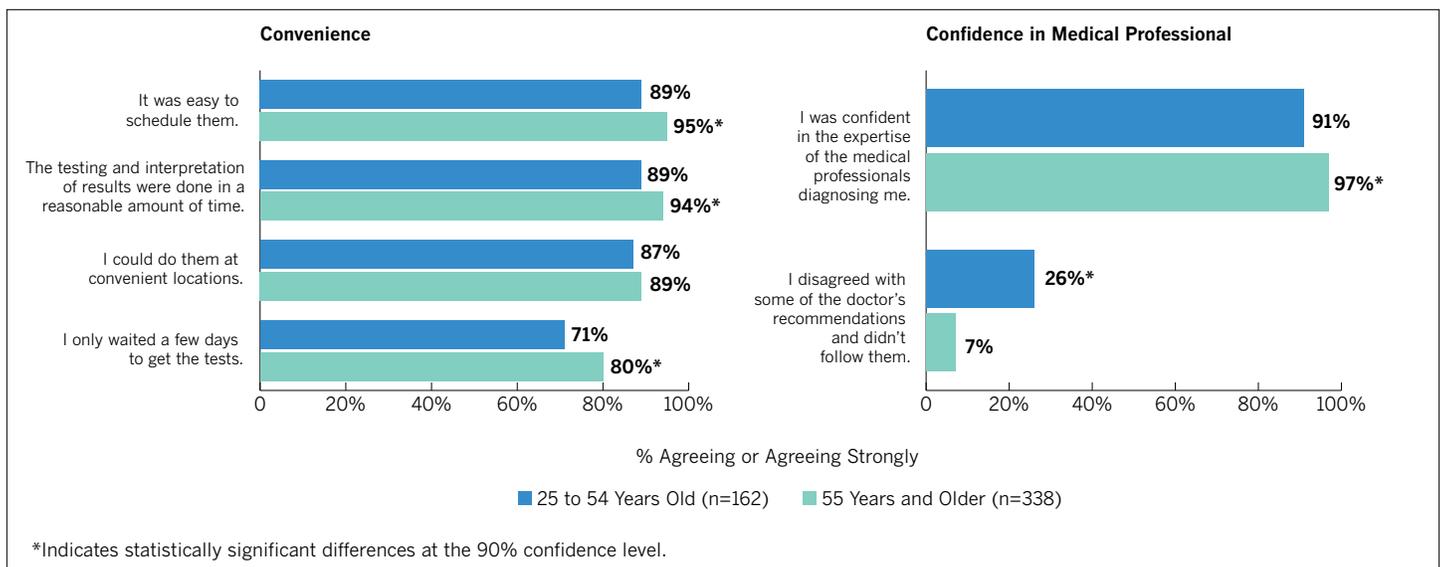
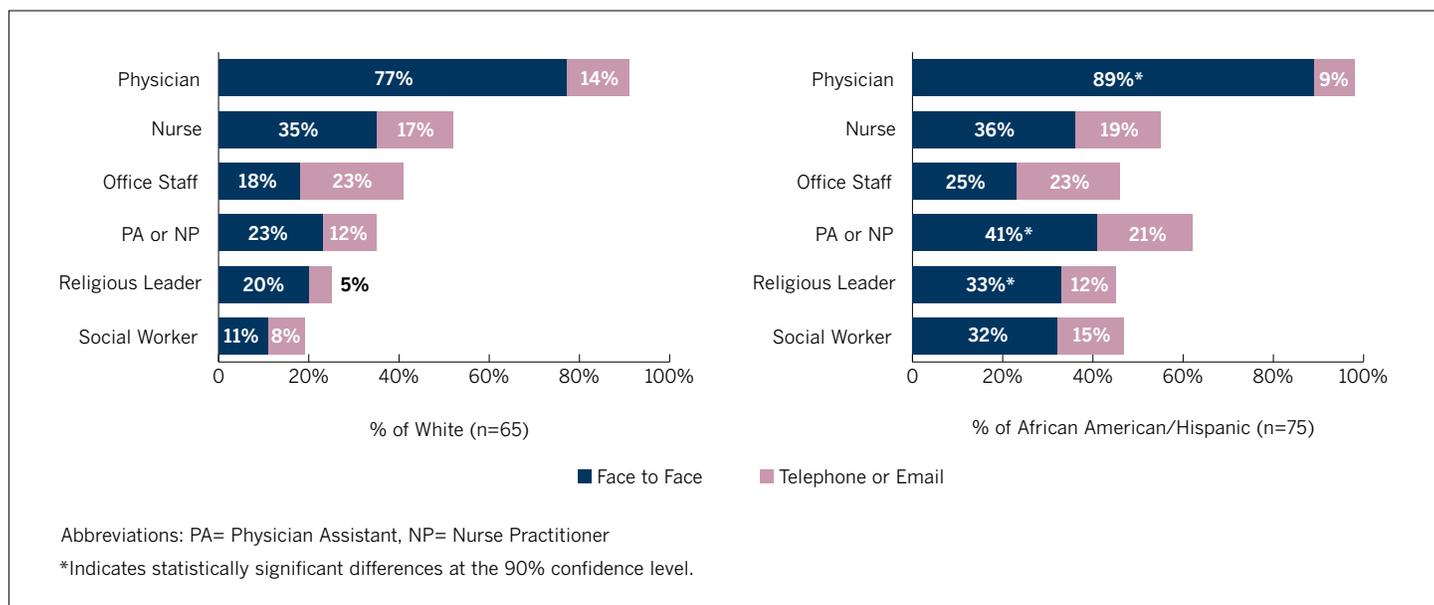


Figure 3: Opinions About Testing



# Survey 1: Understanding the Diagnosis of Cancer

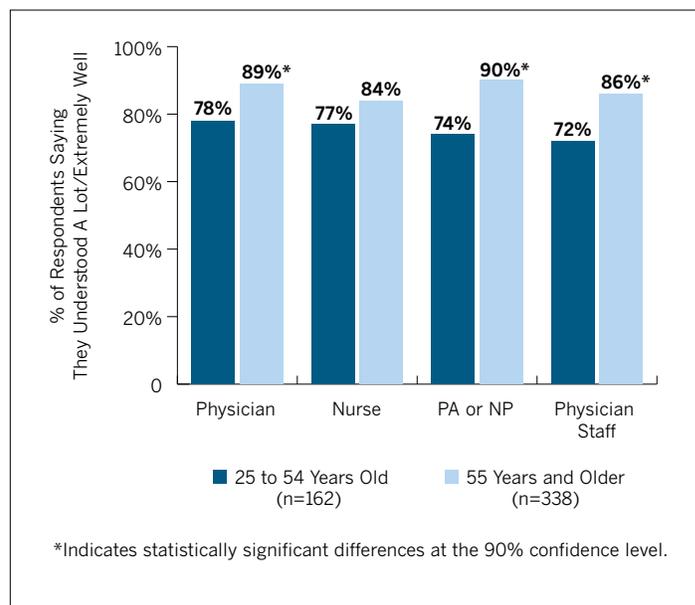
**Figure 4: Conversation After Cancer Diagnosis for Younger Patients (Ages 25 to 54)**



and Hispanics (12%) than white patients (2%), however, were told they had cancer by a PA or NP. Three-fourths of survey respondents met with more than one doctor in order to confirm the diagnosis of cancer. Nearly all respondents had conversations with doctors after learning they had cancer. Patients ages 25 to 54 years engaged in conversations with PAs, NPs, physician office staff, religious leaders, and social workers at a much higher rate than did patients 55 years and older. Interestingly, African American and Hispanic respondents ages 25 to 54 years engaged in more conversations following their diagnosis than did their white counterparts and were significantly more likely to speak with PAs, NPs, social workers, and religious leaders than white patients in this age bracket (Figure 4).

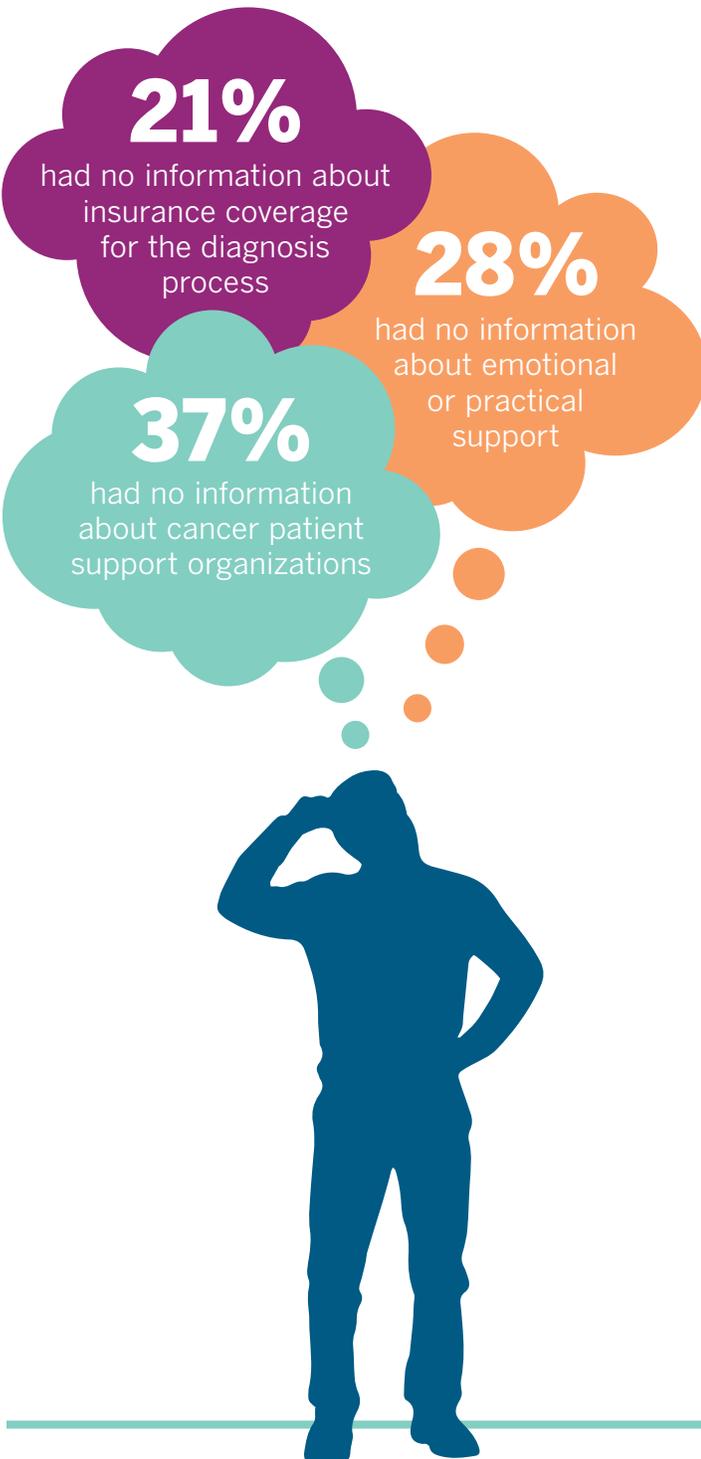
Older respondents were significantly more likely than younger patients to say they understood these conversations with the care team “a lot” or “extremely well” (Figure 5).

**Figure 5: Patients Who Understood Their Conversations With Members of Care Team**





## Patients Need More Information at the Time of Diagnosis



Just over half of respondents received cancer literature and/or videos from their physicians to help them understand their diagnosis. Less than a third reported receiving this information from a nurse, PA, or NP.

## Gaps in Information About Cancer Support Services

The majority of respondents, regardless of ethnicity or age, said they had enough information at the time of their initial diagnosis to understand the type and stage of cancer they had, as well as where to find additional information about their cancer. However, one-fifth to one-third of the respondents said they did not know whether their insurance covered the costs of their diagnostic tests, where to find emotional and practical support to help them cope with their cancer diagnosis, or how to access patient support organizations.

Our survey reinforces findings from the medical literature<sup>2</sup> that large numbers of patients with cancer do not receive adequate information about their disease following a cancer diagnosis. This knowledge gap may impact patients' ability to manage their cancer, to follow through with medical recommendations, and to address their health-related quality of life and any anxiety and depression relating to their diagnosis. Patients whose information needs have been met and patients who experience fewer information barriers generally have a higher health-related quality of life and less anxiety and depression.<sup>3</sup>

## Conclusions and Recommendations

The findings of this survey indicate that high insurance deductibles, copayments, and other costs related to accessing medical care are important barriers to following physicians' recommendations at the time of a cancer diagnosis. New-

# Survey 1: Understanding the Diagnosis of Cancer

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## KEY FINDINGS FROM SURVEY 1: UNDERSTANDING THE DIAGNOSIS OF CANCER

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■ Most patients diagnosed with cancer followed their physicians' recommendations for diagnostic tests, and a large majority understood the purpose and risks of those tests.

■ Nearly all the respondents were able to quickly and conveniently access diagnostic testing to confirm their diagnosis, and more than 90% reported having confidence in the expertise of the medical professionals who diagnosed them.

■ Fewer than half of total respondents discussed the cost of follow-up testing with their physician. Among those ages 25 to 54 years, however, one-quarter of white patients and two-thirds of African American and Hispanic patients talked with their physician about this issue.

■ One-quarter of respondents ages 25 to 54 disagreed with some of their doctors' recommendations and did not follow them.

■ After learning they had cancer, nearly all respondents had conversations with a physician within a few days. They also had conversations with nurses, reli-

**African American and Hispanic respondents had 35% more conversations with the medical team than their white counterparts.**

gious leaders, social workers, physician assistants, or nurse practitioners about their cancer, with those ages 25 to 54 having more than those respondents 55 and older. African American and Hispanic patients ages 25 to 54 had 35% more conversations with the medical team than their white counterparts.

■ Most respondents said they understood the conversations they had with their clinicians regarding their diagnosis. Older respondents were significantly more likely than younger patients (between the ages of 25 and 54) to say they understood conversations "a lot" or "extremely well."

ly diagnosed cancer patients must have access to resources that can help address their financial concerns related to treatment. They also need access to the practical and psychosocial support services that can help them cope with the myriad challenges accompanying the news of their cancer.

We cannot underestimate the importance of patient access to resources at the time of diagnosis. We need visible

and aggressive efforts to generate awareness among medical professionals that patients are forgoing diagnostic testing and treatment due to financial distress. Clinicians should be prepared to shepherd patients toward support services that can help them navigate their financial challenges and prepare them practically and emotionally to engage with providers in treatment planning. In addition, the lay pub-

# Survey 1: Understanding the Diagnosis of Cancer

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lic would benefit significantly from knowing that there are financial, educational, and psychosocial resources available for those affected by cancer. ■

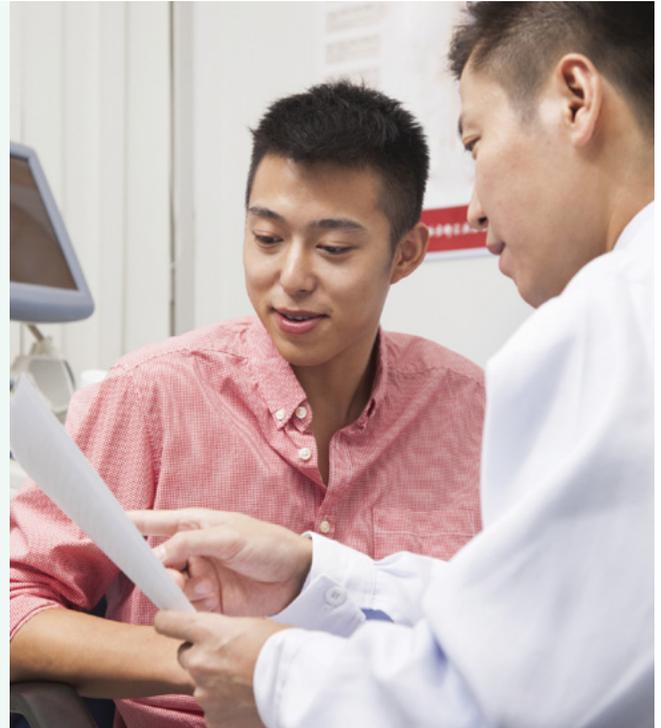
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1. American Cancer Society. Cancer Facts & Figures 2015. Atlanta: American Cancer Society; 2015.
2. Jean-Pierre P, Fiscella K, Griggs J, et al: Race/ethnicity-based concerns over understanding cancer diagnosis and treatment plan. *J Natl Med Assoc* 102:184–189, 2010.
3. Husson O, Mols F, van de Poll-Franse LV: The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: A systematic review. *Ann Oncol* 22:761–772, 2011.

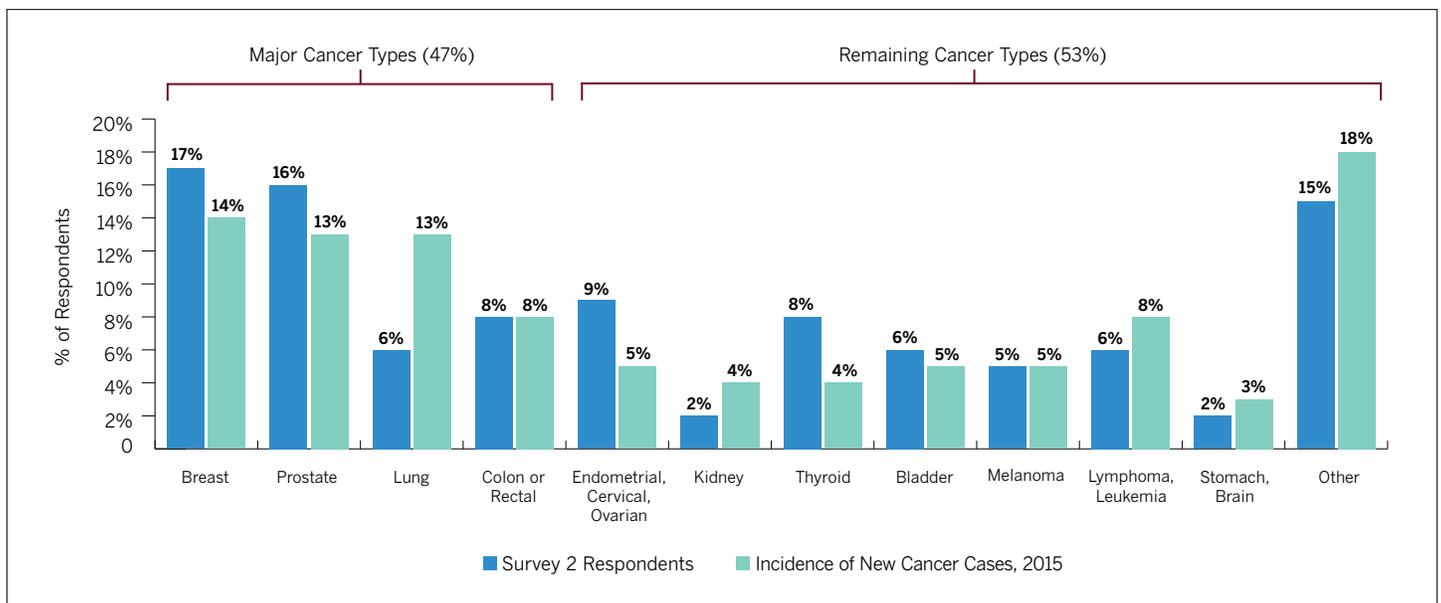




In *Survey 2: Treatment Planning*, we examined the factors impacting—and sometimes impeding—how patients engage and participate with their clinical care team during the planning of their cancer treatment. We surveyed their access to the information they needed to make informed decisions, such as the benefits and risks of treatment options and how they would affect important aspects of their lives, clinical trial opportunities, and their out-of-pocket financial responsibility for the care they were about to receive. We also wanted to know more about how well respondents complied with various elements of their treatment plans, how they perceived their physicians and care quality, how responsive their clinical care team was to their needs and concerns, and what role their caregivers played.

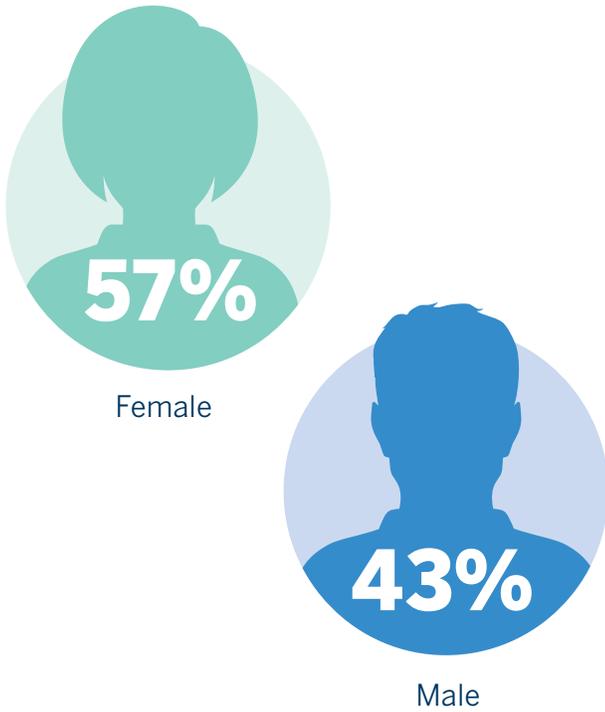


**Figure 1: Distribution of Respondents by Cancer Type (N=504)**

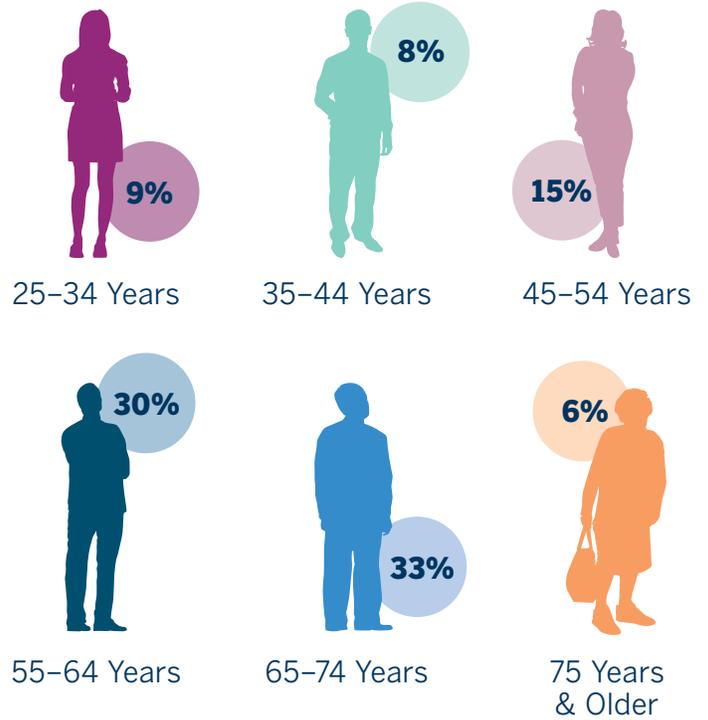


## Survey 2: Respondent Demographics (N=504)

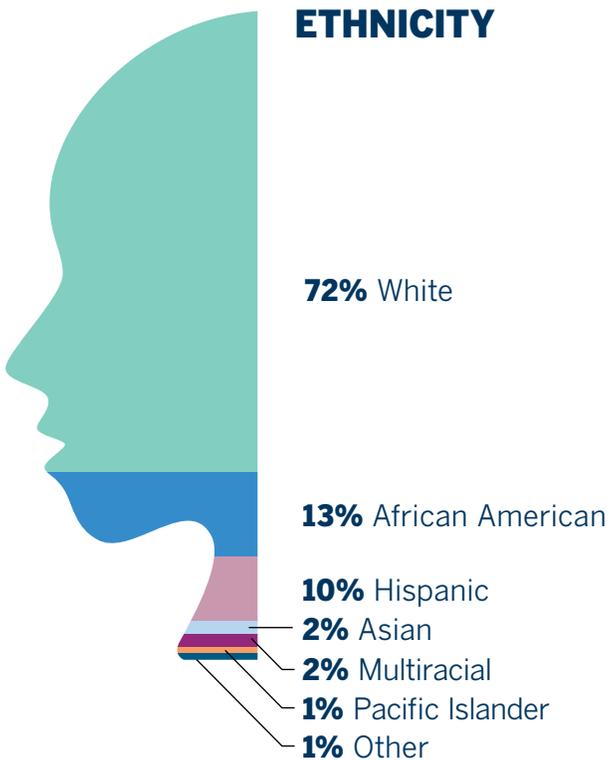
### GENDER



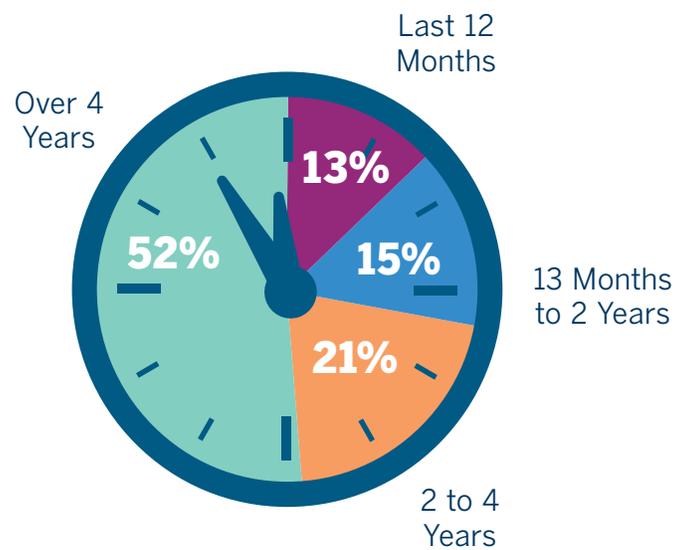
### AGE



### ETHNICITY

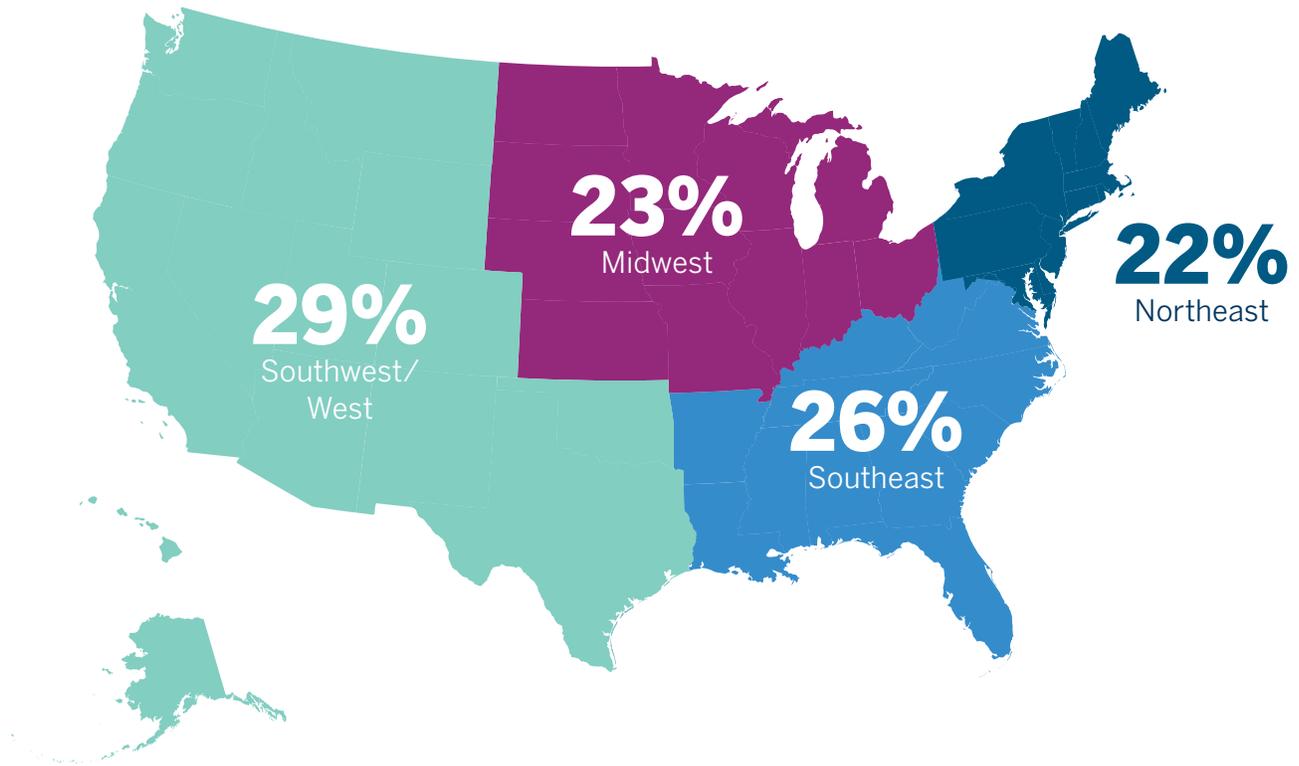


### TIME SINCE FIRST DIAGNOSED

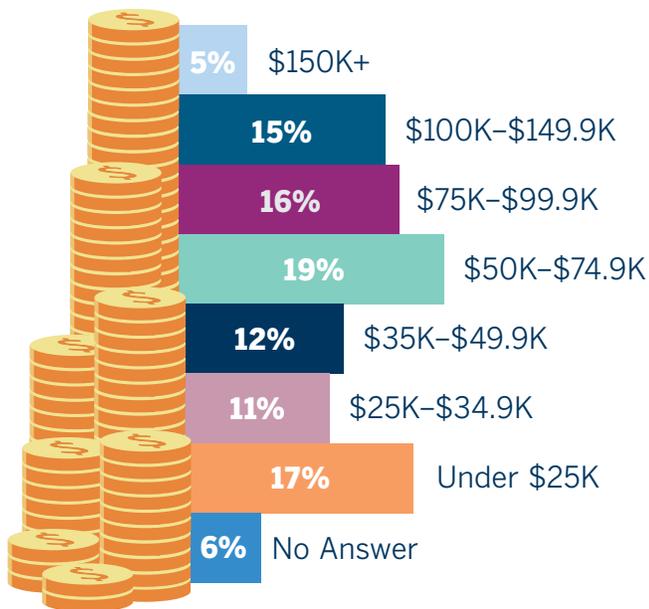


## Survey 2: Respondent Demographics (N=504)

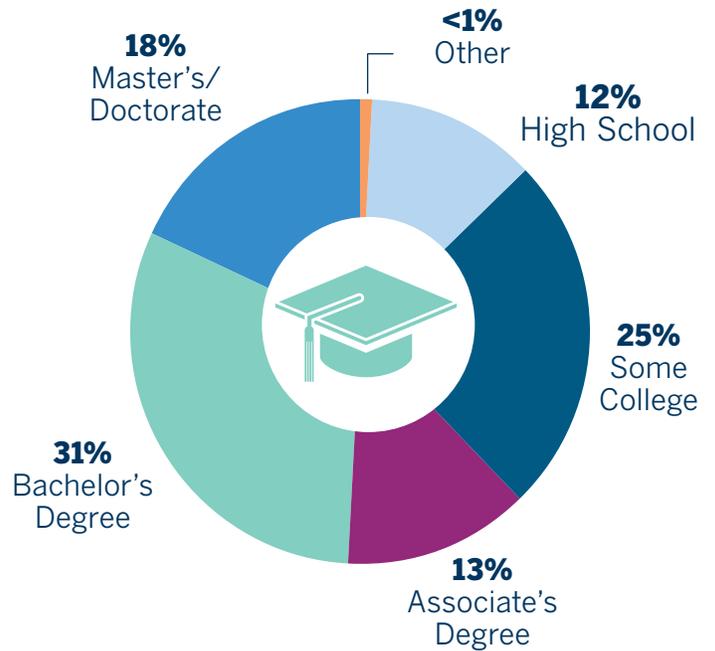
### REGION



### INCOME



### EDUCATION





**Figure 2: Patients With Enough Information About Aspects of Cancer Treatment**

	Treatment Facility	
	Academic Medical Center (n=148)	Community Hospital/Cancer Center/MD (n=325)
Benefits of the treatment plan	72%	66%
Possible side effects of the treatments	69%	63%
Goals of the plan (cure, control, keeping you comfortable)	71%*	60%
Reasons your team recommended this treatment plan	66%	60%
Symptoms you may experience	67%	60%
Medicines you need to take	70%*	52%
Risks of the treatment plan	64%*	54%
Impact on your activities of daily living	62%*	55%
Emotional impact of cancer and its treatment	45%	43%
Care you will need at home	45%	42%
Whether or not you'll be able to work	53%*	38%
Cost to you of the treatment plan	37%	36%
Other treatment options your care team considered	36%	30%
Responsibilities of your caregiver(s)	20%	16%
Clinical trial opportunities	18%	12%

\*Indicates statistically significant differences at the 90% confidence level.

### Observations

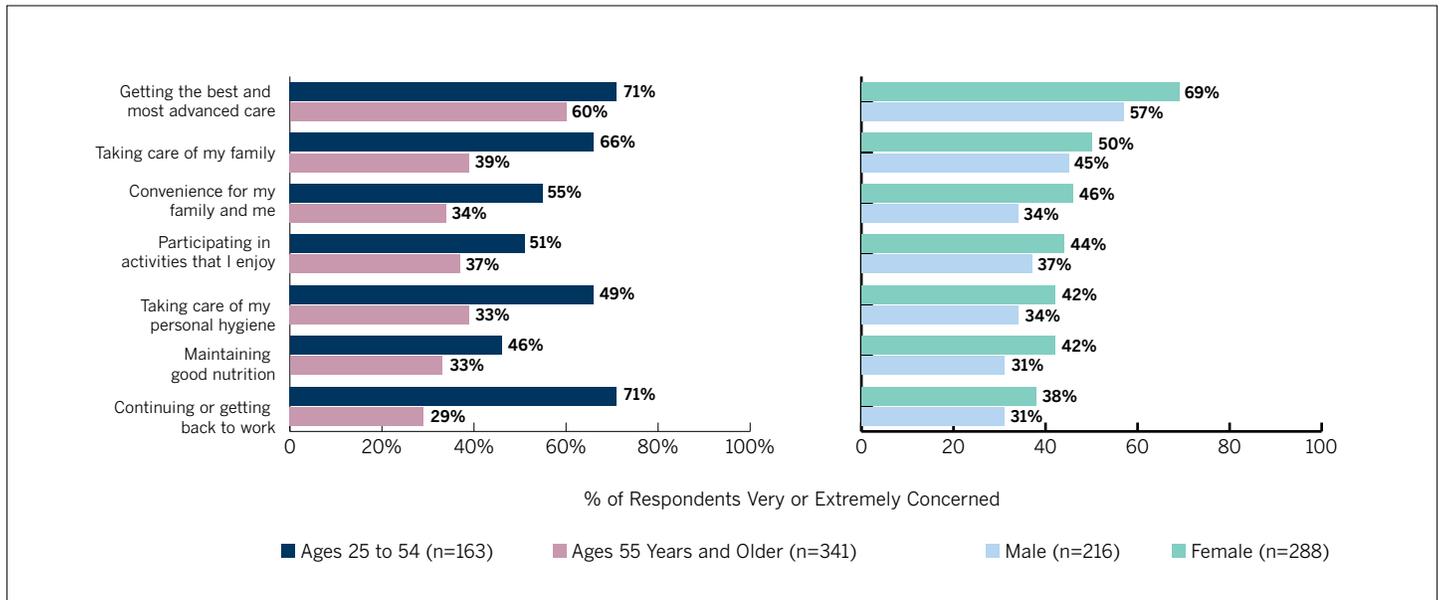
One of the most troubling findings in this survey is the significant proportion of patients who said they did not have enough information about important aspects of their cancer and its treatment. Whether treated at an academic medical center or in a community setting, only about two-thirds of respondents reported having adequate information on the benefits or goals of their treatment plan, its possible side effects, the symptoms

they may experience, and the reasons the plan was being recommended (Figure 2). Only a third had enough information about other treatment options. Especially concerning is that just 12% to 18% were adequately informed about clinical trial opportunities.

Importantly, less than half of our respondents said they had enough information on key aspects of treatment, such as whether they would be able to continue working during treatment, how much home care would be needed, the

# Survey 2: Treatment Planning

**Figure 3: Concerns Regarding Treatment**



emotional impact of having cancer and its treatment, and how much of the cost of care was their responsibility.

Those treated in academic centers were significantly more likely than those treated in the community to say they had enough information regarding the goals of the plan (71% versus 60%), the medicines they needed to take (70% versus 52%), the risks of the treatment plan (64% versus 54%), the impact on their daily living (62% versus 55%), and their ability to work (53% versus 38%).

## Gender Differences in Perceptions of Information Adequacy

In this survey, women were more likely to report having enough information than men regarding treatment side effects (68% versus 60%), goals (67% versus 58%), possible symptoms (71% versus 51%), plan rationale (67% versus 55%), medications (64% versus 47%),

whether they will be able to work (47% versus 38%), and the emotional impact of cancer (50% versus 33%). The study literature suggests that in health-care situations, there are significant differences between men and women with respect to communication styles, confidence in crisis, coping with illness-related distress, the use of psychosocial support, and involvement in medical decision-making.<sup>1</sup>

## Treatment Planning

During the treatment planning process, nearly all patients said they asked questions, and most said that they voiced their concerns. Women were more likely than men to say they and their caregivers communicated actively during this time.

Concerns regarding cancer treatment differed primarily by age and to a lesser degree by gender (Figure 3). Older patients had one major concern, “getting the best



and most advanced care.” Younger patients shared this concern, but were also significantly more concerned than older patients about topics relating to family, participation in activities, hygiene, nutrition, and work.

### Finalizing the Treatment Plan

Fewer than half of respondents got a second opinion about their treatment plan; those ages 25 to 54 were more likely to do so than those 55 and older. Just over half of respondents, regardless of age, were given a copy of their treatment plan. Of those in active treatment when they responded to this survey, 66% were given a written or online copy of this plan.

The majority of respondents (>85%) reported that their treatment plan reflected their goals and values either very well or completely and they were satisfied or very satisfied with the amount of input they provided to their plan. Those patients who disagreed tended to be younger, in active treatment, or in the lowest income bracket.

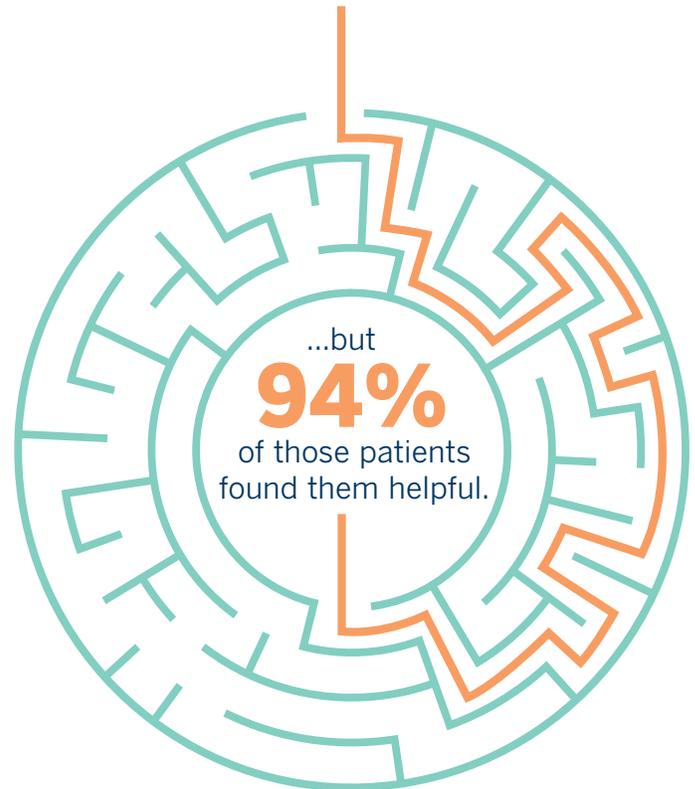
### Clinical Trial Experience

About 20% of respondents ages 25 to 64 took part in a clinical trial, compared to 11% of those 65 and older. Among those in active treatment at the time of this survey, over 40% reported participating in a trial. These participation levels are significantly higher than the US norm of 3%.<sup>1</sup> As noted previously, only 12% to 18% of respondents reported having enough information about clinical trials.

### Access to Patient Navigators

Only a quarter of respondents reported having access to a patient navigator or nurse navigator. Of those, however, the vast majority (94%) said they were helpful. Among patients with the four most common cancers, 29% were

### Only 23% of respondents had access to Patient Navigators...



provided with a navigator, compared with 18% of those with less common cancers.

### Treatment Compliance

The advent of oral therapies has dramatically changed the landscape of cancer therapy, since many medications can now be self-administered rather than having to be infused in the presence of a clinician. Convenience aside, this new modality can pose challenges to adherence, and providers may feel uncertain as to whether patients take their medications as prescribed.<sup>2</sup>

*Continued on page 30*



CANCERcare®

# Cecilia J.

## See Me As a Whole Person

In the fall of 2014, when Cecilia J. was diagnosed with breast cancer, she was determined to do whatever it took to survive. When her oncologist told Cecilia she had between a 50 percent and 60 percent chance of long-term survival, Cecilia, 66, said she would be among that percentage of women who had a good outcome.

To give her the best chance of survival, Cecilia's oncology team plotted an aggressive course of treatment: first chemotherapy to shrink the tumor, then surgery to remove her right breast, followed by radiation. Cecilia planned to have reconstruction of her right breast and reduction surgery on her left breast to bring her body into balance.

To her great relief, by the time she finished her chemotherapy, all traces of Cecilia's cancer were gone and she hoped that maybe surgery and radiation wouldn't be necessary. But Cecilia's oncologist convinced her to complete the full treatment plan to ensure that there were no errant cancer cells circulating in her body and to give her the best shot for a cure.

Today, she is cancer-free. And although she is ecstatic with the results of her therapy, Cecilia regrets that her medical team, so intent on killing the cancer, never considered the impact her treatment was having on her physical and sexual well-being. An avid golf enthusiast and tennis player before her diagnosis, Cecilia found that the mastectomy left her with limited movement of her right arm and shoulder, making it impossible to

play sports. And the side effects from the chemotherapy made intimacy painful.

"When I asked for a prescription for physical therapy to restore mobility in my shoulder, I was told I didn't need it because I was able to do the exercises on my own. And when I mentioned that I was having sexuality issues, I was given a list of over-the-counter drugs to overcome vaginal dryness, which didn't help."

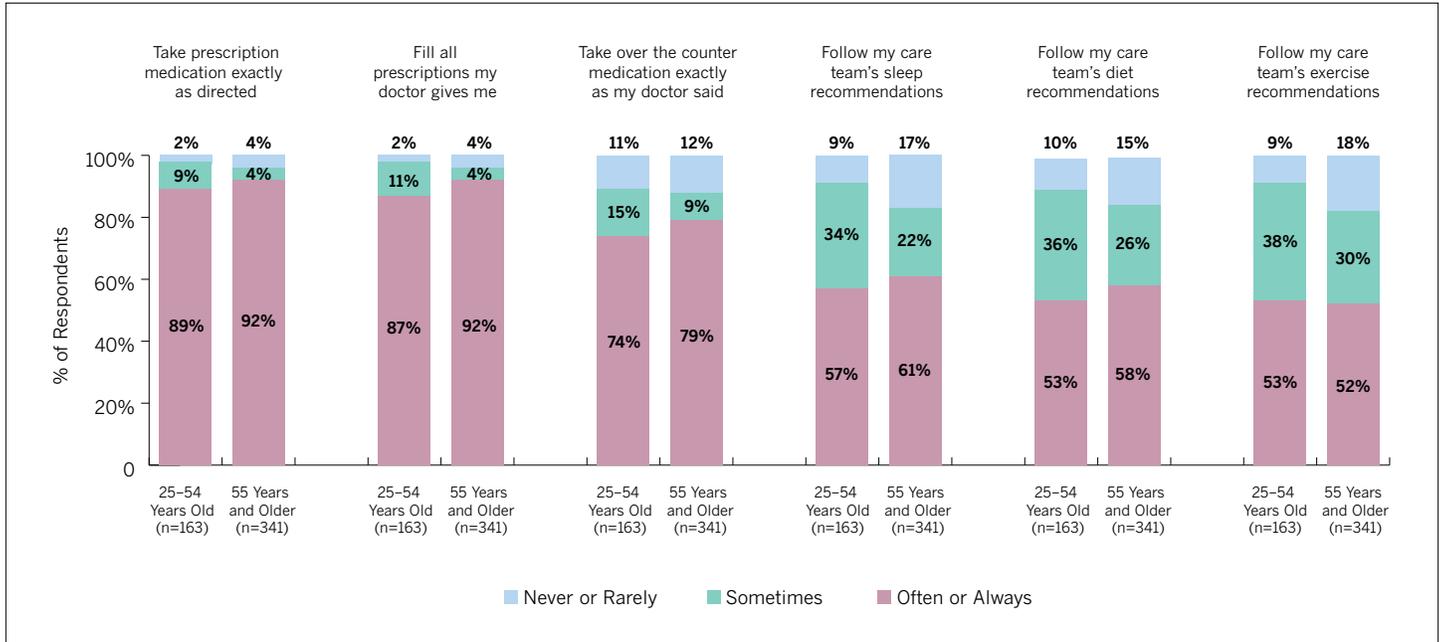
**"I know it sounds harsh, but I never felt my medical team saw me as a whole person with a fully functioning, satisfying life."**

Her medical team even discouraged Cecilia's request for a referral to a cancer support group.

"I know it sounds harsh, but I never felt my medical team saw me as a whole person with a fully functioning, satisfying life. I'm sure my oncologists would say, 'You're cancer-free; isn't that the most important thing?' Of course it is. But when you are getting treated for cancer, it's not just about the results, it's also about the process. And for me, the process was impersonal and left me feeling I was on my own," says Cecilia. ■



Figure 4: Treatment Compliance



Continued from page 28

In response to one of our survey questions, the vast majority of respondents—between 87% and 92%—said they often or always “filled all the prescriptions their physicians gave them” and “took the medication exactly as directed.” (As shown in Figure 4, adherence to physician recommendations in other areas, such as sleep, diet, and exercise, was reported to be much less consistent.) In a separate question, however, only 59% reported that they always take their cancer medications on schedule. This discrepancy indicates a need for more research into patient behavior and perceptions about adherence.

Distress

The proportion of patients reporting physician inquiries about general levels of distress did not differ significantly

by a patient’s treatment status. Roughly 70% to 75% of patients said that their care team asked about their level of distress. Half said the inquiry was repeated each time they visited the physician (Figure 5). Interestingly, in Survey 3, fewer than half of patients reported being asked by their care team if they were distressed about specific issues and aspects of their lives.

Caregivers

About half of respondents indicated their spouses were their primary caregivers and that family members accompanied them to doctor visits. Among younger respondents, ages 25 to 54, 22% reported not having a caregiver, compared to 37% of those 55 and older.

Caregiver support varied depending on the sex of the patient. Support for men was provided almost entirely

# Survey 2: Treatment Planning

by a spouse, while women said they also received support from children, other family members, and friends.

## Perceptions About Their Cancer Treatment

Another piece of good news from this survey is that overall, patients said they trusted their doctors, knew the medications they took, and believed they were getting the best possible care. Among those treated in the community, 30% did not agree they were getting the most advanced cancer care available, compared to only 14% of those treated in academic centers. Fewer than one-half said their care team knows their end-of-life wishes. Younger respondents were significantly more likely than those 55 and older to have suggested new treatment options, considered alternative treatments, switched providers, and taken medicines they did not disclose to their care team (Figure 6).

For most aspects of care, 60% to 80% of respondents reported being very or somewhat satisfied with the

amount of attention paid by their care team. Overall, men were more satisfied than women. Patient satisfaction levels were quite low, however, regarding team attention to clinical trial opportunities and, to a lesser extent, offering new treatment options (Figure 7).

## Conclusions and Recommendations

There are many encouraging findings in this survey. The large majority of respondents reported high levels of trust in their physicians' decisions and advice regarding treatment. These patients also said they understood the purpose of their prescribed medications, complied with their clinical care team's instructions on how and when to take them, and believed they were getting the best possible cancer care (especially those treated at academic medical centers). This is all good news.

There are some disturbing findings as well, especially regarding patient access to information. One-third of respon-

**Figure 5: Frequency Care Team Asks About Level of Distress**

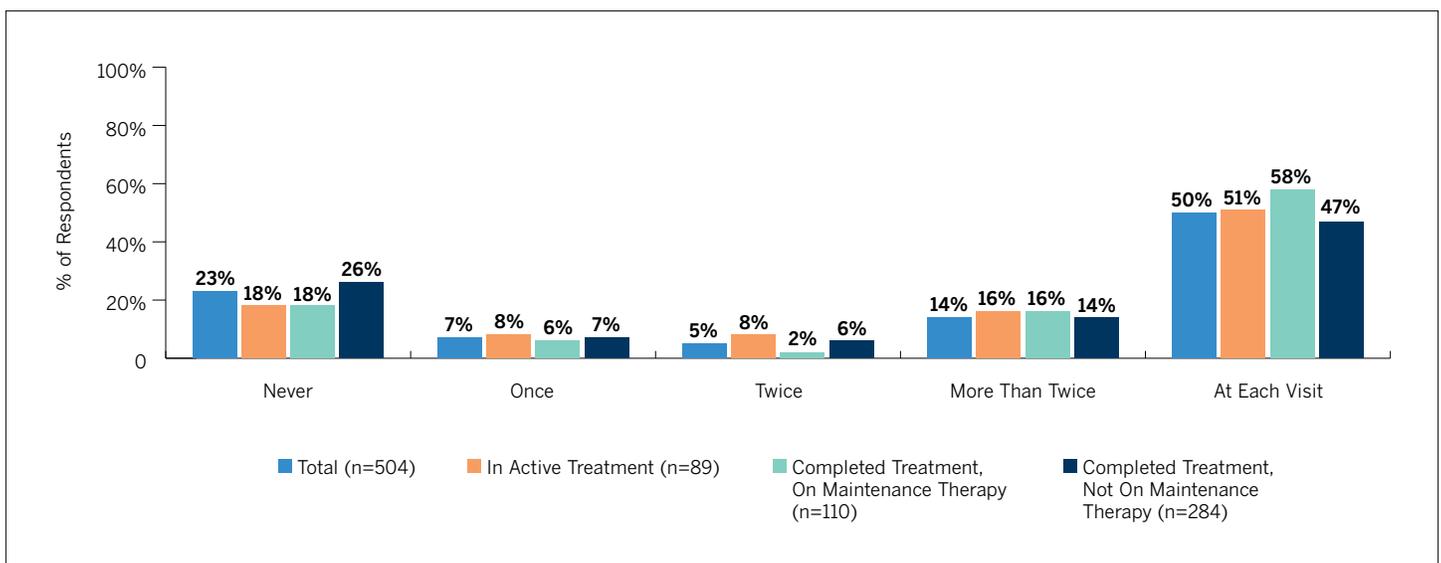




Figure 6: Opinions About Cancer Treatment

	Overall % Agreeing	Age		Treatment Facility	
		25 to 54 Years Old (n=163)	55 and Older (n=341)	Academic Medical Center (n=148)	Community Hospital/Cancer Center/MD (n=325)
I trust my doctor's decisions/advice regarding treatment of my cancer.	90%	89%	90%	93%	89%
I know what each of my medications is for.	84%	83%	84%	89%*	82%
I am getting the best cancer care for me.	83%	81%	84%	94%*	80%
I am getting the most advanced cancer care available.	74%	76%	73%	86%*	70%
I always take my cancer medications on schedule.	59%	69%*	54%	57%	58%
My care team knows my end-of-life wishes.	44%	42%	45%	46%	45%
I am considering or have considered alternative treatments for my cancer.	21%	37%*	14%	24%	20%
I suggest new treatment options or ways to treat my cancer to my doctor.	23%	33%*	18%	23%	23%
I switched to a new doctor or treatment center.	16%	25%*	11%	18%	15%
I take medications that I don't tell my care team about.	9%	17%*	5%	9%	10%

\*Indicates statistically significant differences at the 90% confidence level.

dents reported they did not have enough information about the benefits and possible side effects of their treatment plan. And fewer than half said they had enough information regarding their ability to work and the care they will need at home. It is particularly troubling that 43% reported not knowing enough about the risks of their treatment plan, and nearly two-thirds were not fully informed about what their treatment would cost. Perhaps most concerning of all to those devoted to advancing new treatment options is the extremely low percentage—just 13% overall—who had

enough information about clinical trials.

Before they make treatment decisions, patients need and deserve easily understood, accurate information about their cancer prognosis, treatment benefits and risks, physical and emotional symptoms and side effects, ability to work, expected quality of life, and anticipated treatment response. New thinking may be required around patient education and the sequence of events leading to the start of active treatment. Patients should feel fully engaged and informed at this critical stage.

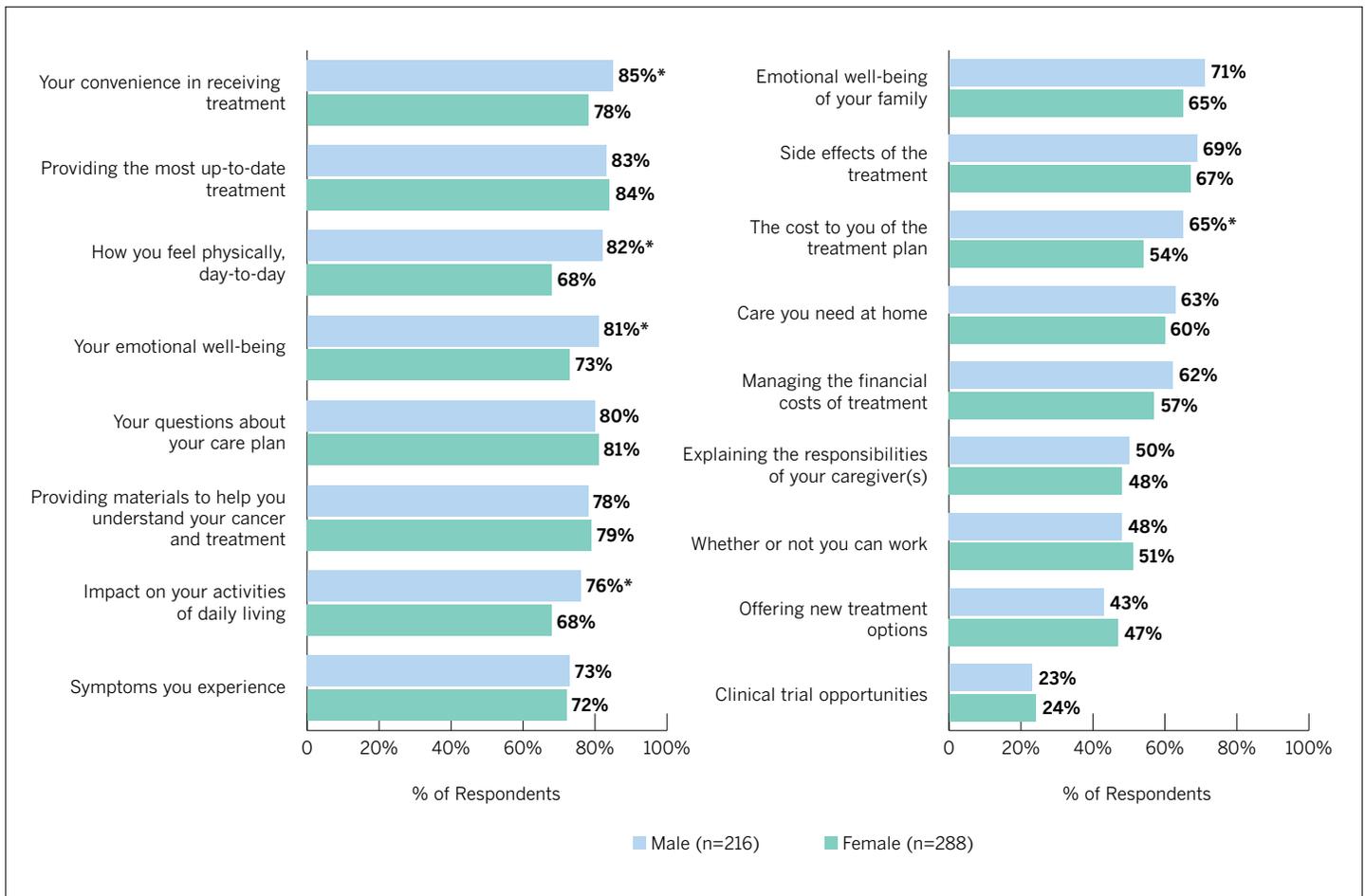
## Survey 2: Treatment Planning

Survey findings also point to areas where patients indicated inconsistent compliance with provider recommendations regarding sleep, diet, and exercise. In some cases, this advice is vital to a patient’s quality of life, as well as to side effect and symptom management. Care team members should consider communicating more fully and regularly on these aspects of the treatment plan.

Effective communication requires mutual respect and trust. Unfortunately, respondents reported that they were not always forthcoming about their use of vitamins, herbal remedies, or prescription and over-the-counter medicines. Clinicians should emphasize the importance of full disclosure from their patients

*Continued on page 35* 

**Figure 7: Respondents “Very” or “Somewhat” Satisfied With Attention Care Team Pays to Aspects of Their Care**



\*Indicates statistically significant differences at the 90% confidence level.



## KEY FINDINGS FROM SURVEY 2: TREATMENT PLANNING

■ Many respondents reported not having enough information about important aspects of their cancer and its treatment. Only about two-thirds reported having adequate information on the benefits or goals of their treatment, the possible side effects, and the reasons why the plan was recommended.

■ Regardless of their treatment facility, only 13% of respondents felt adequately informed about clinical trial opportunities.

■ Less than one-half of the respondents said they had adequate information on whether they would be able to continue working during treatment, how much home care was required, the emotional impact of having cancer and its treatment, and how much of the cost of care would be their responsibility.

■ Fewer than one-half of respondents obtained a second opinion about their treatment plan.

■ The vast majority of respondents (over 87%) said they “filled all the prescriptions their physicians gave them” and “took the medication exactly as directed.” Yet in a separate question, only 59% agreed that they always take their cancer medications on schedule.

■ The majority of respondents (85%) reported that their treatment plan reflected their goals and values very well or completely. However, 43% reported not

having enough information about the risks of their treatment plan.

■ Only a quarter of respondents reported having access to a patient or nurse navigator.

■ About 50% of respondents indicated that their spouses were their primary caregivers and that family members accompanied them to doctor visits. Among younger respondents, 22% reported not having a caregiver.

■ The majority of respondents reported that they trusted their physicians, understood the reason for their medications, and believed they were getting the best care. Only 44% said their clinical care team knew their end-of-life wishes.

■ Among those treated in the community, 30% did not agree that they were getting the most advanced cancer care available, compared to only 14% of those treated in academic centers.

■ Younger respondents were much more inclined to suggest new treatment options to their clinical care team, consider alternative treatments, switch providers, and take medicines they did not disclose to their physicians.

■ For most aspects of care, 60% to 80% of respondents reported being satisfied with the amount of attention paid by their care team.

## Survey 2: Treatment Planning

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 *Continued from page 33*

about the use of products outside of the treatment plans, especially since some of these products may in fact be harmful.

### Ensuring Patient-Centered Cancer Care

In 2016, over 1.6 million Americans are expected to be diagnosed with cancer,<sup>3</sup> and each one of those patients will have to decide on a course of care. The life-threatening nature of cancer and the complexity of its treatment, combined with the emotional, physical, and financial repercussions of the disease, often conspire to make it difficult for patients to make informed decisions about their care.

The Institute of Medicine defines high-quality cancer care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”<sup>4</sup>

At the heart of this patient-centered approach is effective, transparent patient-clinician communication and shared decision-making. Research shows that patients who fail to express their needs, fears, expectations, and preferences with their clinical care team risk poor health outcomes.<sup>5</sup> Encouraging patient participation during office visits, eliciting details about the patient’s lifestyle routines, and checking for patient understanding of what was discussed during the visit can enhance quality of care.

The findings in this survey and the others in this report illustrate the need for health-care providers, patients, caregivers, and advocates to more fully appreciate that a cancer diagnosis and its treatment can affect individuals differently depending on their gender, age, ethnicity, and personal values. Discussing patients’ values and priorities in the context of treatment planning, ensuring that they have sufficient knowledge to make informed decisions, and fostering a partnership approach to care will encourage patients to engage with their clinical team to achieve the best cancer care for them. ■

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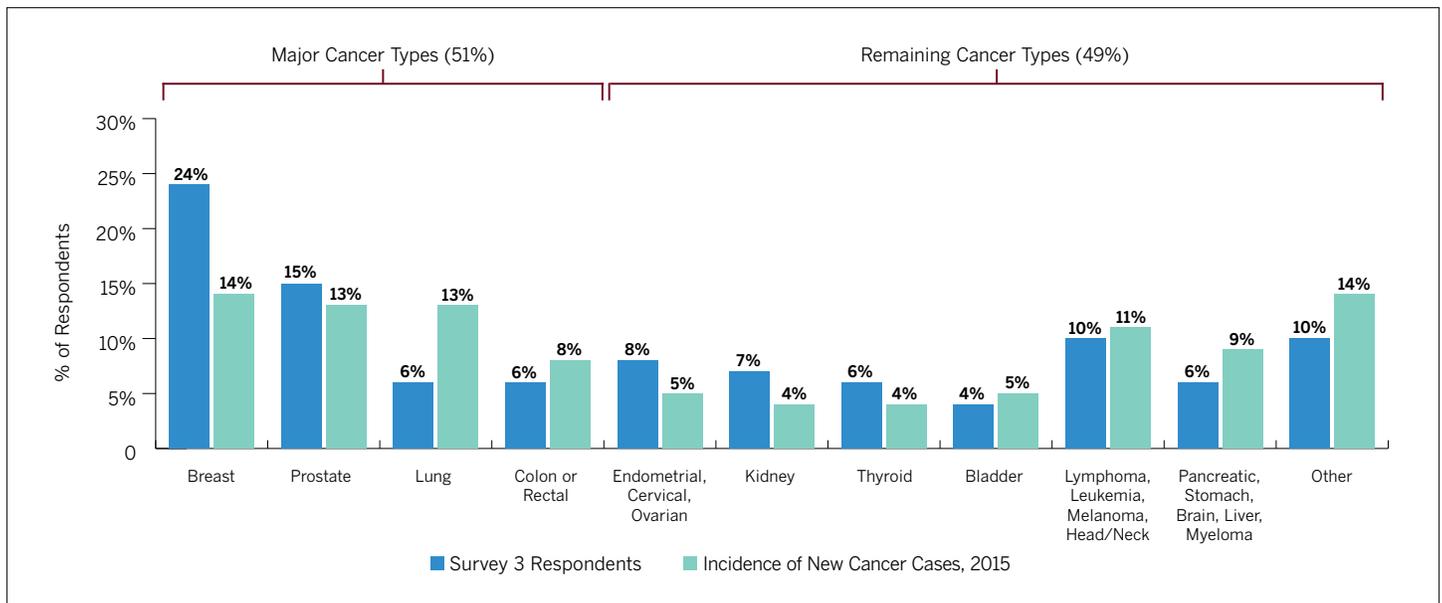


In *Survey 3: Communication With the Care Team*, we investigated patients' perceptions of their relationships with their physicians; how well respondents understood discussions with their clinical care team; how accessible providers were for follow-up discussions and with whom patients preferred to consult; and how responsive medical care teams were to respondents' emotional, physical, and financial distress.

See Figure 1 for the distribution of respondents by cancer type.<sup>1</sup>

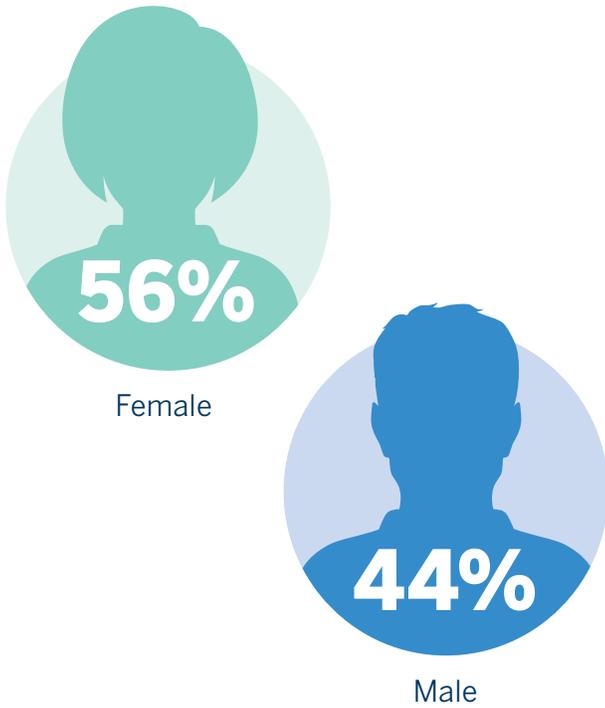


**Figure 1: Distribution of Respondents by Cancer Type (N=501)**

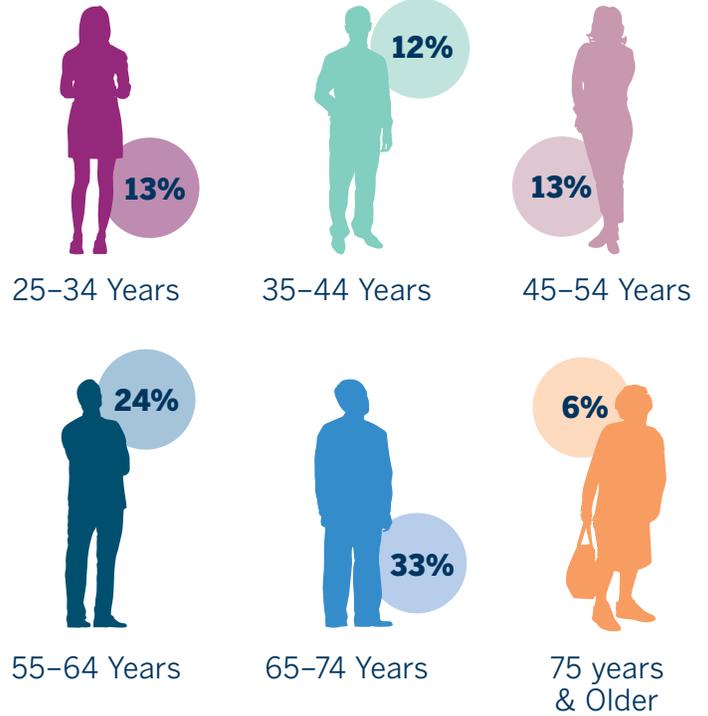


# Survey 3: Respondent Demographics (N=501)

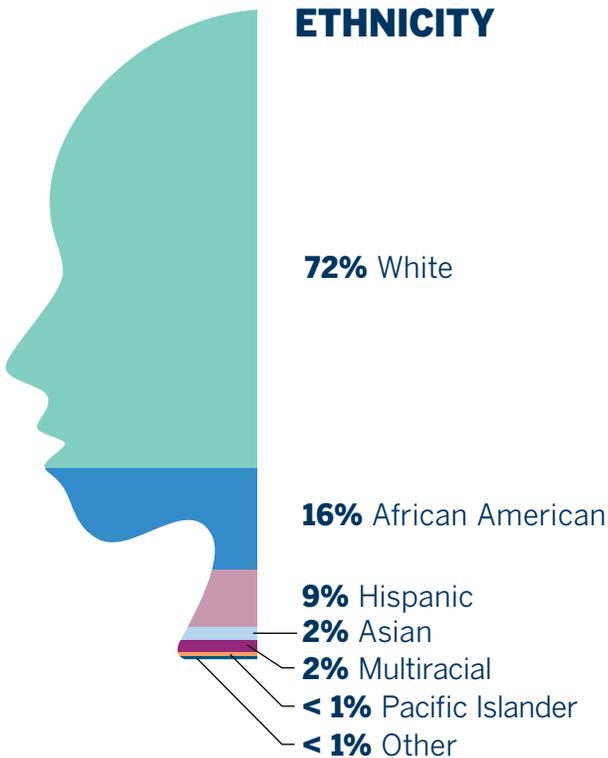
## GENDER



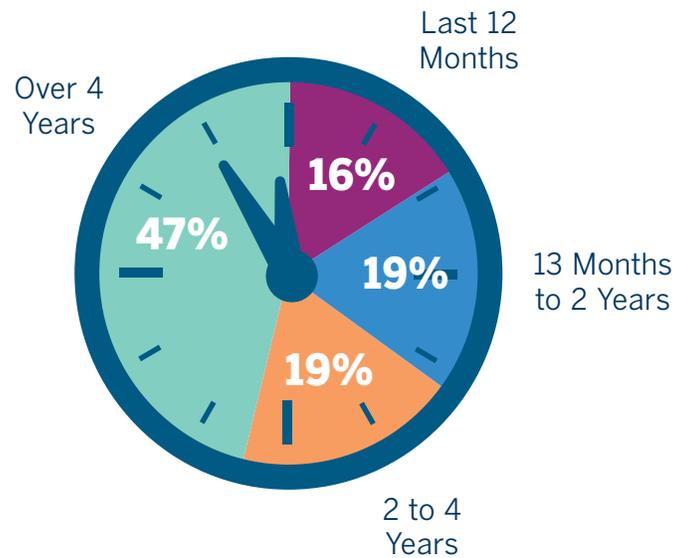
## AGE



## ETHNICITY

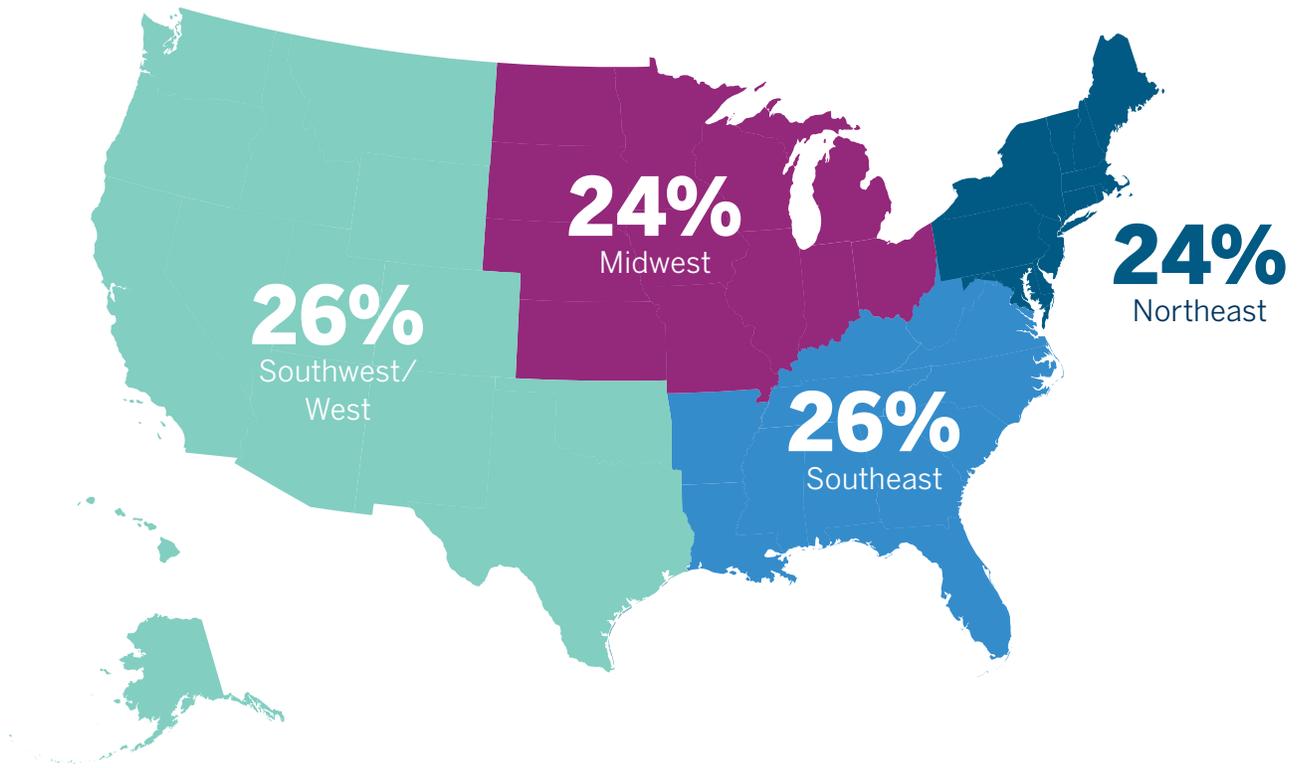


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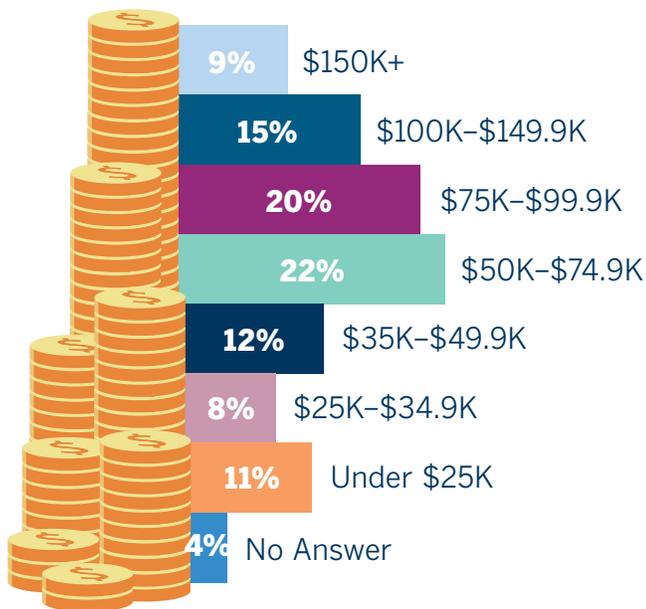


# Survey 3: Respondent Demographics (N=501)

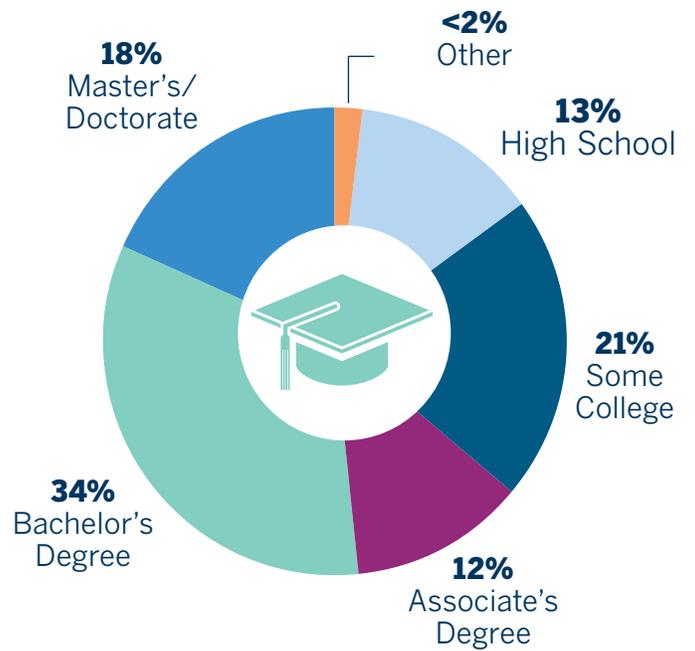
## REGION



## INCOME



## EDUCATION





### Observations

In this survey, the vast majority of respondents, 94%, said they understood what their health-care providers were discussing with them about their cancer and treatment plan, and an equal percentage were satisfied with how well their care was coordinated by their clinical care team. Nearly all respondents also agreed that they were able to connect with their medical team in a reasonable amount of time (Figure 2).

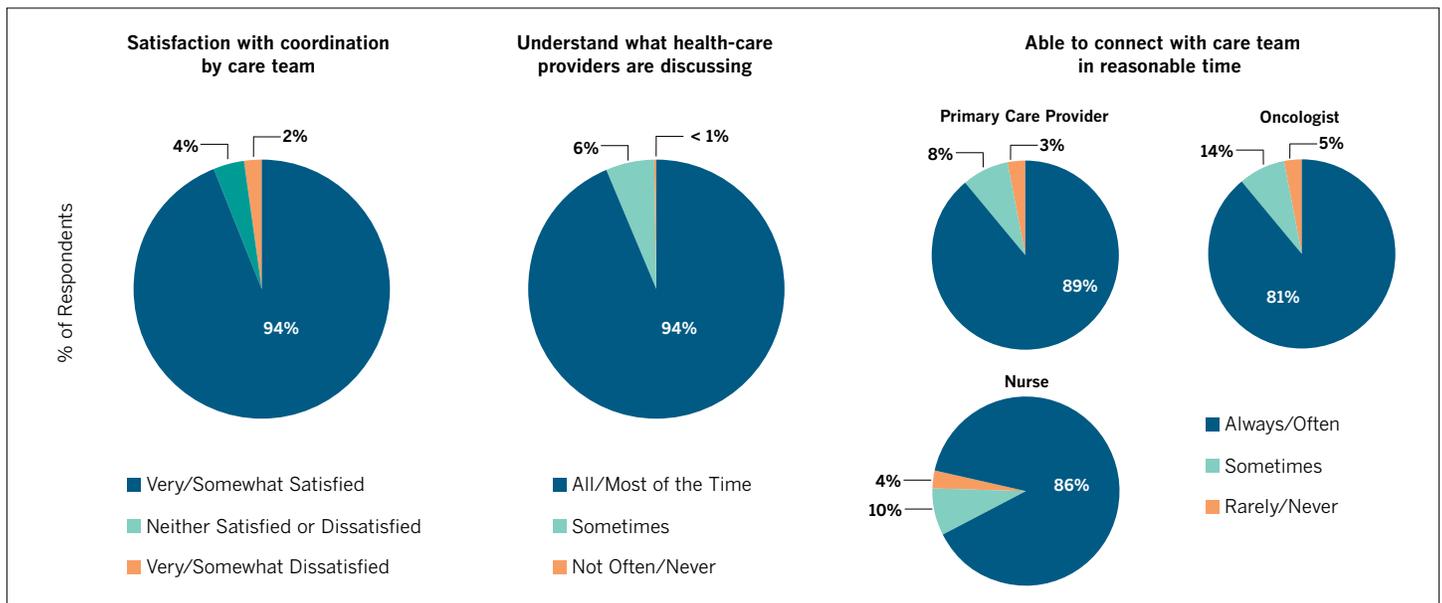
Although respondents had a positive opinion of their encounters with their physicians, age and ethnicity had an impact on how well they perceived those encounters, with older patients saying they had a more positive perception of their physician than did younger patients. Among respondents ages 55 and older, 94% agreed that their doctor used language they understood, and 90% or more said that their physician listened to their con-

cerns, was easy to talk to, and was kind and compassionate (Figure 3).

Notably, fewer African American and Hispanic patients, ages 25 to 54 years, had that experience, with just 76% agreeing their doctor used language they could understand versus 87% of white patients in that age range; and just 72% of minority patients versus 82% of white patients agreed that their doctor was kind and compassionate (Figure 4). African American and Hispanic patients were also less likely than white patients to report that members of their medical team were respectful, attentive, and responsive to their needs, with 20% of minority patients versus just 7% of white patients reporting they felt uncomfortable talking with their care team about how their cultural, religious, and personal values affected their treatment; and four times as many African

*Continued on page 43*

**Figure 2: Interactions With the Care Team (N=501)**



# Survey 3: Communication With the Care Team

**Figure 3: Patients' Perceptions of Their Doctors—All Respondents (N=501)**

	Often or Always Agree	
	25 to 54 Years Old (n=189)	55 Years and Older (n=312)
My doctor listens to my concerns.	84%	92%*
My doctor speaks to me using language I can understand.	82%	94%*
I am confident that I can tell my doctor my concerns even when he or she does not ask.	82%	92%*
My doctor is easy to talk to.	80%	91%*
My doctor is kind and compassionate.	77%	90%*
My doctor shares with me (provides access to) the information in my medical records.	77%	80%
My doctor asks for my input and opinion.	70%	71%
My doctor is open to suggestions about alternative or complementary therapies.	57%*	48%

\*Indicates statistically significant differences at the 90% confidence level.

**Figure 4: Patients' Perceptions of Their Doctors—Ages 25 to 54 (n=178)**

	Often or Always Agree		Never or Rarely Agree	
	White (n=82)	African American/ Hispanic (n=96)	White (n=82)	African American/ Hispanic (n=96)
My doctor listens to my concerns.	57%	82%*	13%*	4%
I am confident that I can tell my doctor my concerns even when he or she does not ask.	87%*	74%	2%	14%*
My doctor speaks to me using language I can understand.	87%*	76%	2%	13%*
My doctor is easy to talk to.	82%	77%	4%	5%
My doctor is kind and compassionate.	82%	72%	4%	8%
My doctor shares with me (provides access to) the information in my medical records.	80%	72%	6%	12%
My doctor asks for my input and opinion.	37%	73%*	30%*	9%
My doctor is open to suggestions about alternative or complementary therapies.	52%	60%	9%	17%

\*Indicates statistically significant differences at the 90% confidence level.



CANCERcare®

# George L.

## Choosing the Right Words

**G**eorge L. was healthy and happy about life for the first 10 years of retirement. But at age 82, George began to feel tired all the time. His blood work was abnormal and he felt a malaise so exhausting, he and his wife Anita knew something was seriously wrong. A bone marrow biopsy clinched the diagnosis: myelodysplastic syndrome (MDS).

“I had never even heard the term, so I had no idea what that was,” George recalls. “Then my doctor said it’s a precursor to cancer that could lead to acute myeloid leukemia. Once I heard the word ‘leukemia,’ which I know is blood cancer, I couldn’t focus on anything else he was telling me.”

The doctor spent just a short time talking to George and Anita about the diagnosis. All they remember from that first conversation was a haze of unfamiliar words and scary-sounding treatments. They felt rushed, overwhelmingly fearful, and unprepared to deal with the information. George says he didn’t even know what questions to ask.

By the time George went for his first treatment session he felt so despondent he was ready to give up. “I just looked at the pharmacist and asked, ‘how long will it be before I die?’ That was my low point.”

This pharmacist, a member of his health care team who specializes in anti-cancer drugs, sat with George and said, “Tell me what you know about your disease and your treatment.” George confessed that he was confused and frightened by the doctor’s explanation. “[The pharmacist] actu-

ally explained my condition in lay language. She reassured me that MDS takes several years to progress to leukemia and that the goal of the chemo is to delay the transition. She explained that my bone marrow was not correctly making red and white blood cells. Without proper red cells, you develop anemia and weakness; without enough white blood cells you’re more prone to infection; without enough blood platelets to clot the blood, you get bruising and bleeding. These were terms that made sense to me, and for the first time I started to understand and have some hope.”

**“Once I heard the word ‘leukemia,’ which I know is blood cancer, I couldn’t focus on anything else he was telling me.”**

George’s MDS is stable now. And these days when he talks to his doctor, he says, “Let me make sure I’m getting this right,” and repeats the explanation in his own words.

“For me, the pharmacist was the best one to explain the disease and the treatments and why I was getting them,” George says. “She spent a lot of time with me and I know it’s an extra workload. But cancer patients need this kind of information so desperately. I certainly did.” ■

# Survey 3: Communication With the Care Team

**Figure 5: Patient Complaints About Medical Care**

	Often or Always Agree		Never or Rarely Agree	
	White (n=360)	African American/ Hispanic (n=121)	White (n=360)	African American/ Hispanic (n=121)
I am uncomfortable talking with my care team about how my cultural, religious, and personal values affect my treatment.	7%	20%*	58%	64%
I can't speak with my care team members in my preferred language.	6%	17%*	51%	60%
The services to translate communication into my preferred language aren't good.	3%	22%*	39%	49%*
My doctors show a lack of respect for my cultural, religious, and personal values.	5%	17%*	72%	65%
I feel that 'I'm not being heard'.	4%	16%*	84%*	69%
It's hard to understand what the doctor is saying about my treatment.	4%	19%*	82%*	66%

\*Indicates statistically significant differences at the 90% confidence level.

 Continued from page 40

American and Hispanic respondents as white respondents agreed that they were “not being heard” by their care team (16% versus 4%, respectively; Figure 5).

These results are consistent with information found in numerous studies investigating the racial and ethnic disparities in patient-provider communication and how survivors in this population perceived the quality of care they received. Effective patient-provider communication helps survivors cope with their illness, improves health information comprehension, engages patients in their own health care, and can also facilitate patients’ willingness to manage their health and health care.<sup>2</sup>

## Members of the Care Team

According to our survey, respondents considered a number of people to be part of their clinical care team, including

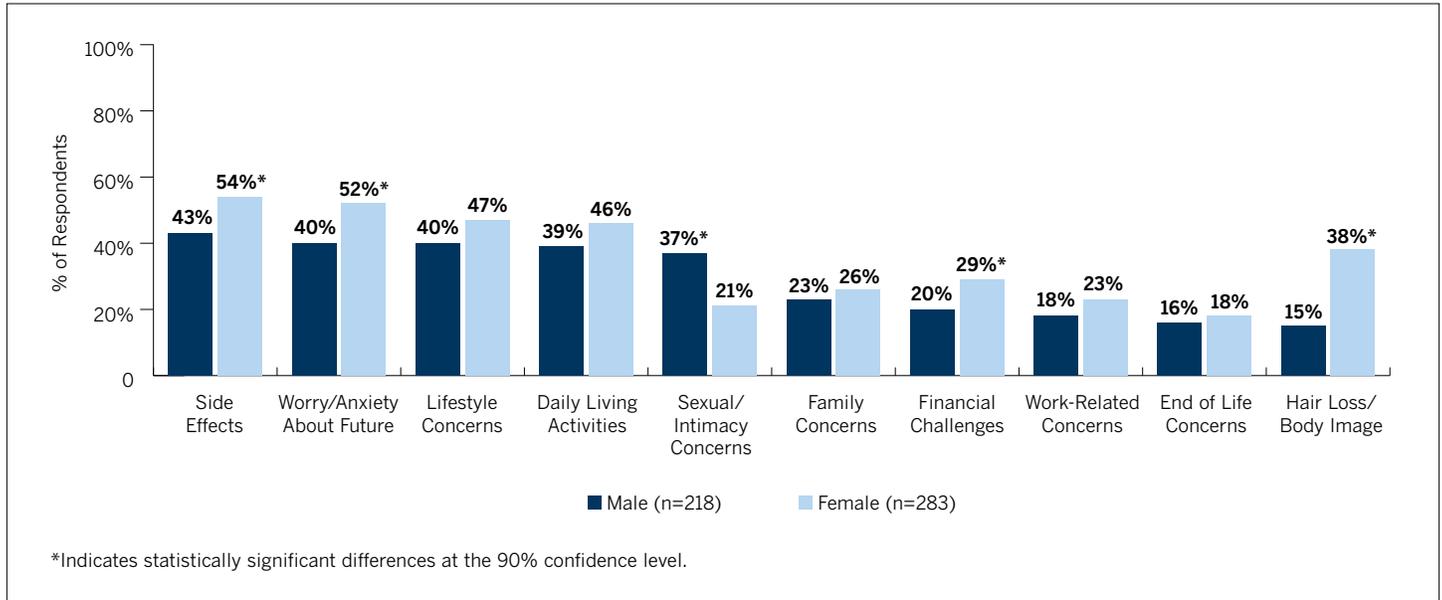
oncologists, primary care physicians, radiologists, nurses, physician assistants or nurse practitioners, family members or caregivers, pharmacists, and social workers or psychologists. Importantly, almost two-thirds named their primary care physician as a team member. Women tended to name more people as team members than men. As patients completed active treatment, family members or caregivers and social workers or psychologists continued to play a vital role on their care teams.

## Patient Portals

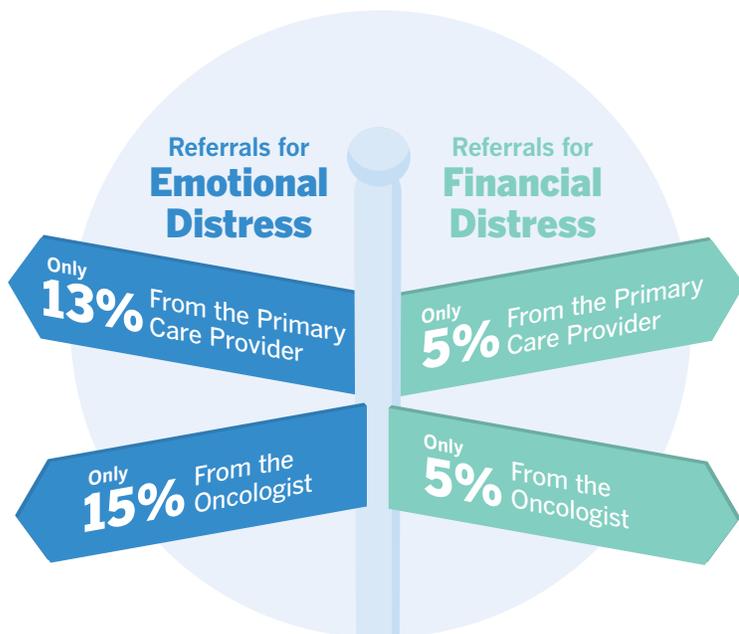
The use of patient portals (a secure website or mobile app patients can use to communicate with their providers and access parts of their medical records) is proving to be an effective and popular way for patients to reference information about their current test results, read their doctors’ notes, request prescription refills, learn



Figure 6: Distress Concerns Raised by Care Team Members (N=501)



### Few Older Patients Receive a Referral for Distress



about treatment side effects, find educational information about their cancer, and communicate electronically with their medical team. In our survey, 81% of respondents in active treatment used a patient portal provided by their physician, with more than half reporting using it always or often. As expected, use of the patient portals was greater among younger respondents.

### Patient Distress

One of the most disturbing findings in this survey is that fewer than half of respondents were asked whether they were feeling distressed regarding key aspects of their lives as a result of their cancer or its treatment (Figure 6). Women were asked more often than men about treatment side effects, such as hair loss and body image; worry and anxiety about the future; lifestyle, family, financial, and

Continued on page 46

# Survey 3: Communication With the Care Team

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## KEY FINDINGS FROM SURVEY 3: COMMUNICATION WITH THE CARE TEAM

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■ Regardless of sex, ethnicity, or treatment location, the overwhelming majority of our respondents were satisfied with their clinical care coordination, understood discussions with their providers about their cancer and its treatment, and were able to connect with members of their health-care team in a reasonable amount of time.

■ Respondents, especially those patients older than age 55, had positive opinions regarding the conversations and relationships they have with their physicians.

■ Among those respondents between the ages of 25 and 54 years, white patients were significantly more likely than African American and Hispanic patients to report that their physicians spoke to them in understandable language and had confidence in their ability to talk about their concerns (87% versus 74%, respectively).

■ African American and Hispanic respondents between the ages of 25 and 54 years were significantly more likely than white patients to report that their physician listened to their concerns (82% versus 57%) and asked for their opinions (73% versus 37%, respectively).

■ Among African American and Hispanic respondents, about one-fifth reported that they experienced

serious communication problems with their clinical care team, including a lack of translation services (22%); difficulty understanding what their doctor said about their treatment (19%); and discomfort talking about how cultural, religious, and personal values affect their treatment (20%).

■ A majority of respondents considered their oncologists and primary care physicians to be part of their cancer care team. Nearly half of respondents included nurses on their care team.

■ Respondents in active treatment or on maintenance therapy reported having access to and using patient portals.

■ Respondents generally chose to discuss treatment-related issues with their oncologists. For lifestyle concerns, they preferred to talk with their primary care physicians.

■ Fewer than half of the respondents were asked by a member of their care team whether they were feeling distressed by their cancer or its treatment.

■ Despite the prevalence of emotional and financial distress in patients with cancer, our respondents said that members of their care team rarely referred them to counseling services or other professionals for support.



 Continued from page 44

work-related concerns; and how cancer impacted their daily living activities. And more men (37%) than women (21%) were asked about sexuality and intimacy concerns. Thus, it is not surprising that the survey data point to low levels of patient referrals by providers for psychosocial support services.

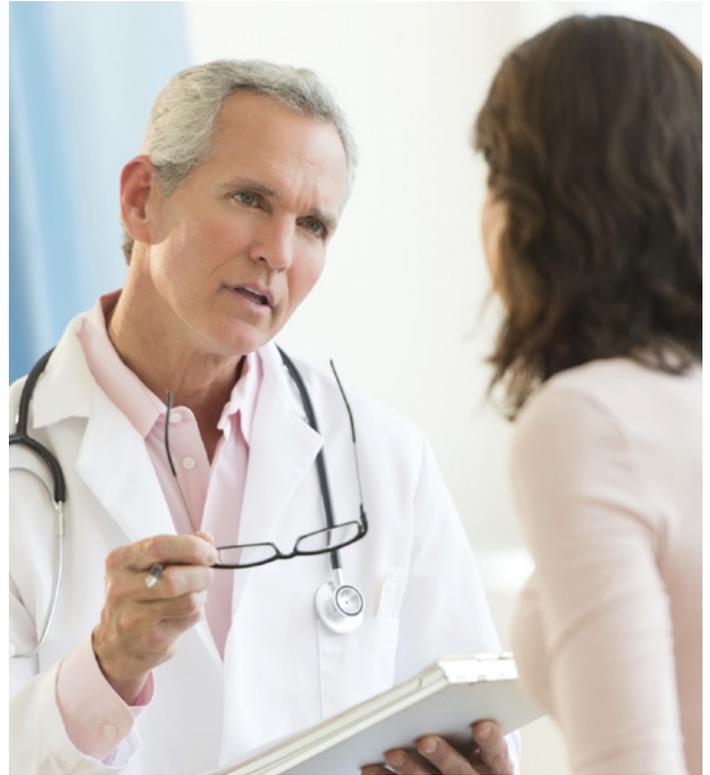
Studies show that virtually all cancer survivors will experience some form of sexual dysfunction following a cancer diagnosis.<sup>3,4</sup> Yet, we found that sexual health was often left out of the conversation between providers and patients.

Age, too, seemed to influence referrals for help coping with emotional distress from cancer; 36% of younger patients received a referral from their primary care physician and 27% received one from their oncologist. Those patients ages 55 and older rarely received referrals from either physician. Referrals for financial distress were even lower than those for emotional support, with just 22% of younger respondents saying they received a referral from their primary care physician, and 19% receiving one from their oncologist. Once again, referrals were rarely made for older patients.

Emerging research suggests that screening for and addressing distress not only enhance quality of life, but may also be associated with improved cancer outcomes.<sup>5-7</sup> Over the next few years, screening for psychosocial distress should become more common. The American College of Surgeons Commission on Cancer<sup>8</sup> mandated in 2015 that a systematic protocol for psychosocial distress screening and referral be implemented as a condition for cancer care accreditation.

### Discussion Topics With Team Members

Survey respondents had differing opinions as to who on their medical team was their first choice for discussing various topics about their care. For example, although



the majority of respondents said their oncologist was the person they would turn to first regarding treatment-related goals, treatment side effects, and clinical trials, a substantial number said that for issues related to diet and exercise, sexual intimacy, work, emotional distress, financial issues (including cost of treatments, insurance matters, and other financial challenges), and family-related issues, they preferred to talk with their primary care physician and family members or caregivers (Figure 7).

### Conclusions and Recommendations

Nearly all survey respondents understood what their providers were discussing, and a large majority perceived their physicians to be good listeners, kind and compassionate, and easy to talk to. Looking at sub-populations,

## Survey 3: Communication With the Care Team

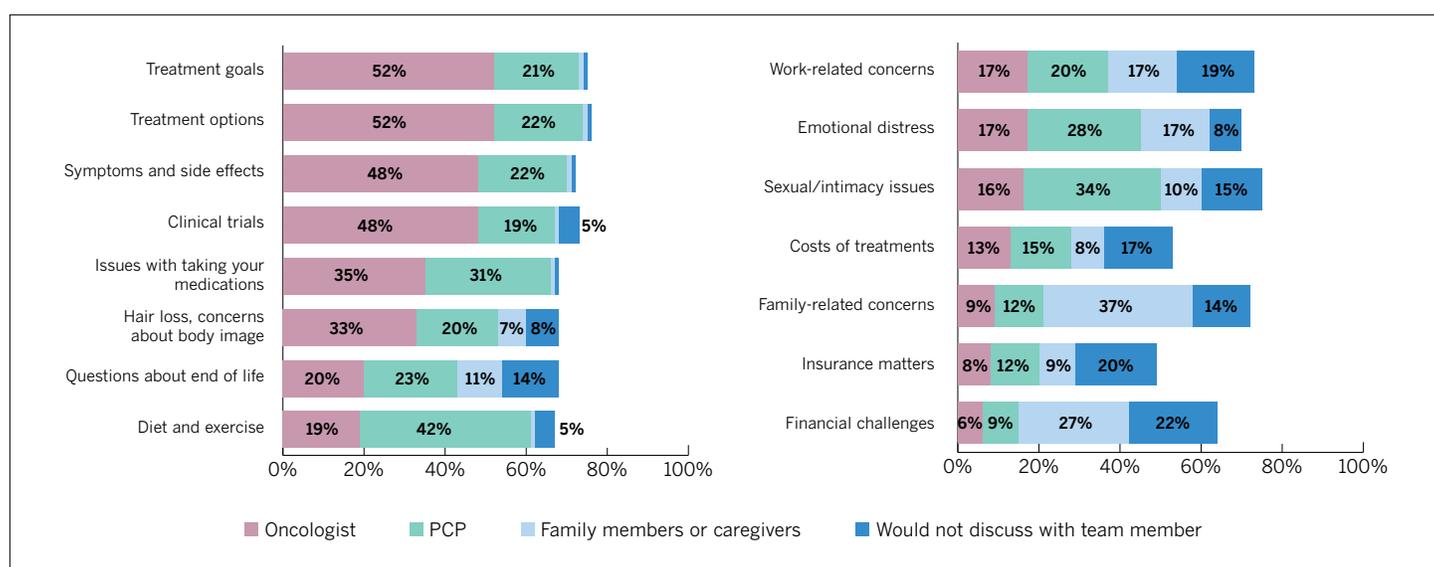
however, suggests less unanimity. Those ages 25 to 54 were significantly less positive about their clinician communication than those 55 and older, and within the younger age group, 5% to 17% of African American and Hispanic respondents reported major lapses in effective communication from their providers. For this group, poor communication is a factor that can significantly jeopardize their prognosis. As noted by the Institute of Medicine (IOM), “studies show that the clinician’s ability to explain, listen and empathize can have a profound effect on biological and functional health outcomes as well as patient satisfaction and experience of care.”<sup>8</sup>

For example, the ability to communicate well correlates with a patient’s ability to comprehend the guidance and recommendations made by a member of the health-care team. This can benefit a patient’s ability to follow medical advice, adhere to recommendations, and understand healthy lifestyle behaviors.

The IOM Report on Health Professions and Training underscored the importance of communication training for clinicians and members of the health-care team.<sup>9</sup> Similar to other health-care abilities, communication skills can be learned and improved. Ongoing collection of patient feedback and behavior data can help identify where providers could benefit from training. In addition, patients should recognize their right to patient-centered care, which includes core communication skills (such as open-ended inquiry, reflective listening, and empathy) as a way to respond to the unique needs, values, and preference of the individual.<sup>10,11</sup>

We were surprised to learn how prominently primary care physicians figured in the care of survey respondents during the time they were treated for cancer. This suggests a need for open communication and coordination of care between oncology providers and the primary care doctor, who are likely not in the same location and may

**Figure 7: Preferred Care Team Member for Discussions (N=501)**





not be connected electronically. According to survey findings, patients relied on a variety of team members for advice and counsel on aspects of treatment and quality of life. To provide comprehensive and individualized cancer care, providers should seek to share this information across the team. Recent initiatives between the American Society of Clinical Oncology and primary care professional organizations are attempting to bridge this gap and facilitate coordinated care. We applaud these efforts and recommend a continuing focus on collaborative care models that provide patient-focused, integrated, and comprehensive cancer care.

Another finding from this survey is the low level of patient referrals for emotional, physical, or financial distress counseling. Knowing these conditions are pervasive following a cancer diagnosis, we urge oncology providers and all members of the patient care team to acquaint themselves with available psychosocial, physical rehabilitation, and financial counseling support services. Further, a designated member of the medical team, such as the physician assistant or other advanced practitioner, should be appointed to advise patients about access to these resources throughout their continuum of care. ■

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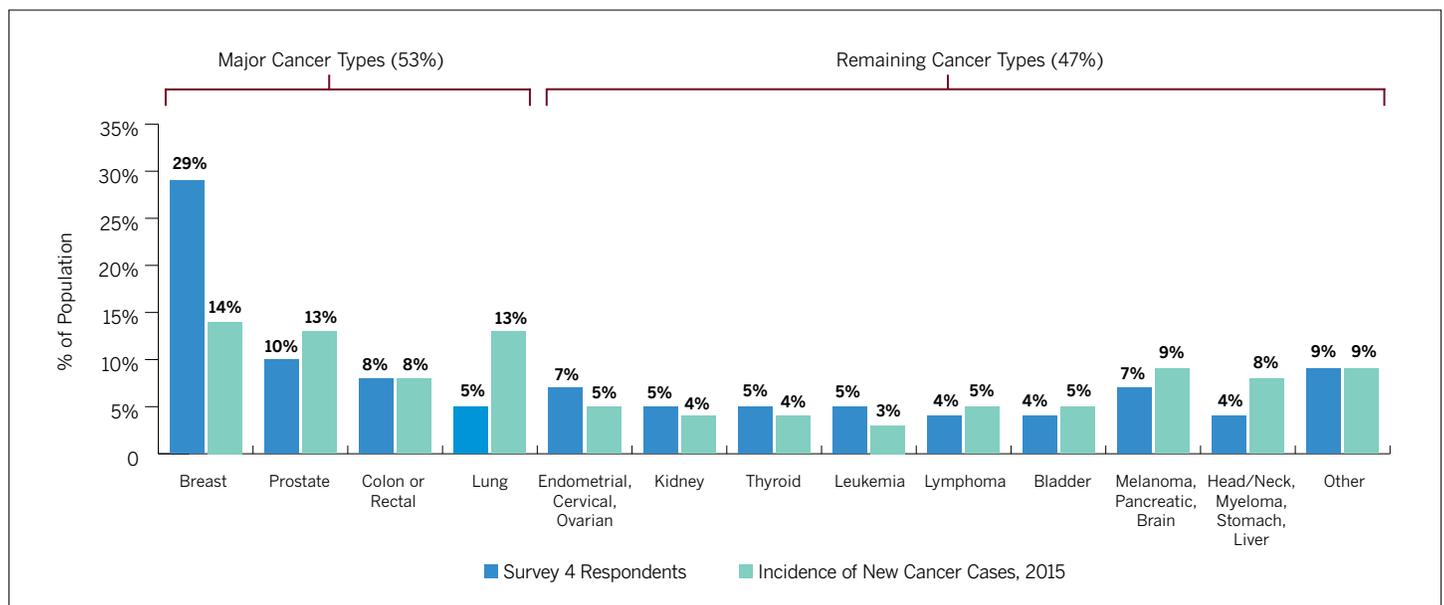
A cancer diagnosis has the potential to jeopardize not only one’s life, but also one’s financial well-being. A 2013 study examining the link between a cancer diagnosis and the increased risk of bankruptcy found that adults diagnosed with cancer are nearly three times more likely to declare bankruptcy than adults without cancer.<sup>1</sup> Even more disturbing is a recent study showing that cancer patients who declare bankruptcy are nearly 80% more likely to die earlier than patients who do not.<sup>2</sup>

The complexity of cancer care delivery, the skyrocketing cost of treatments, and the steady shift of insurance cost-sharing to patients through rising deductibles and co-payments are creating a

cascade of debilitating financial trouble for many patients. In *Survey 4: Financial and Insurance Issues*, we sought to examine the financial impact cancer had on patients, how they compensated for that impact, how well patients understood their insurance coverage and were able to determine out-of-pocket costs before they occurred, and overall, how satisfied they were with their coverage.

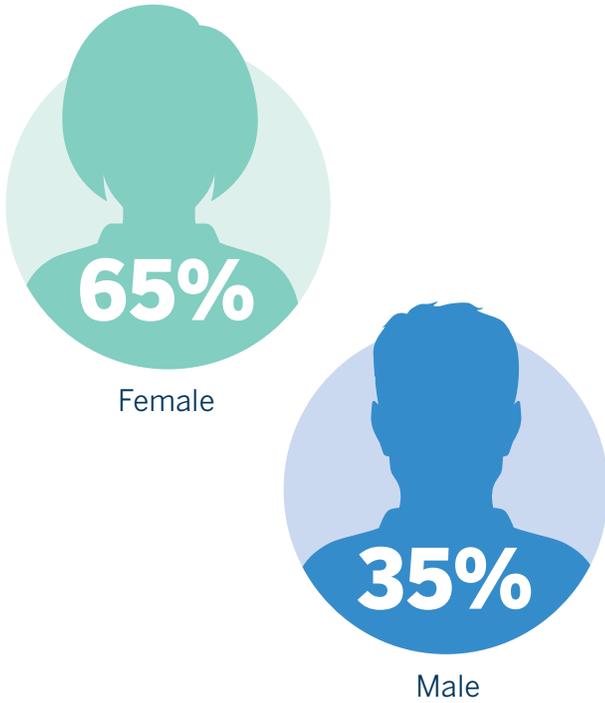
See Figure 1 for the distribution of respondents by cancer type.<sup>3</sup> A slight majority (54%) had health-care coverage through government-sponsored programs such as Medicare or Medicaid; 36% were covered through their employer, and Blue Cross/Blue Shield was the leading private insurer (Figure 2).

**Figure 1: Distribution of Respondents by Cancer Type (N=509)**

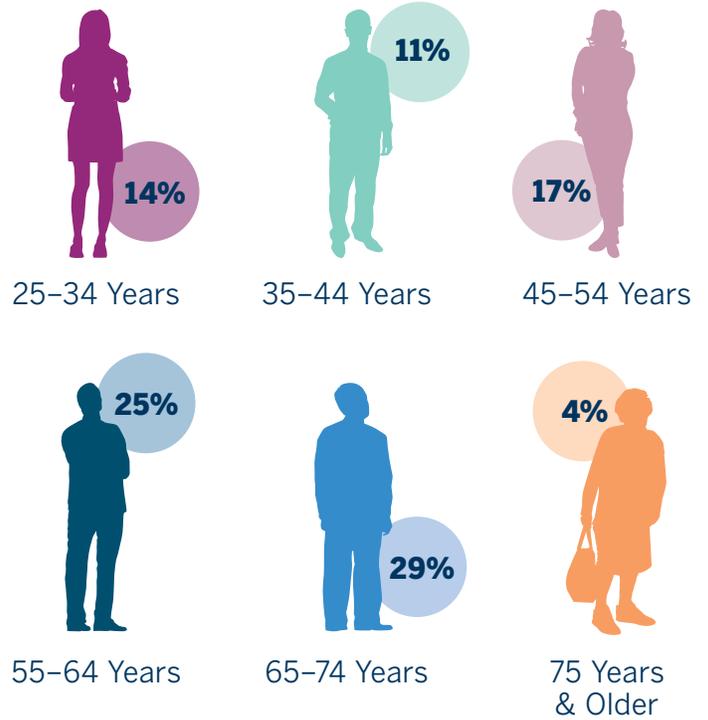


## Survey 4: Respondent Demographics (N=509)

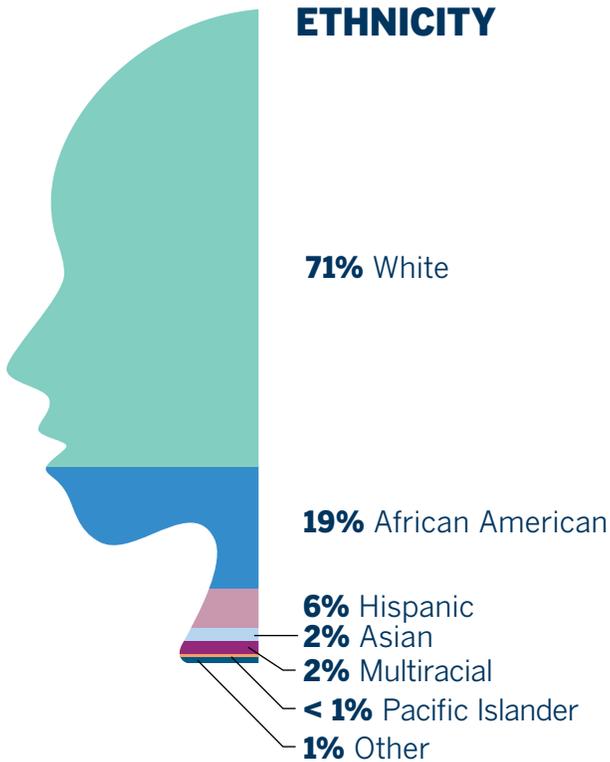
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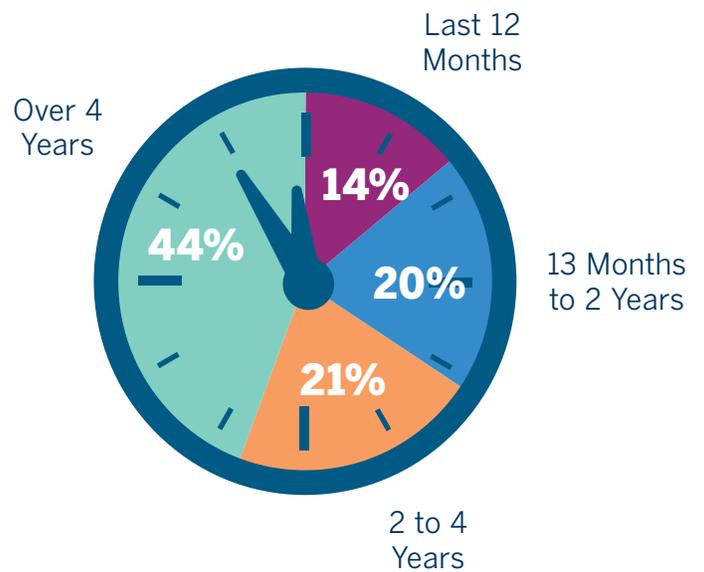
### AGE



### ETHNICITY

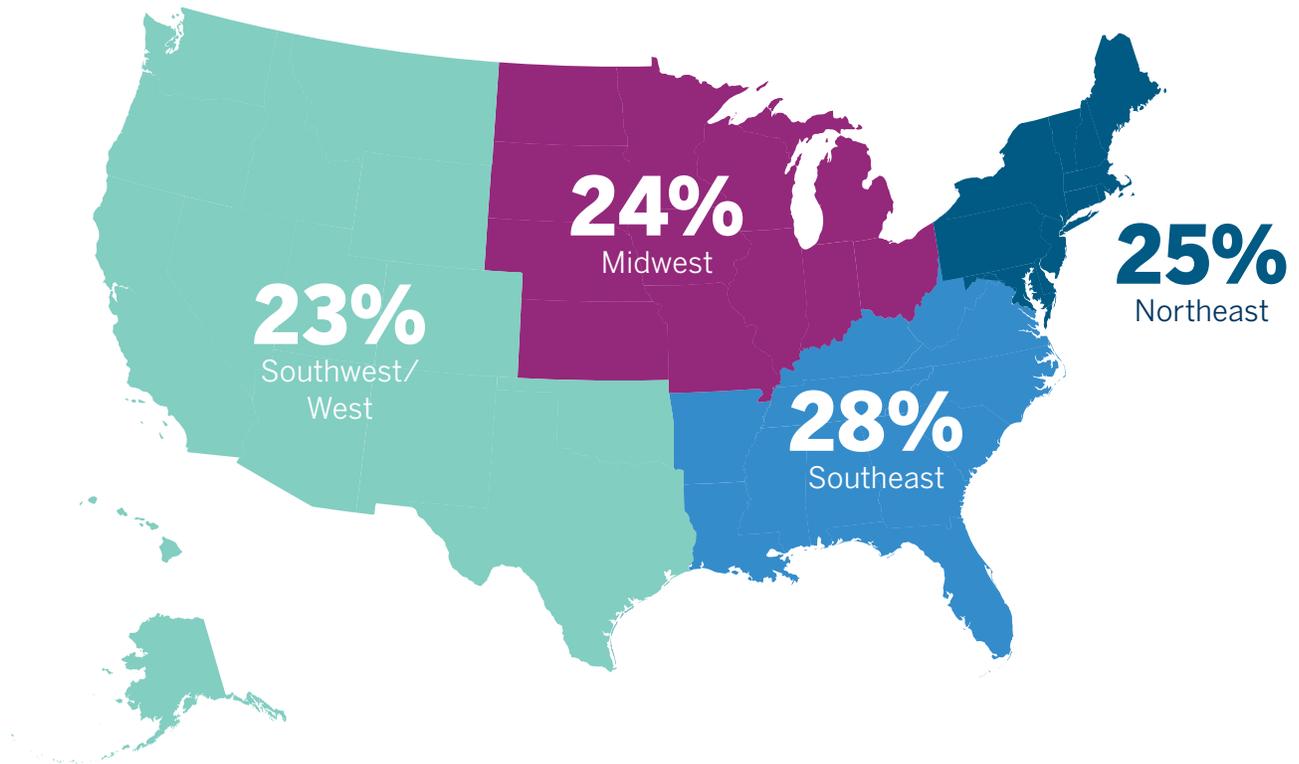


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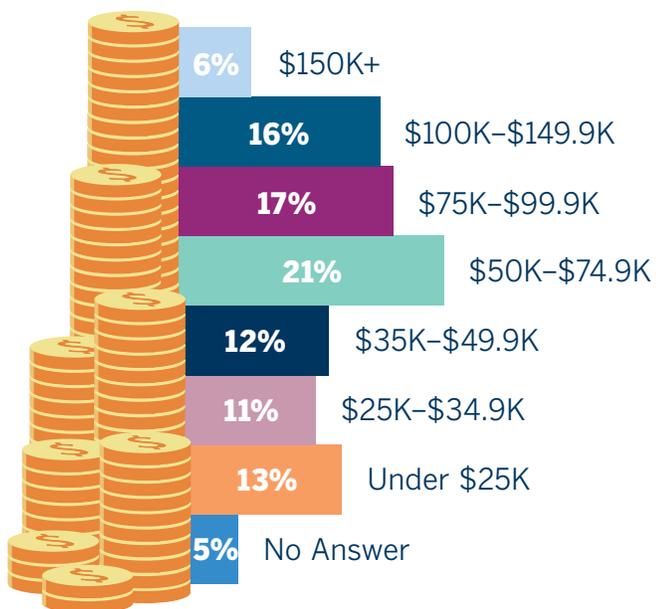


## Survey 4: Respondent Demographics (N=509)

### REGION



### INCOME



### EDUCATION

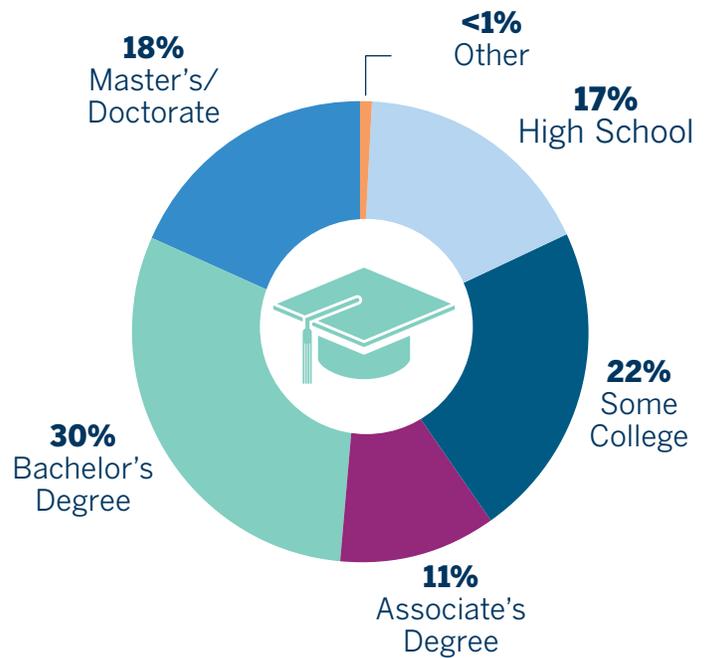
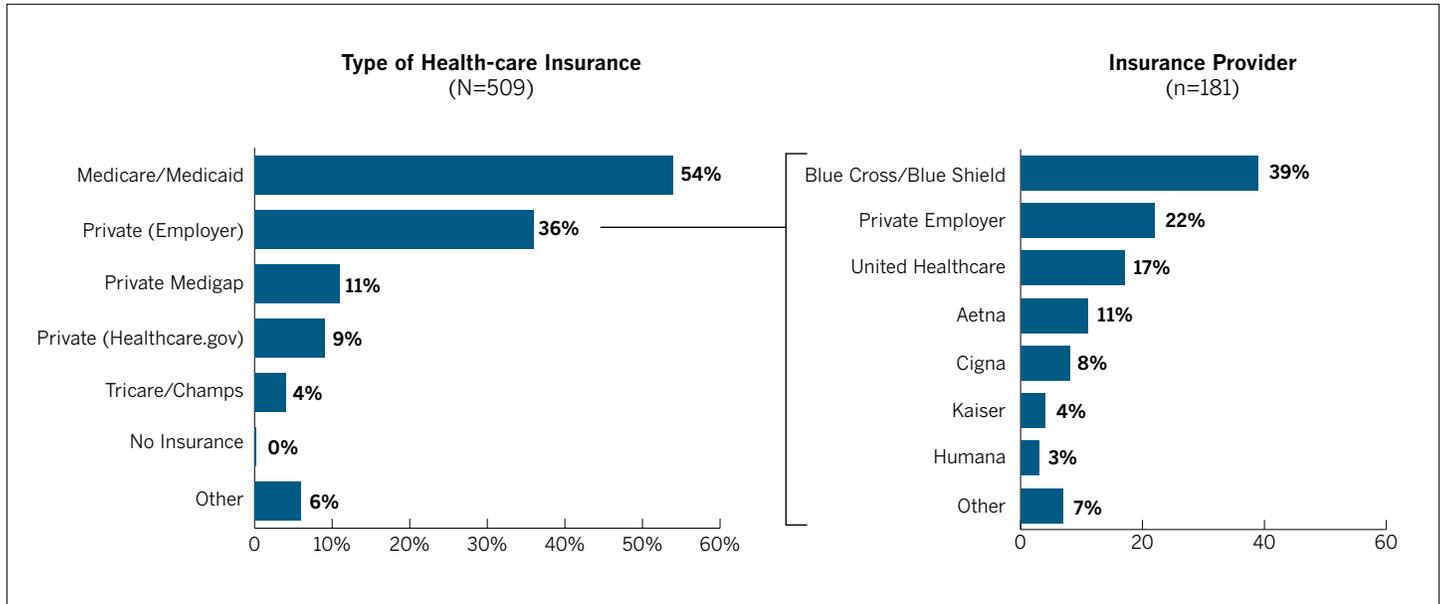




Figure 2: Types and Providers of Insurance



### Perceptions of Insurance Coverage

Only about half of our respondents, 55%, reported understanding their insurance coverage for their cancer “very well” or “completely.” Among African American and Hispanic respondents ages 25 to 64, only about 46% reported they understood their insurance coverage “very well” or “completely,” and just 64% versus 72% of white patients were “moderately” or “very satisfied” with their insurance coverage.

When it came to finding a physician or a “really good” hospital or cancer center in their insurance network, the overwhelming majority of older respondents (55 years and older) agreed that it was “very” or “somewhat easy.” About one-third of younger patients, however, said they had difficulty finding an acceptable physician or a treating hospital in their plan.

Despite our finding of relatively high levels of satisfaction with insurance coverage, about one-quarter of respondents

### Ease of Finding Cancer Treatment



**36%** of younger patients (25–54 years old) did not think that finding a doctor was easy.



**32%** of younger patients (25–54 years old) did not think that finding a treatment center was easy.

25 to 64 years old noted that if it weren’t for insurance network limitations, they would have chosen a different doctor, treatment facility, or treatment plan. Furthermore,

## Survey 4: Financial and Insurance Issues



a quarter reported being dissatisfied with the affordability of deductibles, and nearly 20% were dissatisfied with access to genetic testing, clinical trials, and new treatments or drugs. Sadly, 44% were concerned that they could lose their insurance if they were unable to work.

### Determining Out-of-Pocket Costs

With treatment plans and insurance coverage always changing, it is often difficult for patients to determine exactly which aspects of their cancer treatment are fully covered by health insurance and how much of the cost is their responsibility. And each person's out-of-pocket cost to treat his or her cancer can vary considerably based on the individual's type of treatment, length of treatment, treatment center location, and type of insurance.

In our survey, regardless of the respondent's age, ethnicity, education, or income, about one-quarter of patients report-

### What percentage of respondents (N=509) found it difficult to determine out-of-pocket costs for these expenses?

	Physician Fees	<b>21%</b>
	Scans and X-rays	<b>25%</b>
	Treatments	<b>26%</b>
	Procedures	<b>28%</b>
	Hospital Fees	<b>31%</b>



ed that it was “somewhat” or “very difficult” to estimate out-of-pocket costs before incurring the expense. When asked to tabulate their average monthly out-of-pocket spending for treatment-related expenses, non-elderly respondents reported an outlay of \$1,112, nearly twice as much as those 65 and older. In both cases, this financial burden is well beyond what most families can comfortably afford.

As these surveys have shown, patients often have an incomplete understanding of the terms of their insurance coverage; furthermore, they have difficulty connecting with the case managers who could help. Information on treatment-related costs could help patients better understand the risk of financial toxicity that can accompany the diagnosis and treatment of cancer.

### Talking With the Doctor About Cancer Costs

Although studies show that the rising costs of cancer treatment influence clinical practice, many oncologists still remain reluctant to discuss the cost of care with their patients,<sup>4</sup> and those findings are corroborated in our survey. Among respondents younger than age 65, 25% reported that members of their medical team never considered their financial situation while planning their treatment, with only 34% agreeing that it was sometimes



considered. And a majority, 58%, said thinking about their finances during their cancer treatment caused feelings of distress. (Of note, some studies have found that patients may also be reluctant to discuss costs of care with their physicians.<sup>5</sup>)

### How Treatment Costs May Compromise Care

A large number of patients, especially younger patients, reported that they used one or more care-altering strategies to reduce the financial cost associated with having cancer, some of which may have compromised their cancer treatment. For example, 39% of those between the ages of 25 and 54 said they “often, always, or sometimes” postpone or skip doctor’s appointments; 38% said they postpone or do not fill prescriptions; 34% reported skipping dosages of prescribed drugs; 30% ordered medications online from pharmacies outside of the United States; and 31% cut their pills in half.

*Continued on page 56* 

#### Patient Level of Financial Stress During Treatment



**58%** of younger patients (25–54 years old) said that thinking about their financial situation caused them stress.



CANCERcare®

# Gladys B.

## My Treatment Is Bankrupting Me

A retired elementary school secretary in Texas, Gladys B. and her husband Franklin live on a fixed income of about \$1,000 a month. Three years ago, Gladys was diagnosed with multiple myeloma, the second most common type of blood cancer.

“It came as such a shock,” she said. “I went to the hospital thinking I had the flu, but my blood tests showed that something was very wrong.” Gladys’ kidneys were not functioning properly, a symptom experienced by about 20 percent of people with multiple myeloma.

The second shock, said Gladys, was learning how expensive her treatment would be. “One of the drugs I had to take cost \$9,000 a year. I was very stressed about the bills. My husband and I had both been pretty healthy. To suddenly have so many large medical bills was really hard.”

Never far from her mind was Gladys’ Aunt Helen who, when coping with heart disease, had to choose between heating her home and paying for medication. “Just one room in her house was warm,” Gladys recalled. “It was the only way she could afford to buy the pills she needed. When I got cancer, the finances weighed heavily on me. I was very worried about having to make that kind of decision.”

Gladys said that she began buying less expensive—and less healthful—food to reduce the strain on their

budget. She knew that a poor diet wasn’t good for her, but she felt she had no choice.

Then Gladys learned about a co-pay assistance program at CancerCare. “I called the toll-free number, and someone there said, ‘I think we can help you.’ It was a big relief to hear those words,” she said. Gladys qualified for up to \$7,000 a year in assistance. Between CancerCare and money that her two grown sons could contribute, Gladys felt much more at ease.

**“It’s worrisome that so many people with cancer have to deal with this issue.”**

To help reduce stress, she reads her Bible, meditates, walks, and carves out quiet time to “de-clutter” her mind. “Worry about paying for treatment can send you out of control if you let it,” said Gladys.

Now 66, Gladys is in remission and may be able to finish treatment soon. “I’ve come a long way,” she reflected. “I’m so grateful for the help I received. But it’s worrisome that so many people with cancer have to deal with this issue.” ■



Figure 3: Steps Taken to Reduce Treatment Expenses

	Done Often or Always		Done Sometimes	
	25 to 54 Years Old (n=215)	55 Years and Older (n=294)	25 to 54 Years Old (n=215)	55 Years and Older (n=294)
Apply for co-pay assistance to cover medication costs	27%*	10%	17%*	4%
Choose to use a lower cost medication than what the doctor recommended	27%*	7%	16%*	8%
Delay or skip complementary treatment	27%*	7%	16%*	5%
Apply for financial assistance for non-medical expenses such as transportation	25%*	6%	18%*	5%
Postpone or skip psychological counseling or support	24%*	6%	16%*	4%
Apply for financial assistance from my doctor/hospital	24%*	4%	21%*	7%
Discuss changing my treatment to one that costs less	24%*	3%	19%*	10%
Postpone or skip follow-up testing	23%*	4%	16%*	5%
Postpone or not fill prescriptions	21%*	2%	17%*	6%
Postpone or skip doctors' appointments	20%*	2%	19%*	7%
Skip dosages of prescribed drugs	20%*	2%	14%*	5%
Postpone or skip blood work	17%*	2%	18%*	3%
Order medications on-line from non-US sources	16%*	3%	14%*	2%
Cut pills in half	14%*	4%	17%*	4%

\*Indicates statistically significant differences at the 90% confidence level.

Continued from page 54

Nearly half of younger patients accessed programs that help reduce costs, such as co-payment assistance to cover the cost of their medications or financial assistance for nonmedical expenses, such as transportation to their care center. An equal number discussed changing their treatment regimen to a less expensive one (Figure 3).

### The Impact of Cancer

In addition to potentially compromising the effectiveness of their cancer treatment, the financial burden

placed on the respondents in our survey posed many lifestyle challenges. And, once again, coping with the financial ramifications of cancer was most difficult for our younger respondents. One-third of those between the ages of 25 and 54 reported having to reduce their expenses on such essential necessities as groceries, transportation, and clothing; one-third borrowed money and one-quarter applied for financial assistance from their health-care provider or a patient support organization. Furthermore, 21% missed paying utility bills; 17% missed making their rent or mortgage payment;

# Survey 4: Financial and Insurance Issues

11% considered filing for bankruptcy; and 5% declared bankruptcy (Figure 4).

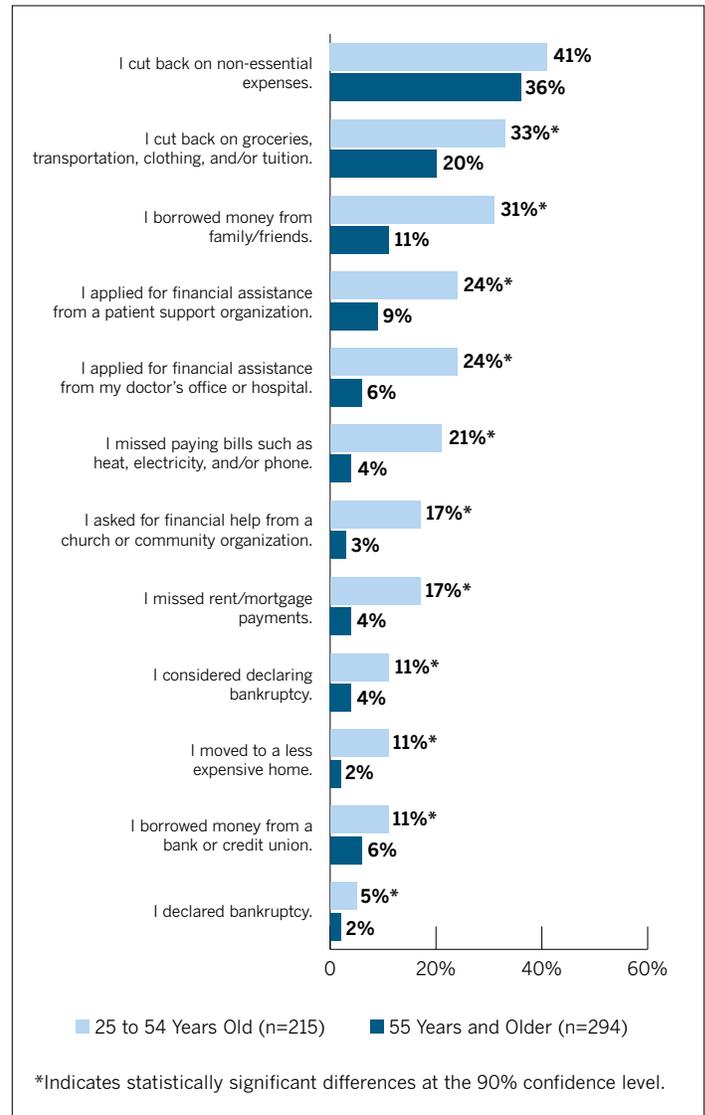
The loss of income exacerbates the pressure of cancer-related expenses. Although more than one-third of all respondents continued working full time during treatment, one-quarter of patients between the ages of 25 and 64 stopped working; and 13% switched from full-time to part-time work (Figure 5).

## Conclusions and Recommendations

The results of this survey indicate that people with cancer frequently have difficulty understanding their insurance coverage and the extent to which the cost-share burden may be passed along to them after a cancer diagnosis. Exacerbating patients' financial insecurity is the general high cost of cancer care within a comprehensive treatment plan. Our survey found that between 20% and 30% of patients had difficulty estimating their out-of-pocket costs before incurring medical expenses, setting the stage for financial uncertainty and insecurity that likely affected many aspects of their lives. In addition, cancer impacted the work life of significant numbers of respondents, who reported either stopping work altogether during treatment or working part-time, thus putting them in even greater financial jeopardy.

The financial consequences of cancer on patients are many, including reducing their ability to pay for such everyday essentials as food, transportation, utilities, and rent. A third of them have to borrow money to meet their needs. Perhaps most concerning of all is that the financial burden placed on patients in our survey caused them to take care-altering steps to save money, such as postponing doctors' appointments, not filling prescriptions, ordering medications from outside the United States, and cutting pills in half.

**Figure 4: Experiences Due to Treatment Bills**



Patients would be well served to learn about the many assistance programs available to provide financial support, and care providers are ideally situated to inform them. It is also incumbent upon physicians to be more sensitive to the

*Continued on page 59*



## KEY FINDINGS FROM SURVEY 4: FINANCIAL AND INSURANCE ISSUES

■ Only about one-half of the respondents to this survey reported understanding their health insurance coverage for their cancer care “completely” or “very well.” Nearly 70% of respondents between the ages of 25 and 64, however, reported being “moderately” or “very satisfied” with their health insurance coverage.

■ Twenty-five percent of respondents between the ages of 25 and 64 stopped working during active treatment, and 13% switched from full-time to part-time employment. Only one-third of our respondents continued working full-time during treatment.

■ Despite 58% of respondents reporting being distressed about their finances during treatment, 25% of respondents younger than 65 said that their medical care team never considered their financial situation during treatment planning; and 34% said it was only “sometimes” considered.

■ Many respondents, especially those between the ages of 25 and 54, used care-altering strategies to reduce the cost of their care, some of which may have compromised their cancer treatment. Thirty-nine percent said they skipped doctors’ appointments; 38% postponed or did not fill drug prescriptions; 34% skipped doses of prescribed

medications; 30% ordered their medications online from sources outside of the United States; and 31% cut their oral medications in half.

■ Expenses related to a cancer diagnosis have a far-reaching impact on patients’ lives. One-third of respondents between the ages of 25 and 54 reported cutting back on daily essentials, such as gro-

**31%**  
of respondents cut  
their oral medications  
in half.

ceries and transportation; and/or borrowed money from family members and friends. One-quarter applied for financial assistance

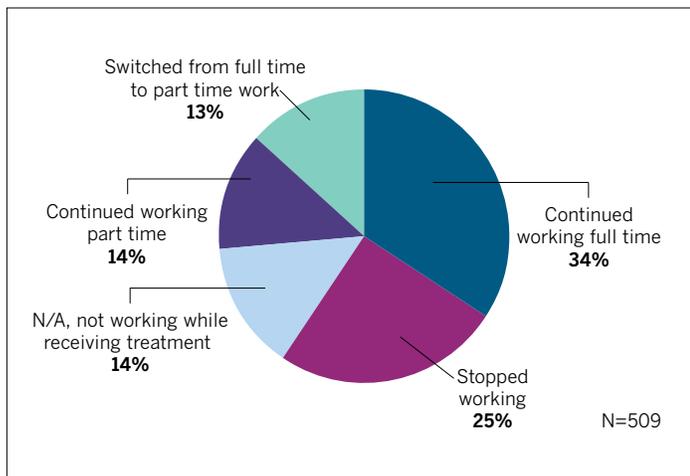
from patient support organizations or their medical providers; 21% missed a utility bill payment; and 17% missed making a rent or mortgage payment.

■ When asked to tabulate their average monthly out-of-pocket spending for treatment-related expenses, non-elderly respondents reported an outlay of \$1,112, nearly twice as much as those 65 and older.

■ Among those ages 25 to 64, 44% were concerned that they would lose their insurance if they were unable to work.

# Survey 4: Financial and Insurance Issues

**Figure 5: Employment Status During Treatment (Ages 25–64)**



 Continued from page 54

financial distress cancer may pose for many patients. More open discussions with patients about the cost of their care can lead to greater understanding of patients' financial and personal circumstances, family responsibilities, and their goals and priorities for treatment. This understanding may help ease the financial distress many patients experience. In a recent study,<sup>5</sup> comparatively few patients discussed their financial burdens, but those who did got results. Fifty-seven percent of patients who discussed their financial concerns saw a reduction in their costs, and 75% of this group received this reduction without any change to their treatment plan. In these cases, the care team was able to press harder for cooperation with the insurer or find the patient some financial assistance.

We recommend that care providers:

- Discuss treatment costs and patients' ability to meet those costs when recommending treatment options;
- Refer patients in need to patient support

organizations and patient assistance programs to ease the financial burden of care;

- Refer patients to social workers and financial counselors associated with their care team, to help them anticipate and cope with financial concerns and related distress;
- Check in with patients at each visit regarding how well they are coping—emotionally, physically, and financially.

We recommend that insurers:

- Help educate policy holders with cancer on the relevant terms of their coverage;
- Refer patients in need to patient support organizations and patient assistance programs to ease the financial burden of cancer-related costs;
- Offer case management services to help patients navigate treatment decisions in the context of their financial circumstances. ■

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3. American Cancer Society. *Cancer Facts & Figures 2015*. Atlanta: American Cancer Society; 2015.
4. Neumann PJ, Palmer JA, Nadler E, et al: Cancer therapy costs influence treatment: A national survey of oncologists. *Health Aff (Millwood)* 29:196–202, 2010.
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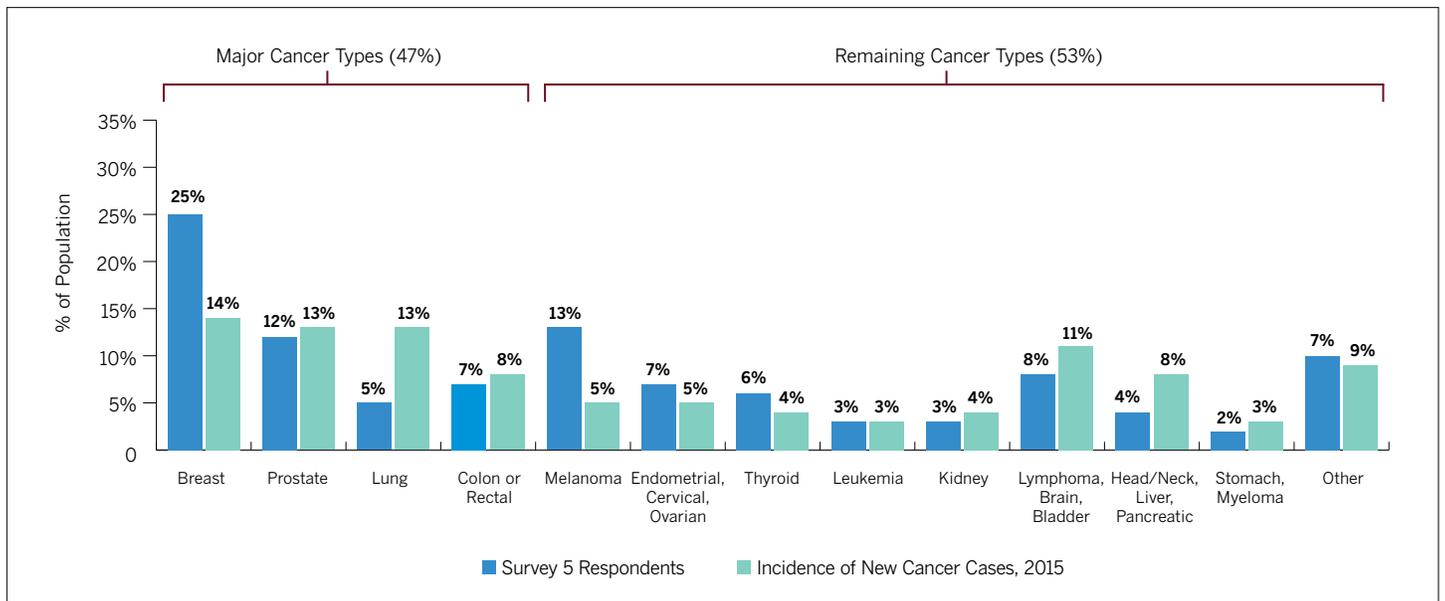


In *Survey 5: Symptoms, Side Effects, and Quality of Life*, we set out to understand how cancer affects patients physically and emotionally, how patients and their care team evaluate and respond to symptoms and side effects, and how the physical and emotional side effects of cancer and its treatment impact patients' daily lives.

See Figure 1 for a distribution of the respondents by cancer type.<sup>1</sup>

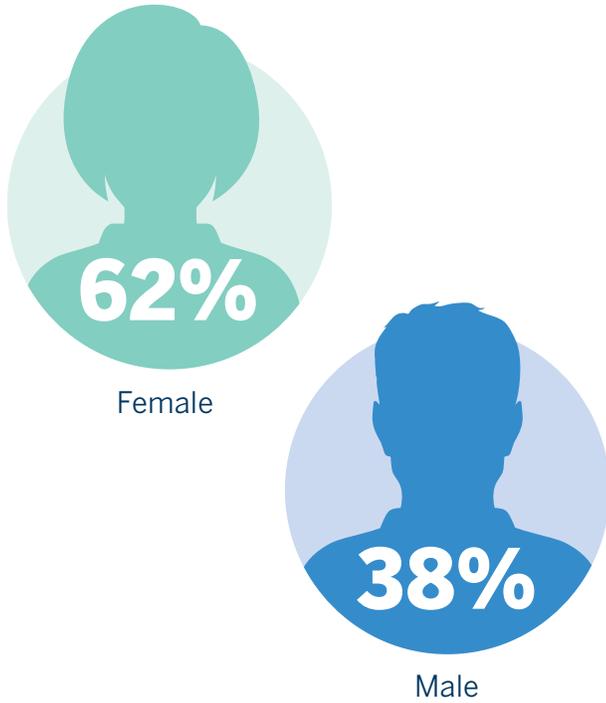


**Figure 1: Distribution of Respondents by Cancer Type (N=527)**

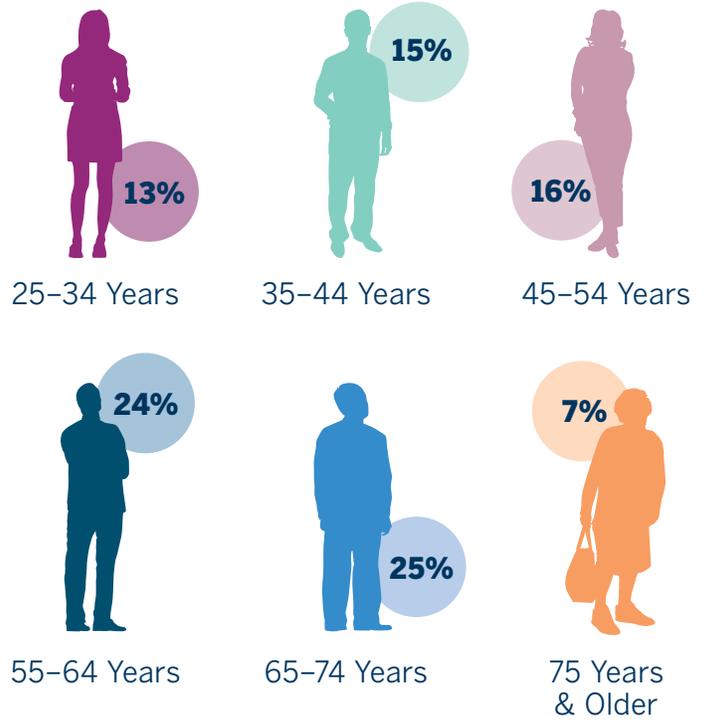


# Survey 5: Respondent Demographics (N=527)

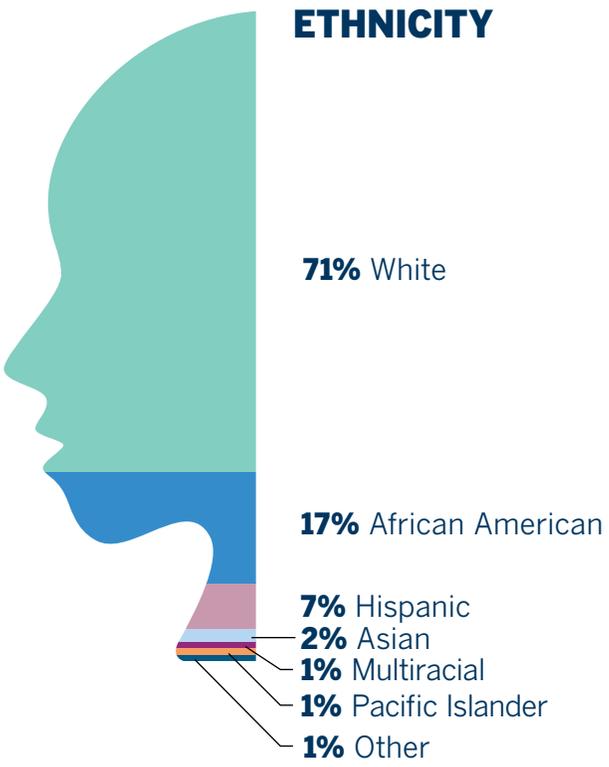
## GENDER



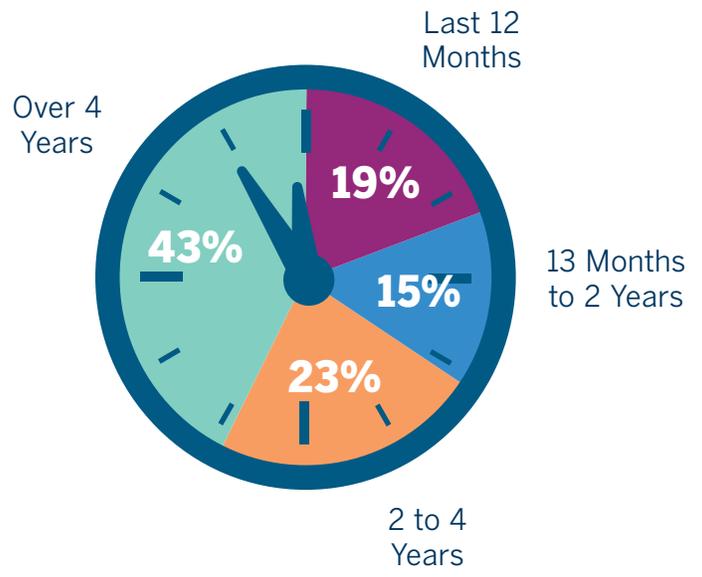
## AGE



## ETHNICITY

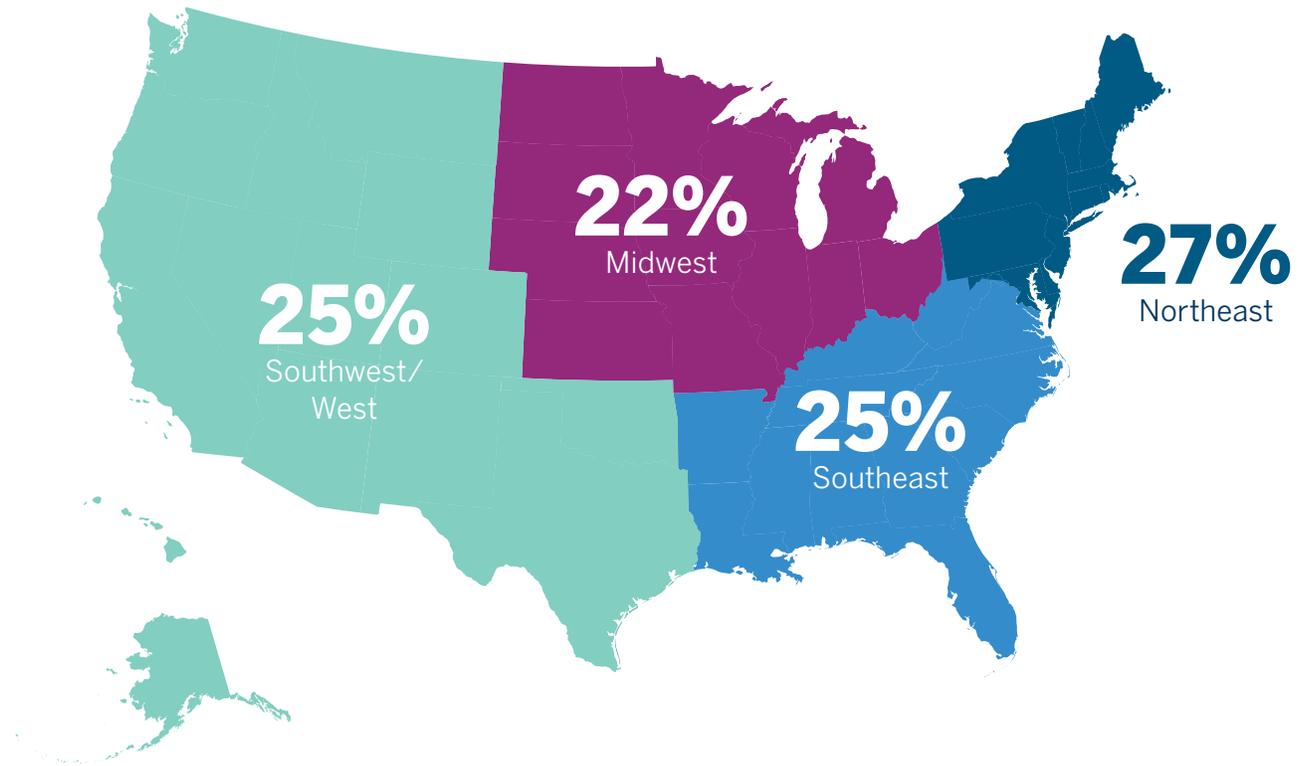


## TIME SINCE FIRST DIAGNOSED

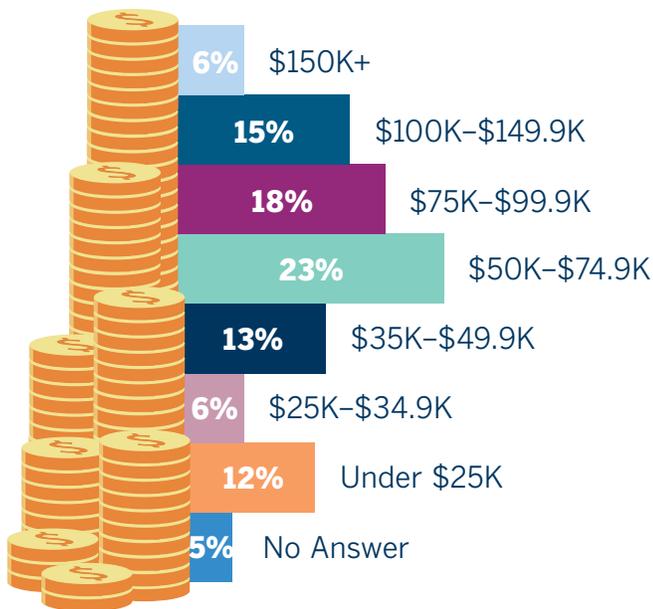


# Survey 5: Respondent Demographics (N=527)

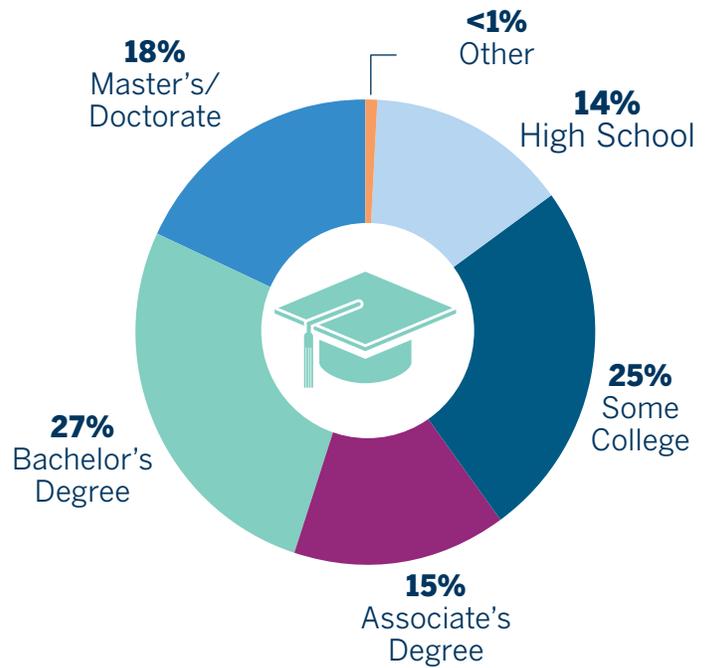
## REGION



## INCOME



## EDUCATION





### Observations

Dealing with the different side effects and life changes brought about by a cancer diagnosis and its treatment is often difficult for patients both physically and emotionally. Just how difficult it is for patients, especially women, was evident from our survey results. Research suggests that most people undergoing cancer treatment will experience fatigue,<sup>2</sup> and that was the number-one complaint in our survey, with both men and women saying that moderate-to-severe fatigue was the symptom that interfered most with their daily activities. Patients on active treatment and those on maintenance therapy suffered from cancer-related fatigue and its impact on their day-to-day lives at similar levels.

Women were roughly one and a half times more likely than men to have moderate-to-severe anxiety; difficul-



**Figure 2: Common Side Effects Experienced by Respondents**

	Moderate to Severe Symptoms		Symptoms Interfering Most With Day-to-Day Activities	
	Male (n=200)	Female (n=327)	Male (n=174)	Female (n=298)
Fatigue	41%	61%*	25%	46%*
Anxiety	30%	43%*	12%	20%*
Difficulty exercising and staying physically active	29%	37%*	10%	16%*
Sexual/intimate relations problems	27%*	16%	8%*	3%
Weight gain or loss	25%	36%*	4%	9%*
Decreased appetite	23%	28%*	8%	7%
Hair loss	22%	40%*	5%	7%
Diarrhea	21%	17%	9%	7%
Nausea or vomiting	15%	25%*	7%	15%*

\*Indicates statistically significant differences at the 90% confidence level.

# Survey 5: Symptoms, Side Effects, and Quality of Life

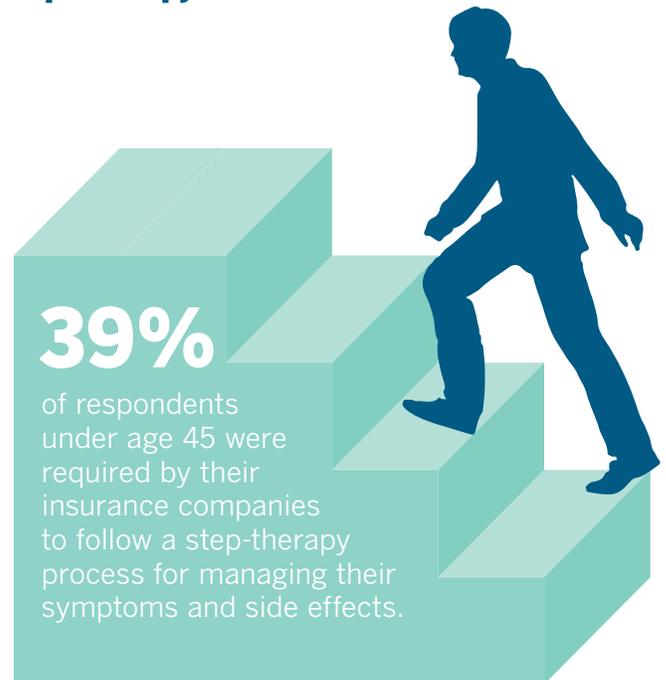
ty exercising and staying physically active; weight gain or loss; decreased appetite; hair loss; feeling of sadness or depression; sleep disturbances; changes in taste; nausea or vomiting; cognition difficulties; muscle aches and cramps; pain, numbness, or tingling in their extremities; and headaches. Men, however, were more likely than women to experience moderate-to-severe sexuality and intimacy issues (Figure 2).

A third of respondents reported suffering regularly from pain, though only 13% reported having a lot or severe pain. For almost two-thirds of those with pain, their doctors used a formal pain scale; nearly all respondents believed their doctors took their pain seriously. Pain was managed by the doctor treating their cancer for nearly half of the respondents and by a PA or NP for a quarter. About 20% of patients saw a pain or palliative care specialist, although more reported having been referred to one, and a third reported having used prescription pain relievers. Overall, concern about becoming addicted to pain killers was only 15%, slightly higher among those 25 to 54 years old and those in active treatment.

## Communicating About the Side Effects of Cancer

Nearly all patients said they most often discussed symptoms and side effects with their physician, and that was true whether the respondent was in active treatment, had completed therapy, and/or was on a maintenance regimen. For two-thirds of patients, these discussions were with the doctor treating them for cancer. Interestingly, nearly half reported having these discussions with a primary care physician. Also of note, only 44% reported keeping track of their symptoms and side effects, though younger patients were much more likely to do so.

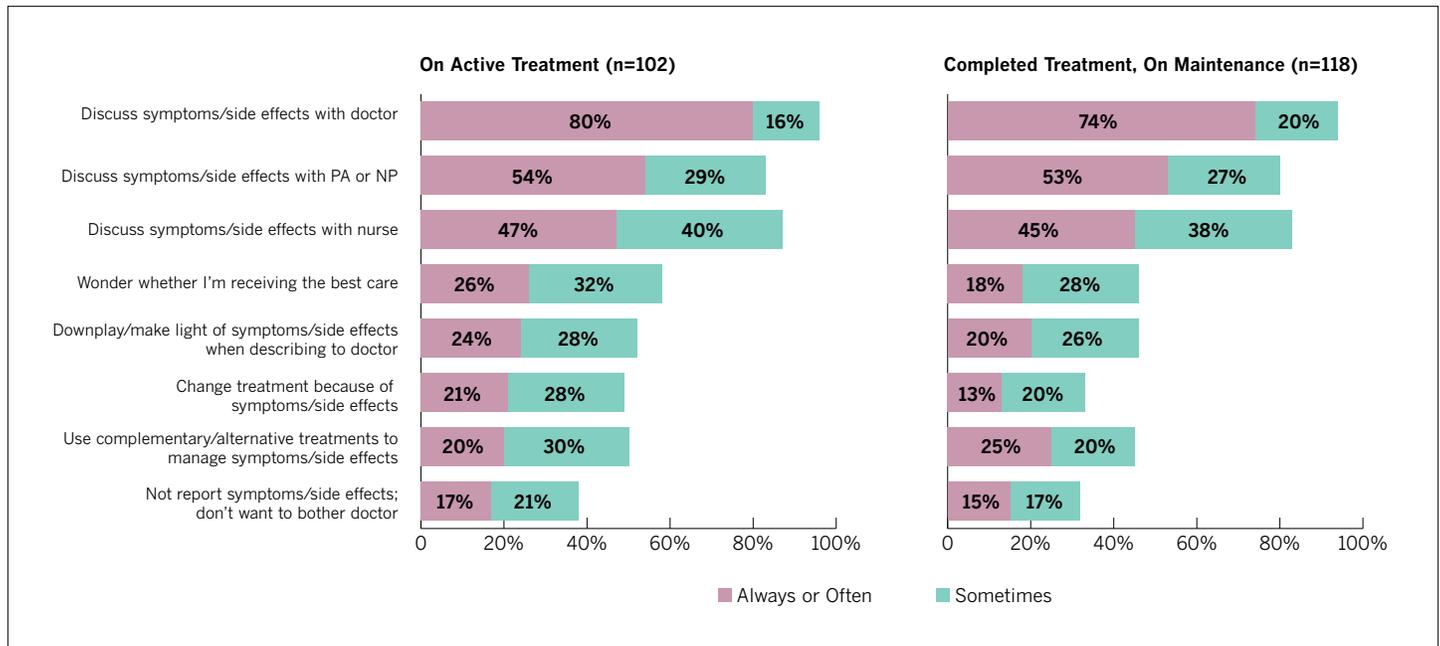
## Step Therapy



Although most respondents in our survey reported feeling “very” or “somewhat satisfied” with the way their clinical care team prepared them for the symptoms and side effects of their cancer treatment, 35% of patients ages 25 to 44 years disagreed, indicating they were “very” or “somewhat dissatisfied” with how well they were prepared. Those on maintenance therapy were also less likely to be satisfied than those in active treatment with the preparation provided by their medical team.

During their time in treatment, about half of our respondents said they “wondered whether they were receiving the best care.” A similar number reported they often or sometimes downplayed or made light of treatment side effects when describing them to their doctors and nearly 40% said they did not report their treatment side effects because they did not want to “bother the doctor.”

**Figure 3: Frequency of Actions Taken Because of Symptoms and Side Effects**



Also of note, nearly half of respondents said they used complementary and/or alternative remedies, such as acupuncture or herbal remedies to manage their symptoms and side effects. Especially concerning is that a significant number—approximately one-half—of respondents said they changed treatment sometimes, always, or often because of symptoms and side effects (Figure 3).

### Step-Therapy Restrictions

One of the most alarming findings in this survey is that a significant proportion of non-elderly respondents, 39%, said that their insurance company required them to follow a step-therapy process in managing their cancer symptoms and side effects. And a majority of those patients, 56%, were required to use a non-preferred medicine for 2 to 3 months.

Also referred to as a fail-first requirement, step therapy is an insurance company cost-saving strategy that denies payment for a drug unless certain other drugs have been tried first. Patients enrolled in Medicare Part D drug plans are less likely to be asked to try and fail with a cheaper drug before the original drug is covered,<sup>3</sup> explaining why 88% of older respondents did not encounter step-therapy restrictions.

### Using Distress Screening to Spot and Remedy Psychosocial Issues

The American College of Surgeons Commission on Cancer has mandated that a systematic protocol for psychosocial distress screening and referral be implemented as a condition for cancer center accreditation.

*Continued on page 68* 



CANCERcare®

# Miguel R.

## What Quality of Life Means to Me

In December 2013, Miguel R., 27, never imagined that the growing tightness in his chest and the insomnia he had been experiencing could be the sign of a serious disease, especially a life-threatening one like cancer. Miguel prided himself on being physically fit. He routinely played basketball with friends, was active in martial arts, and exercised regularly. But when his breathing became severely labored after just a short walk to his girlfriend's house, he knew something was very wrong and immediately went to the emergency room. A month later, he was diagnosed with a rare germ cell cancer that affects young adult men.

Despite four rounds of aggressive chemotherapy, followed by surgery to remove the tumor, Miguel's cancer transformed into another type of tumor called angiosarcoma, which affected his right shoulder. When Miguel's surgical oncologist recommended removal of his acromion bone—a small bone that forms a roof over the shoulder—he worried he would lose full motion in his arm. It would make both his routine daily activities and his sports activities much more difficult.

Miguel talked to his surgeon about his fears that the shoulder surgery would severely impact his quality of life. "I was concerned that I wouldn't be able to go rock climbing anymore, or practice martial arts, or even exercise," Miguel says. "Being physically active and maintaining a

healthy lifestyle is very important to me."

Aware of Miguel's concerns and eager to preserve as much mobility in his upper arm as possible without compromising his medical care, Miguel's surgeon was careful not to damage any of the surrounding tendons when he removed the bone. He prescribed physical therapy to hasten restoration of motion in Miguel's right arm.

**"Being physically active and maintaining a healthy lifestyle is very important to me."**

In August 2014, Miguel completed his chemotherapy and steadily increased his amount of physical activity. Now he is able to engage in the same activities he enjoyed before his cancer.

"Quality of life has a different meaning for every cancer survivor," Miguel notes. "It was important for me to communicate to my oncologists my fears of having a limited physical lifestyle after treatment, and they were receptive to my concerns. Today, I have a nearly normal range of motion in my right arm, which has surprised my oncologist. I'm able to resume an active lifestyle, so I feel lucky." ■



### Distress Thermometer

The Distress Thermometer is a widely used screening tool for assessing psychological distress in people with cancer. Patients are asked to choose a number from 0 to 10 that reflects the level of stress they are feeling today and how much they felt over the past week. Ten is the highest level of stress imaginable, and 0 is no stress at all. In addition, many Distress Thermometer forms include a Problem List of things that may be causing the patient distress, such as family problems, physical issues, spiritual concerns, practical problems, and emotional problems. The patient is asked to check off any of the problems on the list as possible reasons for distress. The care team can then use this list to get the patient the necessary help.



Continued from page 66

The requirement went into effect in 2015 and is meant to assess and help patients communicate their levels of emotional and physical distress with their medical care team.

A disturbing finding in our survey is that only 19% of men and 12% of women were asked to fill out a distress thermometer form by a member of their clinical care team. Younger patients ages 25 to 44 were 10 times more likely to be asked to complete this form than their older counterparts, suggesting that providers are aware of the extraordinary levels of distress experienced by this population of patients. Likewise, usage was relatively high among those patients in active treatment (29%) and those receiving maintenance therapy (19%).

Of note, however, in other surveys fielded for this report (survey 2 and survey 3), approximately one-half of patients in survey 2 reported being asked about distress

at each visit. In survey 3, fewer than one-half of respondents reported being asked about distress related to specific topics. Patients may be asked about distress, but may not specifically be asked to use the distress thermometer tool.

Many studies have reported that patients who could benefit from psychosocial support services do not often receive them. In an effort to address this, the American Society of Clinical Oncology has joined the Commission on Cancer in recommending the use of systematized distress screening. The objective is to identify patients at risk for physical, psychological, or social conditions that may interfere with access to needed care or adherence to therapy or contribute to the excessive and unnecessary use of scarce medical resources. Studies also suggest that the use of psychosocial screening instruments to detect and respond to distress result not only in reduced emotional distress, but better quality of life, patient satisfaction, and improved patient-provider communication.<sup>4,5</sup>

# Survey 5: Symptoms, Side Effects, and Quality of Life

## Overcoming Emotional Distress

Only 26% of total respondents reported using cancer-specific counseling or support services to help them cope with the emotional symptoms and side effects of their cancer or its treatment. Patients between the ages of 25 and 44 years and those in active treatment, however, were twice as likely to have talked with a social worker, psychologist, or psychiatrist specializing in oncology.

## The Impact of Cancer on Day-to-Day Life

As mentioned previously, the side effects of cancer and its treatments can have a profound impact on patients' ability to carry out the normal routines of their daily life, including working, exercising, socializing with family and friends, caring for children, preparing meals, and even maintaining personal hygiene. In this survey, one-quarter to one-third of total respondents reported that having cancer had dramatically compromised their ability to perform those day-to-day activities, with 46% of those in active treatment saying they had difficulty working and 36% reporting their ability to entertain friends and family was significantly reduced.

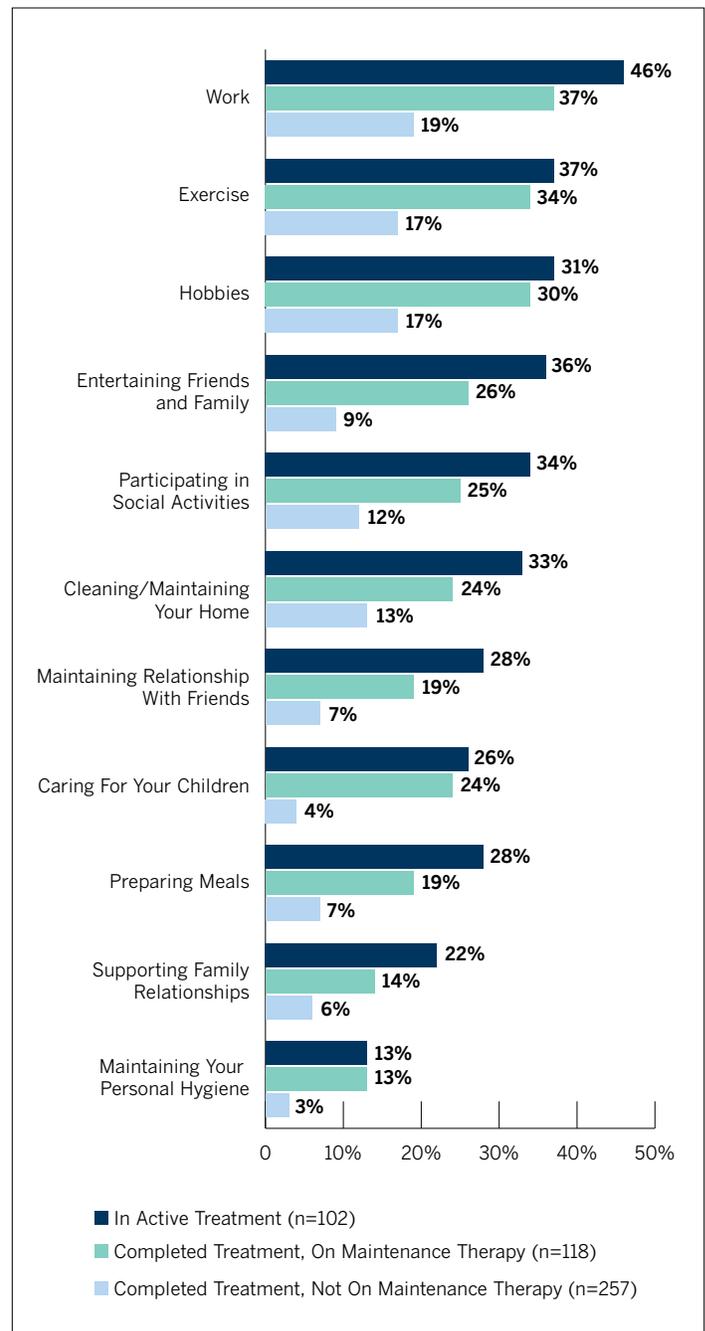
Those who had completed treatment and were on maintenance therapy seemed to suffer from these compromises nearly as much as those in treatment (Figure 4).

Caregivers often play an important role in helping people with cancer through treatment and to handle their day to day responsibilities. Sadly, a third of respondents to our survey reported not having a caregiver (Figure 5).

## Conclusions and Recommendations

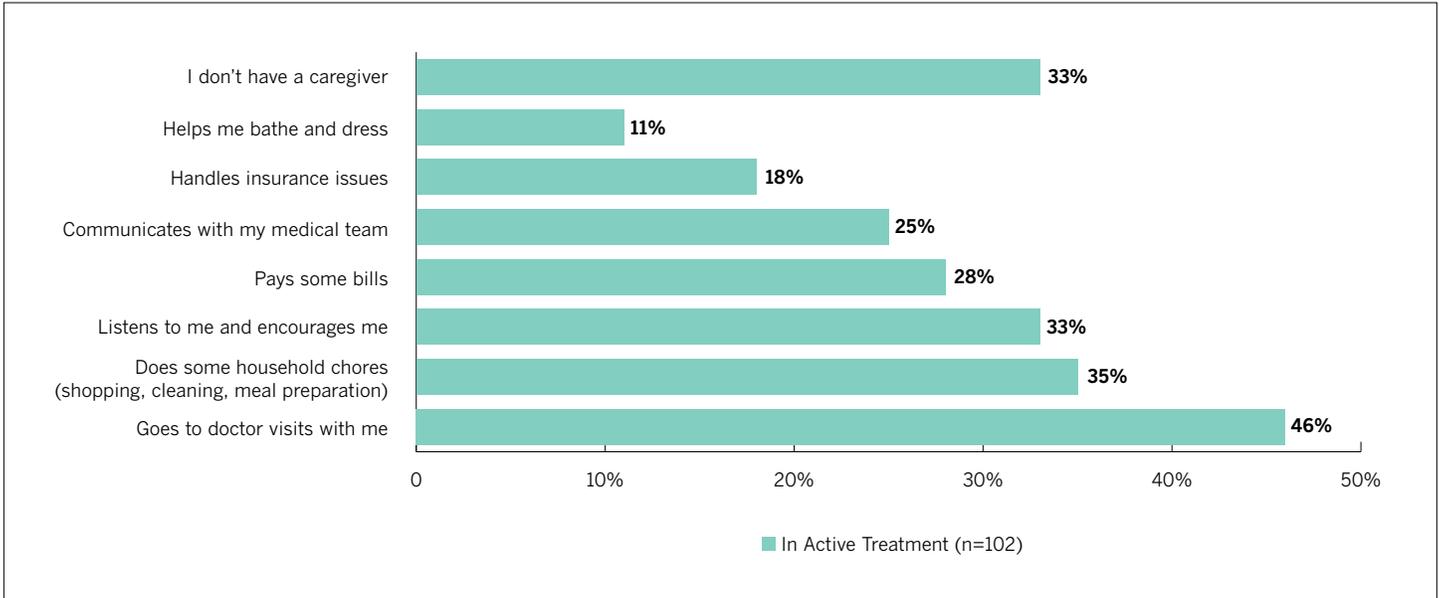
Nearly half of our respondents experienced severe to moderate fatigue as well as other debilitating cancer-related symptoms and side effects that interrupted their daily ac-

**Figure 4: Activities Reduced “Completely” or “A Lot”**





**Figure 5: Roles of the Caregiver**



tivities and work life. Most respondents reported feeling satisfied with the way their clinical care team prepared them for the symptoms and side effects of their cancer and its treatment; more than one-third of those ages 25 to 44 were dissatisfied, however. Clinicians and support organizations can help to fill this void by providing and encouraging patients to access a range of informative materials early in the treatment process. More preparation will likely support patients in better managing their symptoms and may also reduce emergency room visits, which were reported by more than half of survey respondents in active treatment.

Because each person with cancer responds differently to the side effects of chemotherapy, surgery, radiation therapy, and immunotherapy, it would be helpful for patients to keep a log of treatment side effects to bring to medical appointments. Many patients are not fully

and accurately informing their clinical team about their symptoms and side effects, which may be an obstacle to effective management. Physicians may want to probe more deeply regarding their patients' experiences in this area, and perhaps suggest a journal or some other kind of system to regularly track incidence and severity of physical and emotional suffering. A routine systematic review of symptoms and side effects at every office visit may aid in communication and management. Caregivers may be helpful in this effort.

Screening for distress is inconsistent and not widespread despite the attention given to it by the Institute of Medicine, the Commission on Cancer, and the American Society of Clinical Oncology. Clinicians and patients need to be made aware of the negative impact distress has on quality of life and outcomes, and that programs and services are available for patients in need. ■

# Survey 5: Symptoms, Side Effects, and Quality of Life

## KEY FINDINGS FROM SURVEY 5: SYMPTOMS, SIDE EFFECTS, AND QUALITY OF LIFE

■ Moderate to severe fatigue was experienced most often by respondents in this survey, with 25% of men and 46% of women reporting that fatigue interfered with their day-to-day activities. Women were more likely to report experiencing anxiety, difficulty exercising and staying physically active, and bouts of nausea or vomiting.

■ Although the majority of respondents reported feeling satisfied with how well their clinical care team prepared them for cancer-related symptoms and side effects, 35% of those between the ages of 25 and 44 reported feeling “very” or “somewhat dissatisfied.”

■ Respondents most often discussed cancer-related symptoms and side effects with their physicians and to a lesser extent with a physician assistant, nurse practitioner, or nurse. Nearly 40% did not report symptoms or side effects because they did not want to “bother” their doctor.

■ Two out of five non-elderly respondents were required by their insurers to follow a “fail-first” regimen in treating symptoms and side effects. For the majority of these patients, this step-therapy process meant that they used a non-preferred medicine for 2 to 3 months.

■ One-quarter of respondents used cancer-specific counseling or support services to help them cope with their cancer. Those between the ages of 25 and 44 and in active treatment were twice as likely to have used these services.

■ The vast majority of respondents had not received a distress thermometer form from a member of their clinical care team, with only 19% of men and 12% of women reporting use of the form. Younger patients, those under age 45, were 10 times more likely to be asked to complete this form than were patients older than age 45.

■ One-quarter to more than one-third of respondents on active treatment said their ability to perform day-to-day activities, such as working, exercising, entertaining friends and family, caring for children, and preparing meals, was compromised a lot or completely. Among those who completed treatment, 3% to 19% reported being compromised.

■ A third reported they did not have a caregiver to support them through treatment and help with their activities of daily living and household responsibilities

■ More than one-half of respondents in active treatment visited the emergency department for symptoms or side effects related to their treatment.



## References for Survey 5

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Declines in the incidence of smoking, combined with advances in diagnostics and the development of targeted and effective therapies for cancer have led to a steady growth in the cancer survivor population over the past decade. According to the National Cancer Institute, the number of people living beyond a cancer diagnosis reached 14.5 million in 2014, and that number is expected to rise to nearly 19 million by 2024.<sup>1</sup>

Many survivors are able to resume their normal lives after their cancer

diagnosis. But for others, the transition from cancer patient to cancer survivor is difficult, and the physical, emotional, and financial toll of having cancer is often long lasting.

In Survey 6 of this report, *Survivorship*, we set out to gain a better understanding of how cancer changes survivors' lives; how the disease affects their quality of life, relationships and perspectives; and the extent to which they have engaged in end of life planning.

See Figure 1 for the distribution of respondents by cancer type.<sup>2</sup>

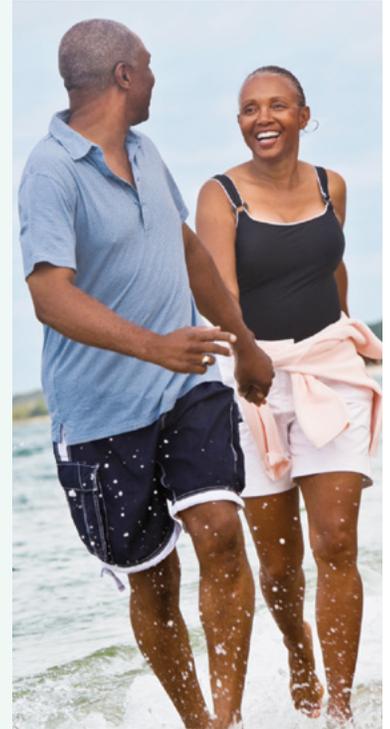
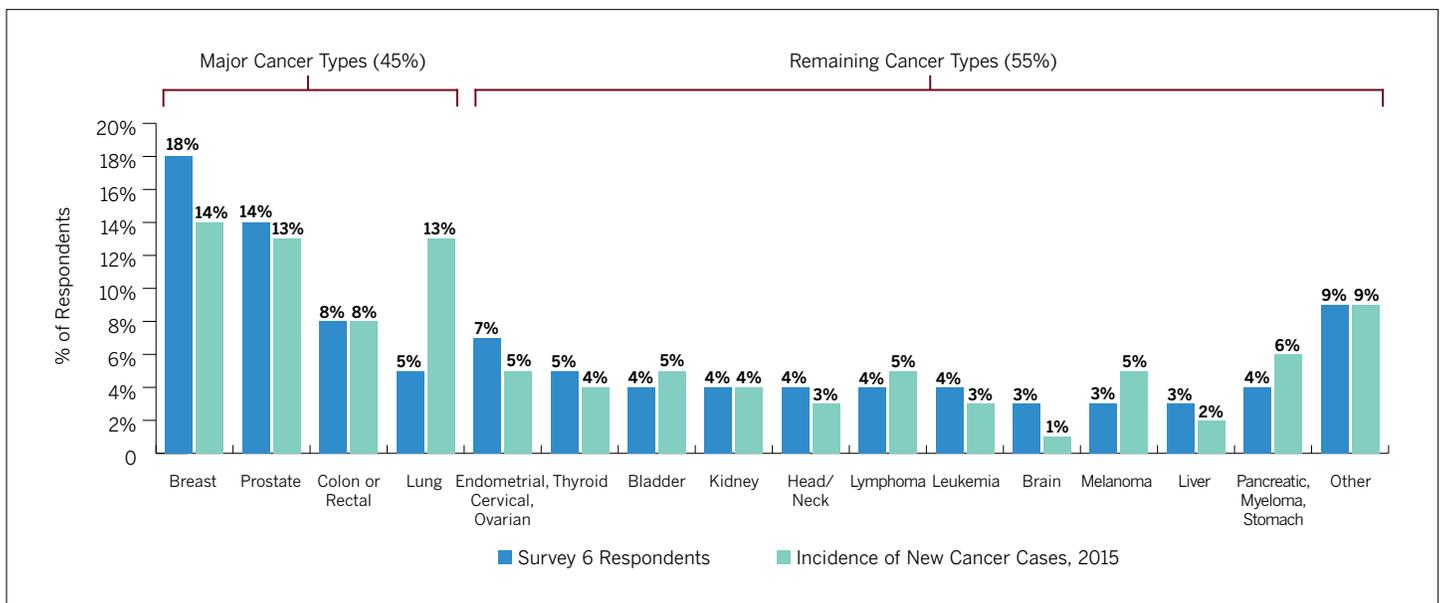
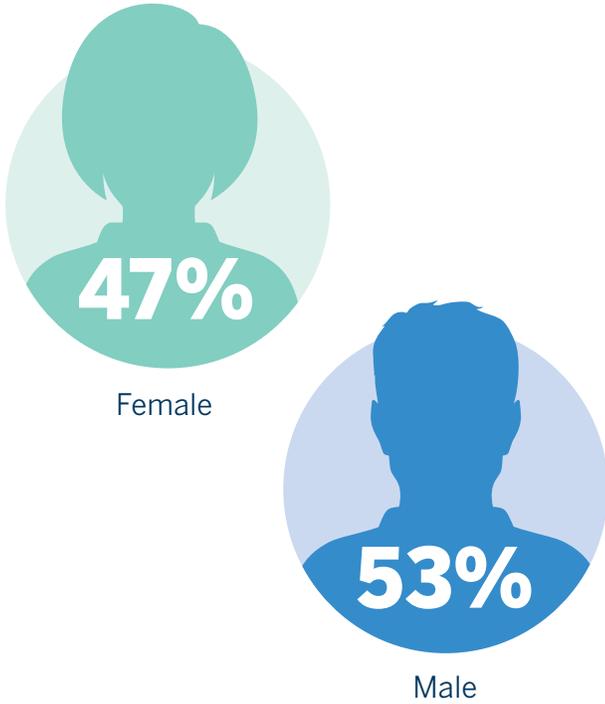


Figure 1: Distribution of Respondents by Cancer Type (N=505)

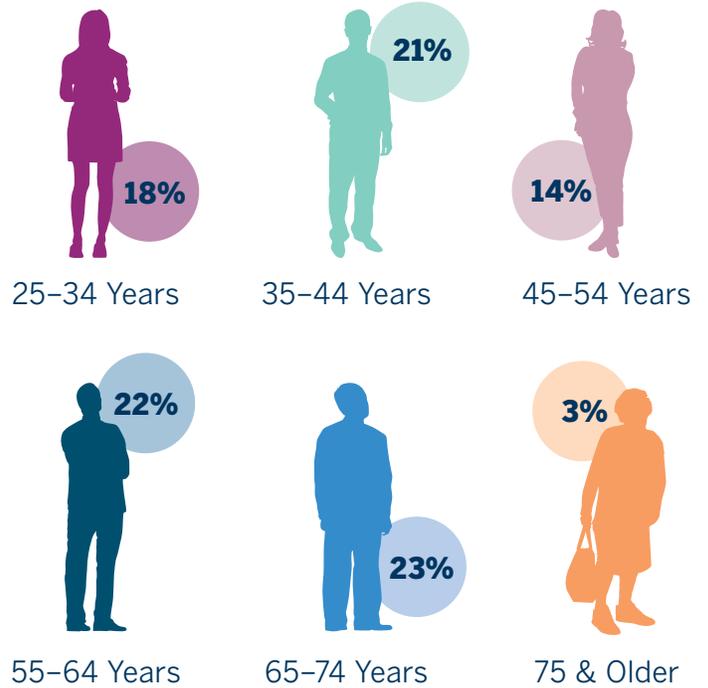


# Survey 6: Respondent Demographics (N=505)

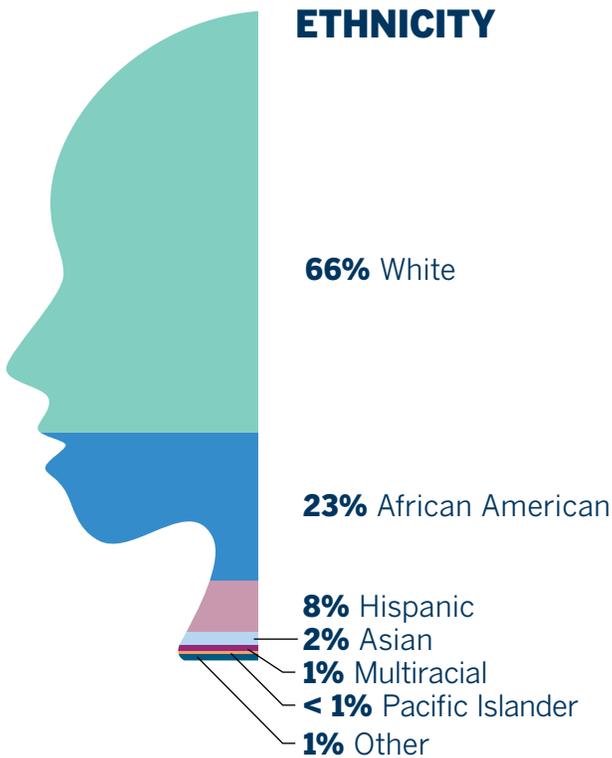
## GENDER



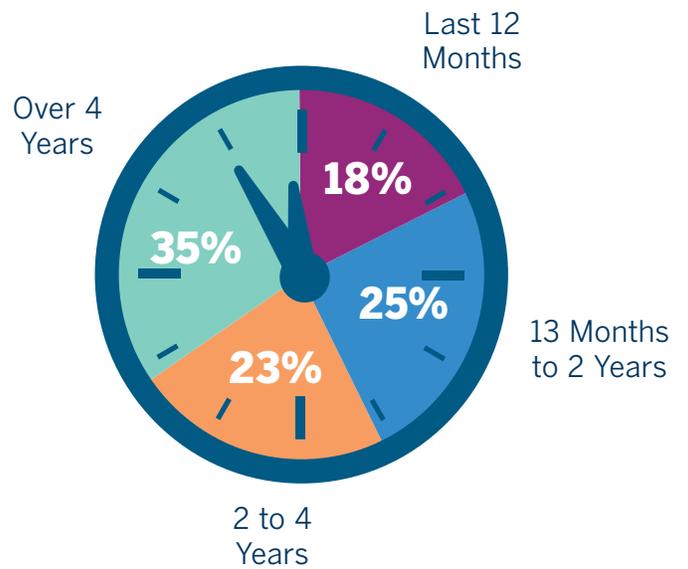
## AGE



## ETHNICITY

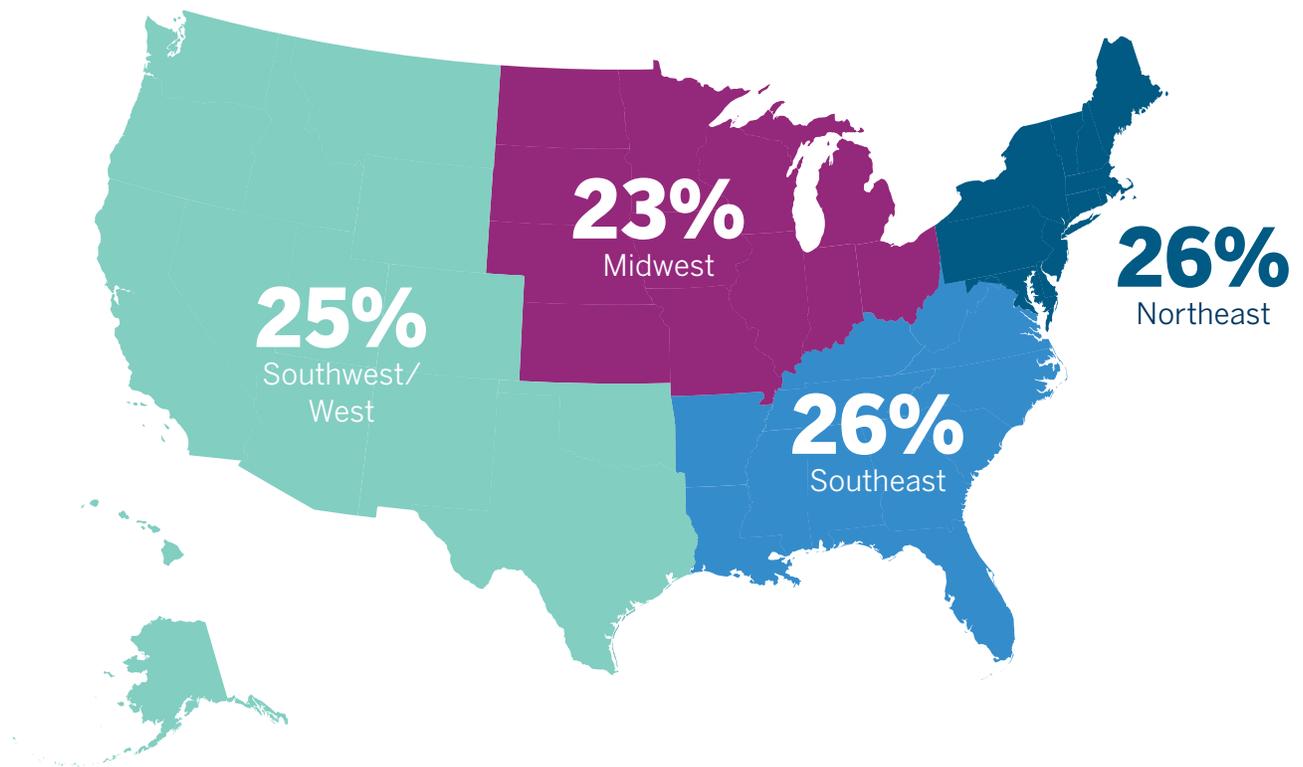


## TIME SINCE FIRST DIAGNOSED

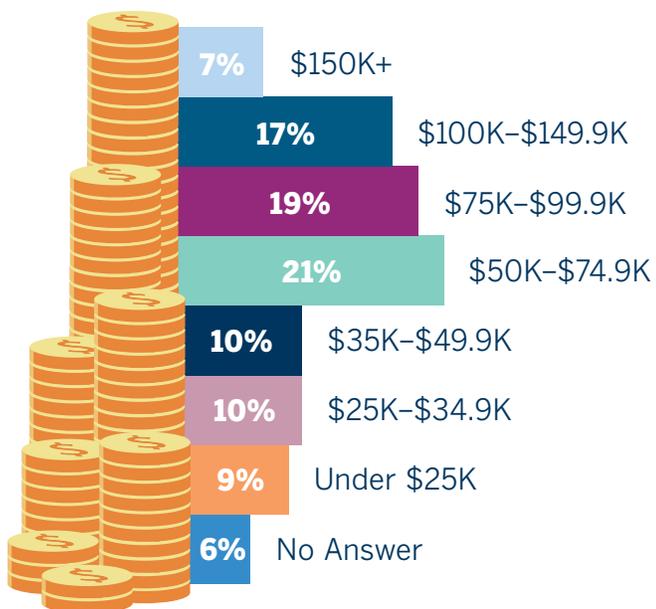


## Survey 6: Respondent Demographics (N=505)

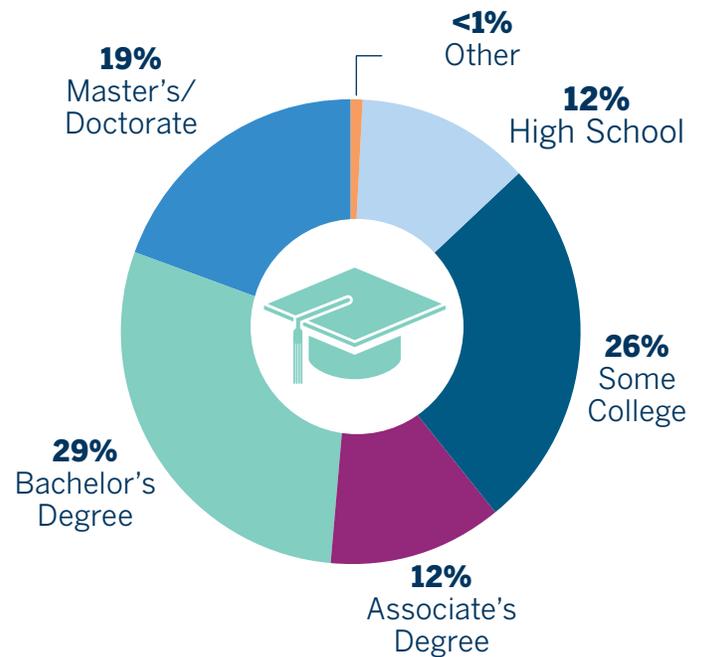
### REGION



### INCOME

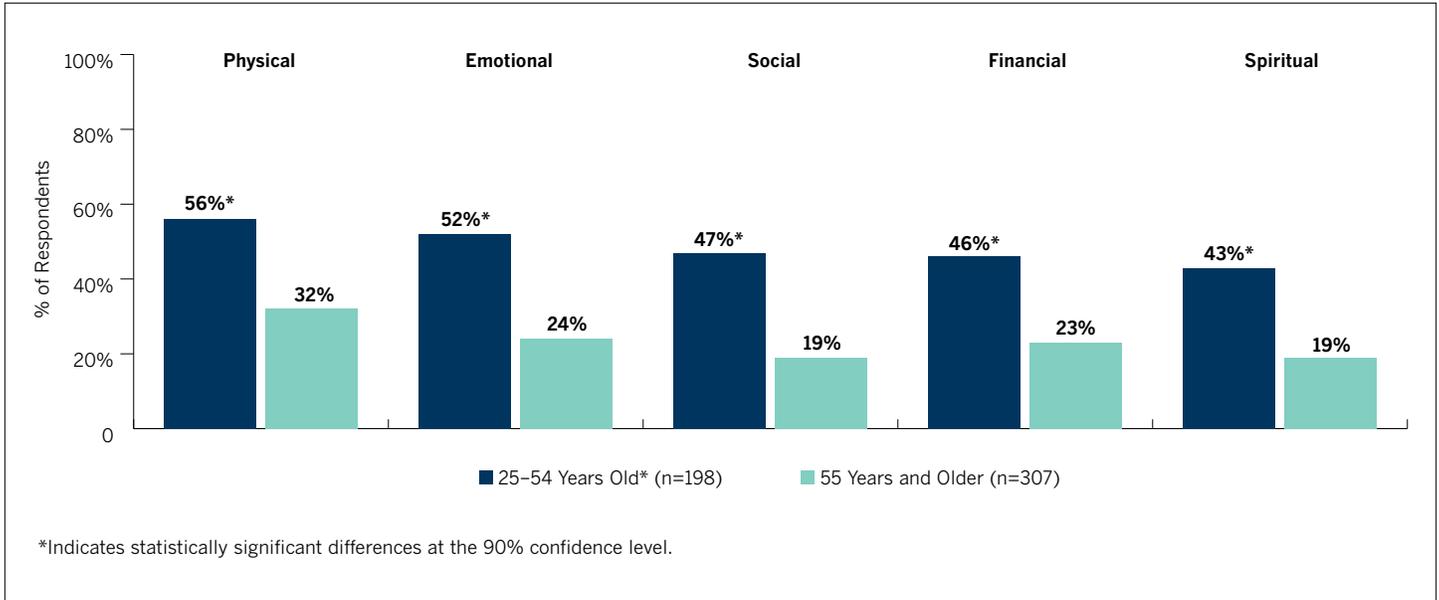


### EDUCATION





**Figure 2: Patients Reporting “A Lot” or “Complete” Change in Life Since Diagnosis**



**More than 40% of patients over 45** have not completed the following legal documents

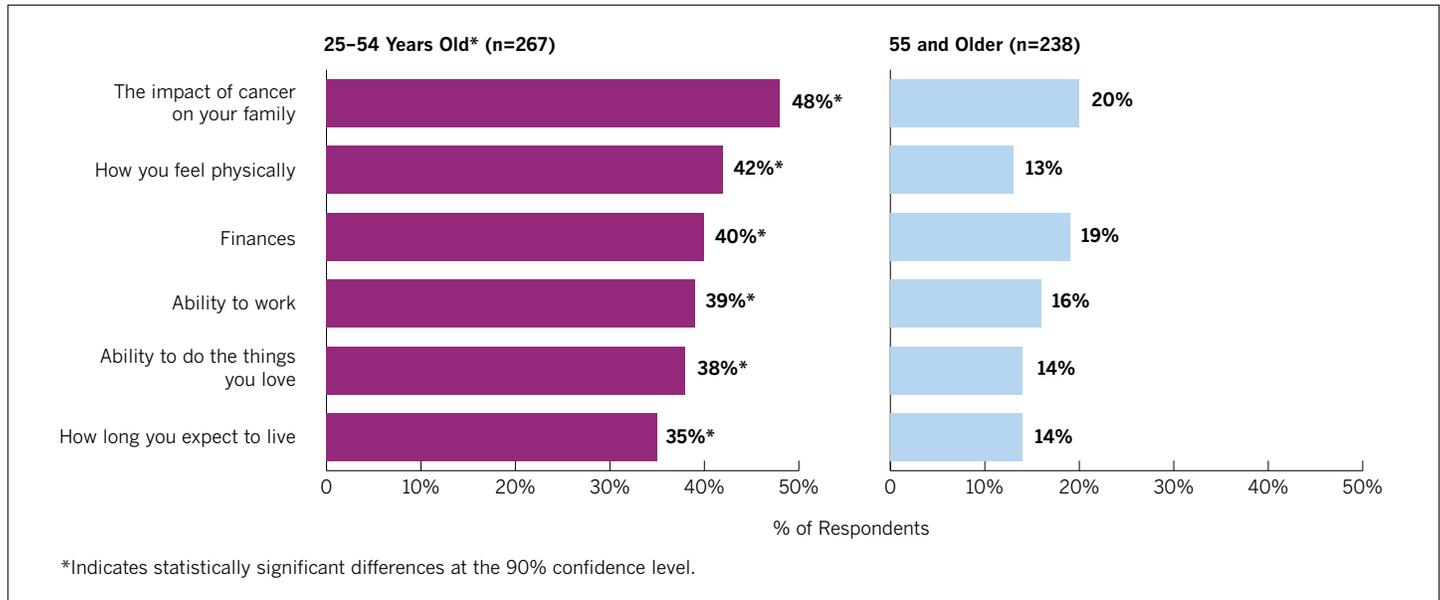
- X Health-Care Power of Attorney**
- X Health-Care Proxy**
- X Living Will**
- X Last Will and Testament**

### Observations

A cancer diagnosis and its treatment have the potential to profoundly alter every aspect of survivors’ lives—their physical, emotional, social, financial, and spiritual well-being, as well as their sense of self and how they think about their future. A cancer diagnosis can cause life priorities to shift and prompt change in careers and relationships with family and friends. This kind of transformation is evident in the findings of our survey.

Although cancer is a disease of older people—more than 60% of cancers in the United States occur in people 65 years of age and older<sup>3</sup>—younger people are not spared this diagnosis, so we have documented many findings that show differences in younger versus older survivor populations. For example, when we asked respondents to indicate how much change occurred in the

**Figure 3: Sources of High or Extreme Cancer-Related Distress**



physical, emotional, financial, social, and spiritual areas of their lives following a cancer diagnosis, about half of those between the ages of 25 and 54 reported “a lot” or “complete change,” roughly double the level of those over 55 (Figure 2).

### Gender Differences in Coping With Cancer

For some respondents, especially women, there was a silver lining to having cancer. Many reported experiencing positive changes in their lives and in their relationships with family and friends after their cancer diagnosis. A large majority of women (76%) compared to men (62%) said that their “friends and loved ones provided me with wonderful support and care.” Sixty-nine percent of women versus just 55% of men also agreed that they “felt more grateful than I did before I was diagnosed with cancer.” And half of women and 42%

of men said their “relationships have become stronger since I was diagnosed.”

### Cancer Is a Family Disease

As anyone affected by cancer knows, a cancer diagnosis can be just as emotionally overwhelming for loved ones as it is for the patient. This was evident from our survey, where half to three-quarters of younger respondents reported that the impact of cancer on their family was stressful. How they felt physically, their finances, their ability to work, to do things they love to do, and how long they expected to live were also significant sources of distress. Generally, respondents between the ages of 25 and 54 were significantly more likely than older survivors to report feeling “highly” or “extremely distressed” (Figure 3).

And although respondents between the ages of 25 and 54 experienced similar levels of distress due to their cancer



diagnosis, African American and Hispanic survivors were significantly more likely than their white counterparts in this age range to report feeling distressed about how long they expected to live, 71% versus 57%, respectively.

### Communicating End-of-Life Wishes

Regardless of age, patients often avoid or delay making decisions about their preferred treatment or care at the end of their lives. In our survey, having cancer prompted many patients younger than age 45 to have conversations about end-of-life concerns with their family or loved ones (Figure 4). Typically, respondents between the ages of 25 and 44 were more likely than respondents' older than age 45 to report having discussed:

- Where they would prefer to spend their last days;
- Their wishes regarding when life-prolonging medical care should be used;

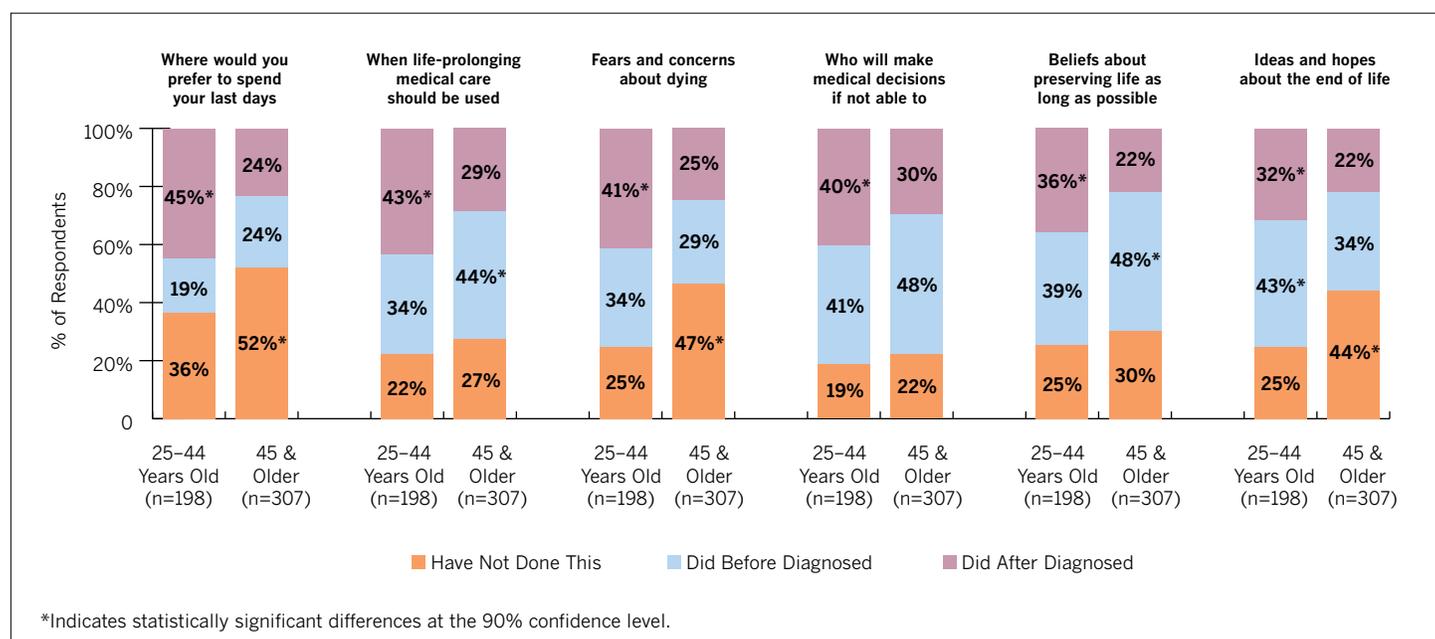
- Their fears and concerns about dying;
- Who will make medical decisions for them if they are unable;
- Their beliefs about whether life should be preserved for as long as possible;
- Their ideas and hopes about the end of their lives.

Conversely, despite their cancer diagnosis, 20% to 50% of respondents older than 45 had not discussed their end-of-life wishes with family members or loved ones.

Younger respondents were also more likely to create legal documents reflecting their end-of-life wishes. About one-third of respondents younger than 45 said they created a medical/health-care power of attorney; chose a health-care proxy; created a living will; or created a last will and testament. However, between 29%

*Continued on page 80*

**Figure 4: Discussion Topics With Family Since Being Diagnosed With Cancer**





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# Tani S.

## I Finished My Treatment: Now What?

**W**hen Tani S., 44, completed treatment for ovarian cancer in August 2014, she felt a mixture of both relief and fear. Relief because it was the end of a nearly year-long odyssey of frequent medical appointments and hospital stays that included surgery to remove her uterus, ovaries, and part of her colon; months of chemotherapy; and colostomy reversal surgery. And fear because being finished with treatment meant she would now only see her oncologist every three months to be monitored for persistent fatigue and shortness of breath—the remaining side effects from her therapy—and checked for any early signs of disease recurrence.

“Being on chemotherapy was sort of like having a safe haven because I was constantly under my doctor’s care and I knew the cancer was being treated,” says Tani. “When my treatment was over, I worried that the cancer would come back.” Every minor pain or ache Tani experienced only heightened that fear. “I wanted to call the doctor every time I felt any twinge of pain,” she says.

To relieve her anxiety and feel less alone, Tani joined CancerCare’s Post-Treatment Survivorship Support Group and is beginning to feel more secure about her future. “The man running the group is a long-time cancer survivor, as are some other people in the support group, so I’m feeling more confident that I will also survive my cancer,” says Tani. “Talking with other people going through a similar experience made me realize that

it’s normal to worry about a cancer recurrence. Now, I’m not overwhelmed by my fear and I don’t feel as alone. It’s like having our own little society and I feel more secure.”

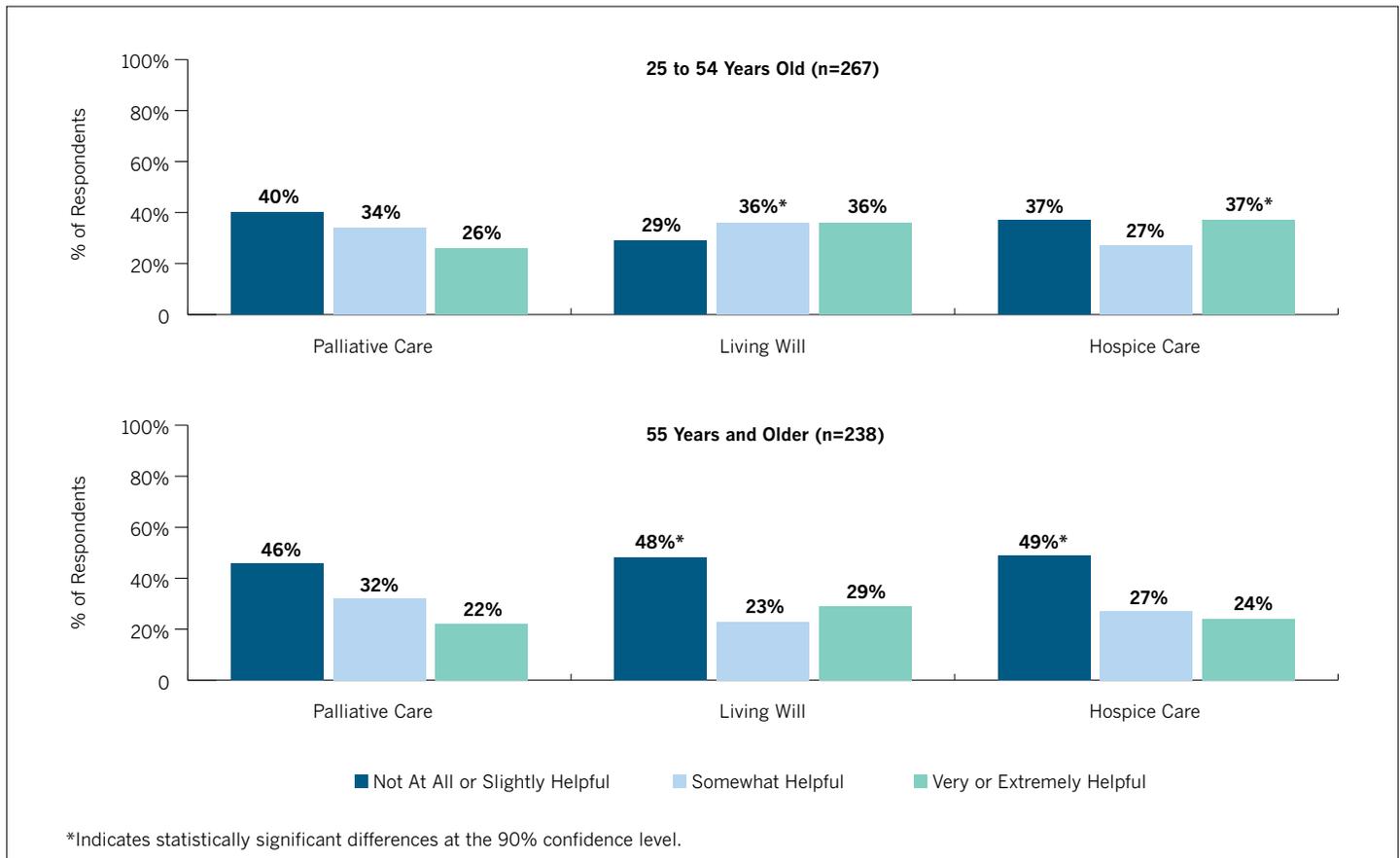
**“Talking with other people going through a similar experience made me realize that it’s normal to worry about a cancer recurrence.”**

The fact that Tani’s oncologist is diligent about following up on her care also provides her with a sense of security. After Tani’s ovarian cancer diagnosis, she was screened for the BRCA gene mutation, which increases a woman’s risk of breast and ovarian cancer, and she tested positive for the mutation. Now, in addition to being monitored for signs of a recurrence of her ovarian cancer, Tani is also being watched for early symptoms of breast cancer.

“Once you have been diagnosed with cancer, your outlook changes,” she says. “I know there is a chance I could have a recurrence, so I’m trying to get better prepared financially if I have to change my lifestyle.”

Staying connected with her medical team and her cancer support group members, says Tani, is providing her with a lifeline to face whatever obstacle the future may bring. ■

**Figure 5: Helpfulness of Information About End-of-Life Concerns**



Continued from page 78

and 46% of respondents had not completed even one of these legal documents.

When asked how helpful it would be to receive additional information about palliative care, living wills, or hospice care, again age seemed to make a difference. More than one-third of respondents between the ages of 25 and 54 said that more information on these topics would be helpful. Respondents older than age 55 were significantly more likely to disagree (Figure 5).

### Palliative Care and Hospice

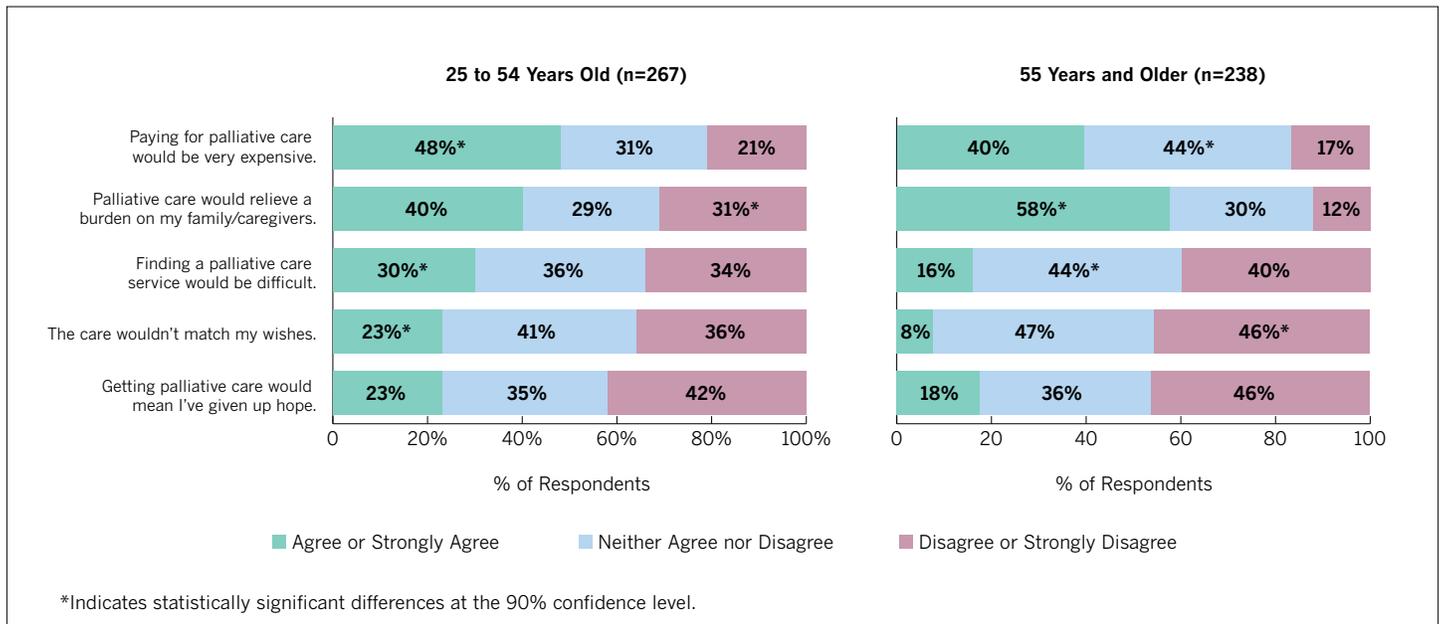
Familiarity with both palliative care and hospice correlated to respondent education levels. However, the survey revealed widespread misconceptions about each. Nearly half of the respondents believed that paying for palliative care would be very expensive. About one-fifth thought that getting palliative care would mean they were giving up hope. Among respondents 25 to 54, nearly 40% feared becoming addicted to pain medicine, 28% said palliative care would delay their death,

Continued on page 82

## KEY FINDINGS FROM SURVEY 6: SURVIVORSHIP

- Having cancer changes lives in profound ways, including physically, emotionally, financially, socially, and spiritually. These changes are especially profound for younger patients between the ages of 25 and 54.
- Women were much more likely than men to report that cancer had a positive effect on their relationships with family members and friends.
- As expected, cancer caused significant stress for respondents, with the impact of cancer on family members causing the most stress. In all aspects of life mentioned in this survey, respondents between the ages of 25 and 54 were significantly more likely than those 55 and older to report being “highly” or “extremely distressed.”
- Regardless of ethnicity, respondents between the ages of 25 and 54 experienced similar levels of distress from their cancer diagnosis.
- Receiving a cancer diagnosis was more likely to prompt 25 to 44 year old respondents to have discussions about end-of-life with family members than it was those 45 and older. Between 20% and 50% of respondents 45 and older said they had not communicated their wishes on these topics to family members or friends.
- After being diagnosed with cancer, about one-third of respondents younger than age 45 created legal documents, such as a health-care power of attorney, health-care proxy, living will, or last will and testament, detailing their end-of-life wishes. Conversely, 29% to 46% of respondents had not taken steps to complete at least one of these legal documents.
- Anywhere from 22% to 37% of respondents said that receiving information about palliative care, living wills, or hospice care would be helpful. Those 55 years and older were significantly more likely than their younger counterparts to report that information on living wills and hospice care would not have been helpful.
- The survey revealed that patients in all age groups had widespread misconceptions about both palliative and hospice care.

**Figure 6: Respondents' Opinions About Palliative Care**



*Continued from page 80*

and 18% thought it would hasten death. With regard to hospice, 40% of respondents believed it would be very expensive, and only 40% of these respondents believed that palliative care would relieve a burden on their caregivers (Figure 6). Patients under 65 were significantly more likely to engage in conversations about hospice care with a clinical care team member than were those 65 and older. Again, the primary care physician was the clinician most likely to have these conversations with both groups of patients.

### Conclusions and Recommendations

The results from this survey clearly show the profound impact cancer has on the lives of survivors. For many respondents, the emotional, physical, financial, and spiritual side effects of cancer and its treatment have

lasted many years, and this can be especially challenging for younger survivors. Comprehensive survivorship care plans should address not just the clinical surveillance necessary to monitor cancer recurrence, late effects from treatment, and secondary cancers, but also the debilitating financial, physical, and psychosocial consequences of cancer.

Our survey findings also point to the need for greater focus on end-of-life education and planning, so patients' wishes are known and respected by clinicians and family members. Providing excellent end-of-life care is essential to a doctor/patient partnership that is based on trust and respect and failing to help survivors plan for their transition to end-of-life care can result in increased psychological distress; medical treatments that are inconsistent with personal preferences; utilization of burdensome and expensive health-care resources that result in little thera-

# Survey 6: Survivorship

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peutic benefit; and more difficult bereavement for family members and loved ones.

Respondents' confusion about palliative care and hospice suggest the need for significant patient education around these topics. Introducing palliative care early in treatment has been shown in many studies to improve patients' quality of life,<sup>4-6</sup> and patients should not avoid it based on misconceptions that it will be costly or hasten their death. Hospice can significantly improve patients' and families' experiences at the end of life, and patients need to learn about it with enough time for it to have an impact. Some patients with advanced cancer may keep receiving chemotherapy at the end of life (within their final 12 to 14 days), even when such treatment may be known to be futile. This may not only have no effect on a patient's survival, but could cause unnecessary toxicity and suffering as well.<sup>7</sup> It is essential that patients know and understand the benefits of palliative care and hospice so they can receive the best quality care at the end of life.

## The Importance of Inclusive, Coordinated Care

Cancer survivors not only look to their oncologists for information about both comprehensive survivorship and end-of-life care. Our survey findings indicate they also depend on their primary care providers for information about many of their cancer-related concerns. Therefore,

we should recognize the importance of inclusion and coordination among patients' broad team of health-care providers to ensure that survivors receive the services and attention they need and deserve throughout their lives, as well as their preferred end-of-life care. ■

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