



CANCERCARE®

The Cancer Gap: Landmark Study Reveals Disconnects and Changing Pressure Points in Cancer Care

The 2016 CancerCare Patient Access and Engagement Report Fact Sheet

CANCER CHANGES EVERYTHING. CANCERCARE® CAN HELP.

Despite a record 14.5 million cancer survivors—a number expected to grow to 19 million by 2024ⁱ—there has been surprisingly little comprehensive research done on how people experience life with and beyond cancer. CancerCare, working with an advisory board of oncologists, researchers, and cancer advocates, published a landmark study to provide a comprehensive view of how people experience life with and beyond cancer.

Three thousand adults diagnosed with cancer participated in the study, which consisted of six surveys on real world topics that impact patients everyday: understanding the diagnosis of cancer, participation in treatment decisions and planning, communication with the care team, financial and insurance issues, symptoms, side effects, and quality of life, and survivorship. It is the first study of its kind to tackle this depth and breadth of issues across a diverse population of cancer patients.

Survey recruitment was done via email from online consumer panels in order to capture 3,000 unique cancer patients. Each survey, completed by at least 500 respondents, was designed to reflect a nationally representative sample so there is broad diversity in terms of ethnicity, income, education, geography, age, insurance, cancer type and treatment stage.

THE BIG PICTURE:

A topline look at the data shows generally where the communication is breaking down between patients and their clinical care teams, but also offers insights that can help oncologists and patients work together to close those gaps.

THE INFORMATION GAP. People in all stages of their cancer experience say they don't have enough information about their illness, treatment options, benefits and risks, clinical trials, insurance coverage, and how to find emotional, financial and practical support.

THE IMPACT GAP. Many of the physical, emotional, financial, and social "costs" of cancer are unaddressed and cause debilitating and long lasting distress for patients and families.

BRIDGING THE GAP. By identifying the kinds of challenges cancer patients face, the report provides insights to the oncology community that can be used to improve care, support, communication and patient engagement—all of which are associated with better outcomes, enhanced quality of life and lower health care costs.

PRESSURE POINTS:

Several pieces of data stood out, some not unsurprising, given the dramatic changes in health care and technology.

PRIMARY CARE PHYSICIANS PLAY A CRITICAL ROLE. Patients were more likely to be referred for financial and emotional support by their PCPs than their oncologists. Fewer than half reported that their cancer care team

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has ever asked about emotional or financial issues, despite a significant number of respondents admitting to experiencing both emotional and financial distress.

YOUNGER PATIENTS = MORE STRESS. Younger patients report significantly greater information needs, dissatisfaction with their care and care teams, and financial and emotional distress than their older counterparts.

MISSED OPPORTUNITIES. Despite there being more than 17,000 open cancer clinical trials on clinicaltrials.gov, more than 80% of respondents said they didn't have enough information on clinical trial opportunities. About 25% said they were not getting the most advanced care available—and some clinical trials can offer patients access to advanced care.

Survey 1

Key Findings: Understanding the Diagnosis of Cancer

- Most patients diagnosed with cancer followed their physicians' recommendations for diagnostic tests and said they understand the purpose, costs and risks of those tests.
- One-quarter of respondents ages 25 to 54 disagreed with some of their doctors' recommendations for diagnostic testing and did not follow them, with the majority citing cost as the reason. Fewer than half of respondents discussed the cost of follow-up testing with their physician.
- Patients ages 25 to 54 had nearly twice as many post-diagnosis conversations about their cancer with nurses, religious leaders, social workers, physician assistants, or nurse practitioners as patients 55 and older. African American patients had about a third more conversations than white patients in the same age range.

Survey 2

Key Findings: Treatment Planning

- About one-third of respondents reported having inadequate information about the benefits, potential side effects and the goals of their treatment plan. Fewer than half of respondents obtained a second opinion.
- Less than half of respondents said they had adequate information about concerns such as working during treatment (43%), the emotional impact of having cancer and its treatment (38%), and their financial obligations associated with their care (36%).
- The overwhelming majority said they trusted their physicians and believed they were getting the best care.
- Only about half reported their care team regularly inquired about their level of distress.

Survey 3

Key Findings: Communication with the Clinical Care Team

- Most respondents (94%) were satisfied with their clinical care coordination, understood discussions about their cancer and its treatment, and were able to reach members of their health care team in a reasonable amount of time.
- About 20% of African American and Hispanic respondents reported they experienced serious communication problems with their clinical care team, including a lack of translation services; and difficulty understanding what their doctors said about their treatment.
- For lifestyle concerns, such as diet and exercise; sexuality and intimacy; work; emotional distress; and questions about end-of-life issues, respondents often preferred talking with their primary care physicians.
- Despite the prevalence of emotional and financial distress among cancer patients, survey respondents reported rarely being referred by members of their care team to counseling service or other professionals for support.

Survey 4

Key Findings: Financial and Insurance Issues

- About one-half of respondents reported understanding their health insurance coverage for their cancer care "completely" or "very well."
- Twenty-five percent of those ages 26 to 64 said their medical care team never considered their financial situation during treatment planning, and 34% said it was only "sometimes" considered.
- Fifty-eight percent of respondents reported being distressed about their finances during treatment. Among those 25 to 54, three-quarters said cancer caused them financial hardship.

- In order to afford treatment, one-third of respondents ages 25 to 54 reported cutting back on daily essentials, such as groceries and transportation, and/or borrowed from family members and friends; 21% missed a utility bill payment; and 17% missed a rent or mortgage payment.

Survey 5

Key Findings: Symptoms, Side Effects, and Quality of Life

- Women were more likely than men to report experiencing anxiety, difficulty exercising and staying physically active, and suffering from nausea or vomiting.
- In discussions with care providers, about half of patients downplayed their side effects and symptoms. Nearly 40% did not report symptoms or side effects because they did not want to “bother” their doctors.
- One-fifth of respondents ages 25 to 64 were required by their insurers to follow a “fail first” regimen in the management of symptoms and side effects.
- One third reported they did not have a caregiver to support them through treatment and help with their activities of daily living and household responsibilities.

Survey 6

Key Findings: Survivorship

- Women were much more likely than men to report that in some ways, cancer had a positive effect on attitudes and relationships with family members and friends.
- For most respondents, cancer caused distress in multiple aspects of their lives, with the impact cancer had on family members causing the most distress.
- Receiving a cancer diagnosis prompted most respondents under age 45 to have end-of-life discussions with family members. However, a significant proportion of respondents ages 45 and older had not communicated their wishes on these topics to family members or friends.
- Respondents from all age groups had widespread misconceptions about palliative and hospice care.

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, for more than 70 years. Yet, we know there is still much to learn. Ultimately, these data will be used to help the development of programs that accurately represent and address the needs of patients throughout their continuum of care and after clinical treatment is complete.

Full survey results are available at www.cancercare.org/accessengagementreport.

¹ 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. Accessed March 18, 2016.