CANCER SUPPORT COMMUNITY™
A Global Network of Education and Hope

Insight into Patient Access to Care in Cancer

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

MARCH 2015

ABOUT THE CANCER SUPPORT COMMUNITY

The mission of the Cancer Support Community® (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community® and Gilda's Club® joined forces to become the Cancer Support Community. The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of 50 Affiliates, more than 120 satellite locations and a vibrant online and telephone community, touching more than one million people each year.

Backed by evidence that the best cancer care includes social and emotional support, the Cancer Support Community offers these services free of charge to men, women and children with any type or stage of cancer and to their loved ones. As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community delivers a comprehensive menu of personalized and essential services including support groups, educational workshops, exercise, art and nutrition classes and social activities for the entire family. Through cutting-edge psychosocial, behavioral and survivorship research, the Cancer Support Community's *Research and Training Institute* is helping CSC change the future of cancer care through education and training. The Cancer Support Community's *Cancer Policy Institute* ensures that the voices of 13.7 million cancer survivors and their families are heard in the nation's capital and in state and local legislatures across the country. In 2014, the CSC network delivered nearly $46 million in free services to patients and families. The Cancer Support Community is advancing the innovations that are becoming the standard in complete cancer care.

Dear Friends,

Today we are witness to both tremendous change and tremendous challenge in health care in the United States. With the rollout of the Affordable Care Act (ACA), fewer people are expected to be uninsured over time, there will be greater access to preventative services and no longer can an individual with a pre-existing condition (including cancer) be denied health insurance. Cancer care is also progressing at a quickening pace, with many new therapies and treatment options already available or on the horizon. These developments in the field hold great potential for improving the lives of individuals with cancer.


Kim Thiboldeaux, Chief Executive Officer

Yet, more work is needed. Namely, as much as cancer is a physical experience, it too is an emotional, personal, family, community and cultural experience. Thus, as noted by the Institute of Medicine, care for patients must attend to both medical and psychosocial needs. We also know that not all patients with cancer have access to the latest advances in care, thus disparities in outcomes continue to exist.

Awareness of these changes and challenges is exactly why it is essential to tap into the pulse of those affected by cancer. Our patient surveys tell stories of what it is like to be in need of care as a cancer patient — what it is like to be overwhelmed, anxious and concerned about the broad impact of the disease on you AND your family. These stories are powerful in relaying both the individual and collective experiences of those impacted by cancer. And, coupled with research, we aim to provide insight into patients' experiences around access to comprehensive care.

Because of the patients who took the time to complete our survey, we are able to summarize patient experiences related to key aspects of care. We asked questions about access to insurance, access to services, access to providers and the direct and indirect costs of care. We wanted to know from patients what is working well and what needs refinement, improvement, heightened awareness or further research.

On behalf of the Cancer Support Community, I would like to thank the patients, physicians, researchers and funders who made this project possible. Also, thank you for your part now and in the future in ensuring that all people diagnosed with cancer have access to the comprehensive, quality cancer care they deserve.

All my best,

Kim Thiboldeaux
Chief Executive Officer

The Human Experience of Access to Care in Cancer

Over the next several decades, more people than ever will receive a diagnosis of cancer, and more people than ever will survive cancer. The need for services, from cancer screening to survivorship care, will also rise as more people gain access to health care services as a result of the Affordable Care Act (ACA). Meeting this growing demand for care may be difficult in light of physician shortages and declines in community practices in cancer care (ASCO, 2014).

Despite these challenges, the charge is to meet this demand with high quality care for all patients. The Institute of Medicine's (IOM) 2001 report "Crossing the Quality Chasm: A New Health System for the 21st Century" remains a beacon even today toward ensuring high quality care. This involves exploring IOM's named expectations of care, including whether care is: 1) safe for patients, 2) effective or evidenced-based, 3) patient-centered or inclusive of the needs and values of patients, 4) timely in delivery, 5) efficient and 6) equitable across populations and geography. The IOM (2013) also recently named essential elements of high quality cancer care, such as ensuring that patients are engaged or well-informed, and care is evidenced-based, accessible and affordable.

The goal of this Access to Care Project is to better understand the challenges patients face in accessing care. We focus specifically on the following topic areas:

- Access to and satisfaction with insurance
- Access to providers, including availability, time and discussions with providers
- Access to services, including those services deemed vital by the IOM (2008) in the report, "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs"
- Concern about direct costs of cancer and care

In essence, patient perceptions about access—challenges and triumphs—underscore our shared goal of patient-centered care. Their collective voice will direct future research efforts and, ultimately, inform policy discussions.

With the foremost goal of improving the lives of patients with cancer and their families, the Cancer Support Community (CSC) provides psychosocial services and programs to those affected by cancer, conducts research and advocates for change through policy. The experiences of patients with cancer, survivors and their families and friends provide the foundation for much of CSC's research. Through various initiatives, including the Cancer Experience Registry, CSC collects, synthesizes and disseminates findings to the public and academic audiences.

Key Findings about Patient Access to Care

Our full report contains a number of findings on patient access to care.
Here is a preview of several key findings:

TOPIC AREA	FINDING
ACCESS TO PROVIDER	• 22.1% of patients reported experiencing delays in accessing care – The most common type of delay for those who experienced delays was for scheduling a test or medical procedure (61.9%) followed by a delay in referral to a physician or health care team (46.7%) • Nearly 20% of the patients did not feel they had adequate time with their health care team • The proportion of patients talking to their provider about direct and indirect costs of treatment was lower than the proportion of patients talking to providers about other treatment-related topics – Only 34.4% of patients talked to their health care team about the financial cost of their treatment
ACCESS TO SERVICES	• 71.1% of these reported not receiving social and/or emotional support services, including screening for distress during cancer care – 55% of those who did not receive such services “didn’t know they existed or where to find such support” (33%) or “did not receive a referral” (22%)
COST OF HEALTH CARE	• Nearly half of these patients (47.7%) reported paying more for their health care over the past 12 months – Reasons for paying more were most often because of insurance premiums (61.2%), deductible (46.7%) and treatment co-pays (45.8%) • Over one-third of patients expressed high concern about out-of-pocket costs for hospital stays, medications, lab tests or scans • 37.1% reported being seriously or very seriously concerned about bankrupting their family
ACCESS TO INSURANCE	• 7 people reported now having health insurance despite having a pre-existing condition • Most patients had an employer-based plan at the time of the survey or Medicare in some form • 18 people purchased a plan through a Health Insurance Marketplace • 5 patients in our sample reported not having health insurance, and all of these individuals indicated not being able to afford a plan

Note: Sample sizes are reported in the “Overview of Findings” section.

Overview of Findings

This report is based upon a cross-sectional survey of adults (18 years and older) affected by cancer. The survey was administered online through Survey Monkey during October 2014. Outreach efforts included CSC's online network and Cancer Experience Registry, advocacy partners and social and traditional media outlets. We performed descriptive analyses for survey items as well as explored potential associations between some variables of interest. All analyses were conducted using data analysis software (i.e., SPSS) and significance level was set at .05 if associations were explored.

PARTICIPANTS

Six hundred and ninety two individuals initiated the survey with 511 complete respondents (i.e., clicked "done" at the end of the survey). Among the 511 complete respondents, 31 lived outside of the United States. The sample includes 480 adults living in the U.S. who had been diagnosed with cancer. Sample item responses are 480, unless otherwise noted, as not all patients answered every question. These individuals affected by cancer were predominately non-Hispanic, white and female.

CHARACTERISTICS	PERCENTAGE
AGE (n=478)	
18-44	7.3%
45-64	62.8%
65 AND OLDER	29.9%
GENDER (n=472)	
FEMALE	88.6%
RACE (n=479)	
CAUCASIAN	90.0%
MINORITY OR MULTI-RACIAL	5.8%
PREFER NOT TO SHARE	4.2%
ETHNICITY (n=450)	
HISPANIC OR LATINO	2.7%
NOT HISPANIC OR LATINO	93.5%
PREFER NOT TO SHARE	3.8%
EDUCATION (n=476)	
ASSOCIATES DEGREE OR LOWER	33.4%
COLLEGE DEGREE OR HIGHER	65.5%
PREFER NOT TO SHARE	1.0%
EMPLOYMENT (n=476)	
FULL-TIME (30 HOURS PLUS)	32.8%
PART-TIME (LESS THAN 30 HOURS)	13.0%
NOT EMPLOYED, RETIRED	31.5%
NOT EMPLOYED, DISABILITY OR OTHER	22.7%

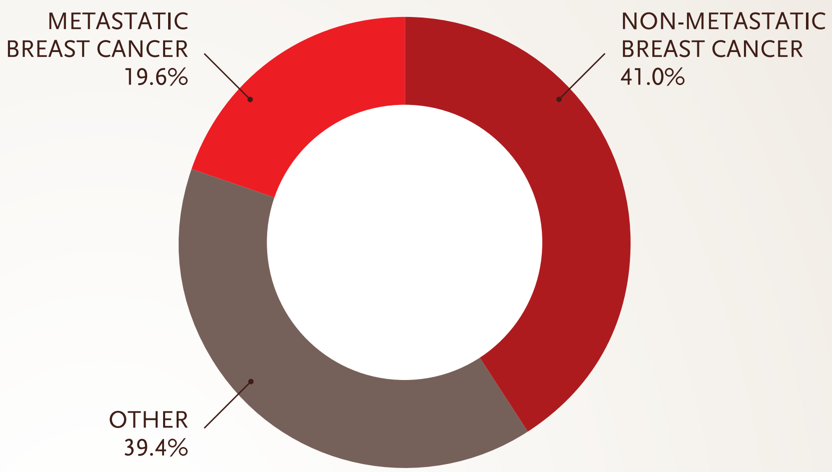
> *"I am in complete remission. Last chemo was in 1998. I do have severe neuropathy from the chemo though…so I am unfortunately disabled."*
>
> – Access to Care Participant

The majority are patients with breast cancer having either metastatic breast cancer (MBC) (19.6%) or non-metastatic breast cancer (non-MBC) (41%). Nearly 40% have other forms of cancer. Among the "Other" category (over 35 forms of cancer), the most prevalent are multiple myeloma (8.1%), chronic myeloid leukemia (6.5%) and prostate cancer (3.8%).[1]

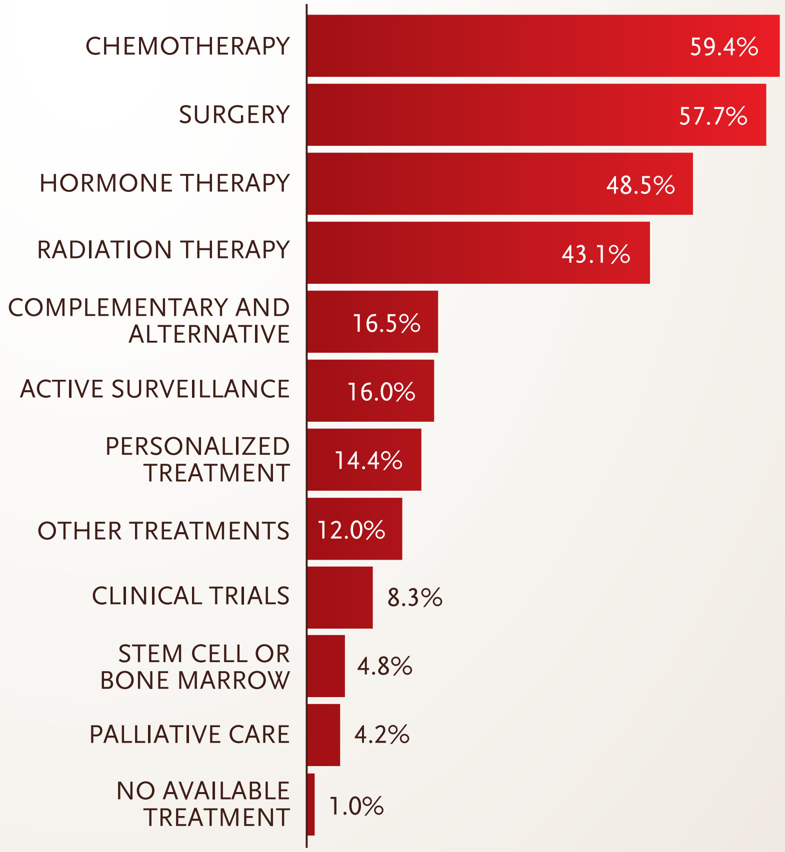
Our findings on treatment type support the immediate and long-term need of services for those affected by cancer. Across all participants, the most commonly used types of treatment included chemotherapy (59.4%), surgery (57.7%), hormone therapy (48.5%) and radiation therapy (43.1%). Patients most often reported taking medication orally (51%), through IV infusion (13.3%) or injection (12.3%).

Over half of the participants (53.9%, n=477) were in treatment at the time of the survey. Among patients not receiving treatment, most patients (93.2%) were in remission. Patients in remission noted continuing to use care, including follow-up visits with the doctor (87.4%), follow up tests (60.9%), reconstructive surgery (15.9%), services with other specialists (12.1%), rehabilitation or physical therapy (10.1%), fertility treatments (1.4%) and other services (4.3%), while only 8.2% reported no additional care.

CANCER DIAGNOSIS



TREATMENT TYPES FOR ALL RESPONDENTS



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[1] The high proportion/over-representation of breast cancer, multiple myeloma and chronic myeloid leukemia participants is from CSC's outreach efforts through the Cancer Experience Registry. For more information, please see the Index Report 2013-14 Elevating the Patient Voice.

Health Insurance Coverage

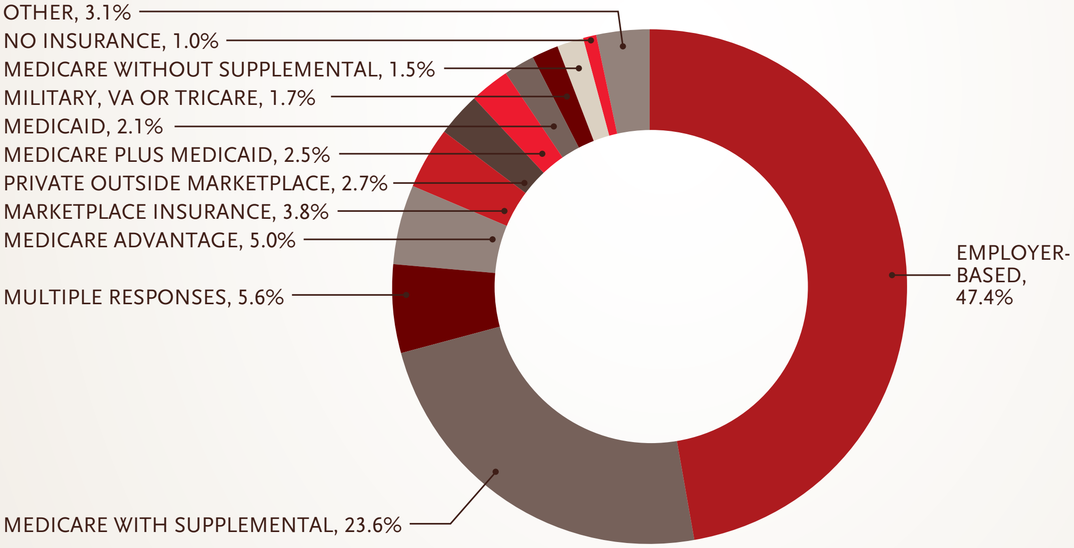
ACCESS TO HEALTH INSURANCE

The role of health insurance is to improve access to medical services and reduce the likelihood of financial burden due to illness or disability. There is evidence of a decline in the number of uninsured working-age adults between 2010 and the second half of 2014 (The Commonwealth Fund, 2015).

Five patients in our sample reported not having health insurance, and all indicated not being able to afford a plan. These individuals are all women, predominantly with breast cancer (4 of 5), white (4 of 5), employed full-time (3 of 5), highly educated (college degree or more, 4 of 5), with household incomes of less than $60,000 (4 of 5 with only 1 of 4 having an income less than $20,000) and between the ages of 45-64 (4 of 5). These women are also mostly not in treatment (4 of 5) because of being in remission.

HEALTH INSURANCE COVERAGE

(n=479)



At the time of the survey, most patients had an employer-based plan or Medicare in some form. Those who purchased coverage through the Health Insurance Marketplace (n=18) were predominantly in treatment (61.1%) and diagnosed with breast cancer (66.7%) with 16.7% having metastatic disease. Other forms of cancer included chronic myeloid leukemia, endometrial or uterine cancer, lymphoma, multiple myeloma, myeloproliferative neoplasms and sarcoma. They are nearly all women (94.4%), white (77.8%) and highly educated (college or more; n=17, 70.6%) with just over a quarter (27.8%) employed full-time (another 33% employed part-time). Future efforts should continue to track use of the Health Insurance Marketplace among patients with cancer and whether it is particularly valuable to certain groups over others.

Most patients (69.8%, n=471) report having the same coverage as they did one year ago. The most common reason for a change in coverage was because of a switch to another employer-based plan (34.4%) followed by gaining eligibility into Medicare (15.4%).

One groundbreaking element of the ACA is that those with a pre-existing condition cannot be denied health insurance. This provision is critically important in cancer because it means that patients and/or families have the flexibility of pursuing career advancement opportunities and/or changing jobs without the fear of losing coverage. Seven individuals with a pre-existing condition reported becoming eligible for health insurance. These individuals are predominantly female (85.7%), between the ages of 45-64 (85.7%) and have an annual household income of less than $40,000 (57.2%). Four of these individuals purchased their insurance through the Health Insurance Marketplace. This provides a good reminder to continue to monitor those patients with cancer who previously had been denied access to health insurance coverage because of a pre-existing condition (cancer or otherwise).

Further, also because of ACA, some states expanded Medicaid coverage, which can also have positive implications for those with less means and a diagnosis of cancer. Six patients reported becoming eligible for Medicaid over the past year and were from the following states: CA (2), MA, MN, NJ and PA. Five of these patients were in treatment for cancer.

SATISFACTION WITH HEALTH INSURANCE COVERAGE

More than 8 out of 10 patients (82.8%, n=472) reported liking their health insurance coverage. Among those who reported not liking their current coverage, most (43.2%) had an employer-based plan followed by Medicare with supplemental coverage (18.5%). Among those reporting not liking their health insurance, top concerns pertained to paying high out-of-pocket costs for premiums, co-insurance and medications.

CONCERNS WITH THEIR HEALTH INSURANCE (MULTIPLE RESPONSES ALLOWED)	% AMONG THOSE WHO DO NOT LIKE THEIR COVERAGE (n=81)	% AMONG THOSE WHO LIKE THEIR COVERAGE (n=391)
HIGH OUT-OF-POCKET COSTS FOR CO-INSURANCE TO COVER SERVICES OR PROCEDURES	66.7%	37.6%
HIGH OUT-OF-POCKET COSTS TO PAY INSURANCE PREMIUMS	58.0%	40.7%
HIGH CO-PAY COSTS FOR MEDICATIONS	54.3%	37.6%
I HAVE LIMITED OR NO ACCESS TO MY HEALTH CARE TEAM OF CHOICE	23.5%	6.6%
I HAVE LIMITED OR NO ACCESS TO MY HOSPITAL OF CHOICE	17.3%	3.3%
I HAVE TO DRIVE A LONG DISTANCE TO RECEIVE CARE	8.6%	7.4%
I DON'T HAVE ENOUGH INFORMATION TO MAKE DECISIONS ABOUT INSURANCE	8.6%	4.6%
OTHER	22.2%	18.7%

Access to Providers

As important as it is to think about access to providers in its strictest terms (i.e., getting seen by a provider), it is also important to think about time with a provider and what is discussed with that provider. Patients who report good communication with their providers have better quality of life, lower distress and are more satisfied with their treatment (Bernacki et al., 2014). Understanding these elements of access to providers—availability, time and information through discussion—from the perspective of the patient is even more vital with the evolution of personalized medicine.

PROVIDER AVAILABILITY

Responses were positive among patients in terms of access to one's health care team. The majority of patients (86.9%, n=444) expressed having the same level of access to their provider over the past 12 months as a year ago, while only 10% of the patients reported having less access.

Despite little reported change in access, 22% of the 475 patients who responded reported experiencing delays in accessing care. The most common type of delay for those who experienced delays was for scheduling a test or medical procedure (61.9%), followed by a delay in referral to a physician or health care team (46.7%).

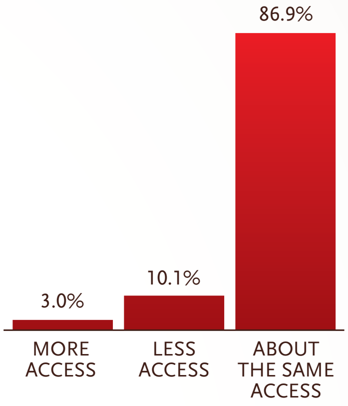
TYPE OF DELAYS EXPERIENCED BY PATIENTS REPORTING DELAYS (n=105, MULTIPLE RESPONSES ALLOWED)	PERCENTAGE
DELAY IN SCHEDULING A TEST OR MEDICAL PROCEDURE	61.9%
DELAY IN REFERRAL TO PHYSICIAN OR HEALTH CARE TEAM	46.7%
DELAY IN OBTAINING A PRESCRIPTION	22.9%
OTHER	25.7%

Despite positive findings among this sample in terms of availability to providers, at least 20% of those responding to the following items indicate concern about having to switch health care providers and institutions. Concern about getting a second opinion was also evident for 21% of the patients responding to the item.

PATIENTS SERIOUSLY OR VERY SERIOUSLY CONCERNED ABOUT	PERCENTAGE
HAVING TO SWITCH DOCTORS BECAUSE OF NETWORK LIMITATIONS (n=465)	21.0%
BEING ABLE TO GET A SECOND OPINION (n=462)	21.0%
HAVING TO SWITCH HOSPITALS OR CLINICS BECAUSE OF NETWORK LIMITATIONS (n=465)	20.5%

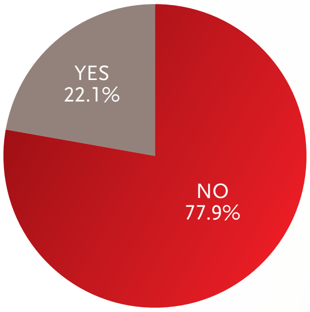
HAVE YOU NOTICED A CHANGE IN YOUR ACCESS TO YOUR HEALTH CARE PROVIDER IN THE LAST 12 MONTHS?

(n=444)



HAVE YOU EXPERIENCED DELAYS IN GETTING ACCESS TO CARE?

(n=475)

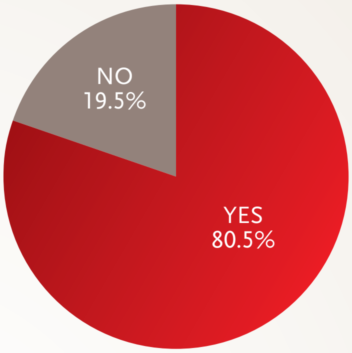


TIME WITH HEALTH CARE TEAM

Nearly 20% of the patients (n=476) felt they did not have enough time with their health care team. A significantly higher percentage of patients with lower incomes reported not having enough time with their health care team compared to those with higher incomes. This is particularly concerning given previous data from CSC noting that (1) lower income survivors are more likely to request help for their social and emotional needs, and (2) higher distress predicts the likelihood of wanting to talk to a staff person. Future research should evaluate efforts to provide tailored resources for low income survivors, particularly within the first six months post-treatment when distress levels are highest (Buzaglo et al., 2014).

DO YOU FEEL YOU HAVE ENOUGH TIME WITH YOUR HEALTH CARE TEAM?

(n=476)



DISCUSSIONS WITH PROVIDERS

When patients take an active role and participate in treatment-decision counseling, they experience decreased distress, greater confidence and have more productive consultations with the medical team (Bernacki et al., 2014; Belkora et al., 2013). Our findings show that these patients have had discussions with their providers about topics such as their goals of treatment, the risks and benefits of treatment and their perspective on what they value in treatment. These patients reported less patient-doctor communication about financial related issues, including direct (e.g., treatment costs) and indirect costs (transportation, child or elder care costs or impact on work).

Indeed, only 34% of patients reported talking to their doctor about the financial cost of their treatment. A higher proportion of men (48.1%) reported talking about the financial cost of treatment with their doctor than women (32.8%). Men were also more likely to talk with their doctor about indirect costs than women. A significantly lower percentage of white patients (33.2%) had a discussion about the financial cost of treatment as well as indirect costs (13%) compared to those of another race or reported mixed race (56.3%; 28.1%, respectively). Further, younger patients were also significantly more likely to talk with their doctor about the impact of treatment on work.

PERCENT TALKING WITH THEIR HEALTH CARE TEAM ABOUT THE FOLLOWING WHEN MAKING THEIR CARE DECISIONS	PERCENTAGE
YOUR GOALS OF THERAPY, FOR EXAMPLE: CURE, QUALITY OF LIFE, ETC. (n=473)	79.5%
THE RISKS AND BENEFITS OF EACH TREATMENT OPTION (n=471)	78.8%
MORE THAN ONE TREATMENT (n=472)	78.2%
WHAT YOU VALUE ABOUT YOUR TREATMENT (n=464)	62.3%
PALLIATIVE CARE, SUCH AS TREATING SIDE EFFECTS, MANAGING PAIN (n=468)	62.2%
IMPACT ON WORK (n=467)	51.8%
CLINICAL TRIALS AS A TREATMENT OPTION (n=471)	48.8%
THE FINANCIAL COST OF TREATMENT (n=468)	34.4%
NON-TREATMENT RELATED COSTS SUCH AS TRANSPORTATION, CHILD OR ELDER CARE (n=465)	14.0%

While we are used to talking about the physical toxicities of treatment regimens, we are less familiar with thinking about the financial toxicities of cancer on individual patients and their families. Cancer places a financial burden on patients that is associated with patients taking measures that may significantly impact quality of life and may negatively affect treatment outcomes. Implications for future research and practice include the development and evaluation of interventions to enhance oncology team-patient communication and support (e.g., financial counseling and assistance) to help ensure that the financial burden of cancer does not negatively impact the patient's quality of life, course of cancer care and health outcomes.

As noted below, over 20% of the patients expressed concern about gaining information related to cancer treatment and management. It should be noted that over 20% of patients also reported high concern about receiving a written plan from the doctor.

PATIENTS SERIOUSLY OR VERY SERIOUSLY CONCERNED ABOUT	PERCENTAGE
GETTING A WRITTEN PLAN FROM MY DOCTOR (n=464)	23.5%
GETTING RELIABLE INFORMATION ABOUT ILLNESS, TREATMENT AND SERVICES (n=462)	24.2%

Access to Services

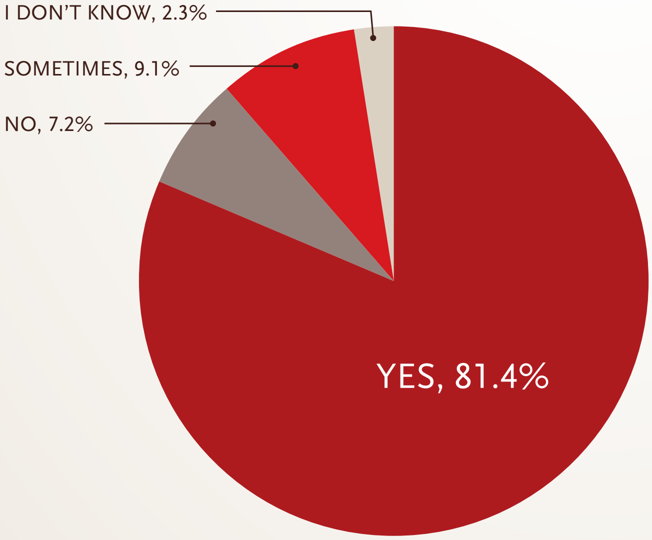
Patients with cancer require numerous and diverse services in order to effectively manage their cancer, which should be continued into survivorship for routine checkups or because of lingering limitations (e.g., speech or mobility).

ACCESS TO MEDICAL CARE

Nearly 20% of patients felt they were not able to get the medical care that was needed. Among those who reported not being able to access needed medical care (i.e., "no" response, n=34), 94% had health insurance and had household incomes less than $60,000 (60.7%, n=33). They were also predominantly white (82.4%), female (75.8%) and between the ages of 45-64 (64.7%). 52.9% were currently in treatment and 52.4% had forms of cancer other than breast cancer. The type of insurance among these 34 individuals included: employer-based (29.4%), Medicare with supplemental (17.6%), multiple insurance types (e.g., Medicare and military-related) (11.8%), Medicaid (8.8%), Marketplace insurance plan (8.8%), Medicaid and Medicare (5.9%), no insurance (5.9%), other (e.g., COBRA) (5.9%), military-related (2.9%) and private non-Marketplace (2.9%).

When comparing a yes response to otherwise (i.e., responses of "no," "sometimes," or "I don't know"), those with higher incomes were significantly more likely to report having access to medical care than those with lower incomes. A higher percentage of those 65 and older (88.1%) also reported better access to care than younger patients (45-64, 78.3%; 18-44, 68.6%).

ARE YOU ABLE TO GET THE MEDICAL CARE YOU FEEL YOU NEED?
(n=475)

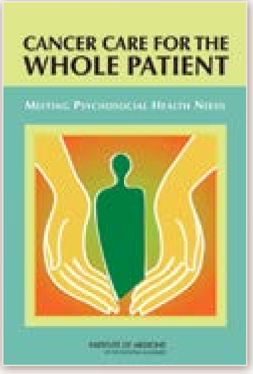


Patients also reported on their concern about access to other medical services. The highest expressed concerns pertained to accessing genetic/biomarker testing and counseling, accessing clinical trials and getting emotional support.

PATIENTS SERIOUSLY OR VERY SERIOUSLY CONCERNED ABOUT	PERCENTAGE
HAVING ACCESS TO GENETIC/BIOMARKER TESTING AND COUNSELING (n=466)	20.8%
HAVING ACCESS TO CLINICAL TRIALS (n=463)	20.3%
HAVING ACCESS TO EMOTIONAL SUPPORT SERVICES (n=471)	19.9%
HAVING ACCESS TO PHYSICAL THERAPY (n=462)	16.5%
HAVING ACCESS TO HOME HEALTH CARE (n=462)	16.2%
HAVING ACCESS TO HOSPICE CARE (n=458)	14.2%
HAVING ACCESS TO FERTILITY PRESERVATION (n=456)	3.1%

RECEIPT OF PSYCHOSOCIAL CARE

In the 2008 report entitled “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs,” the IOM reported that the psychosocial needs of patients with cancer were not being adequately addressed, and by meeting such needs, patients might experience improvement in quality of life. The report highly recommends psychosocial distress screening, referral and follow-up care for all patients.



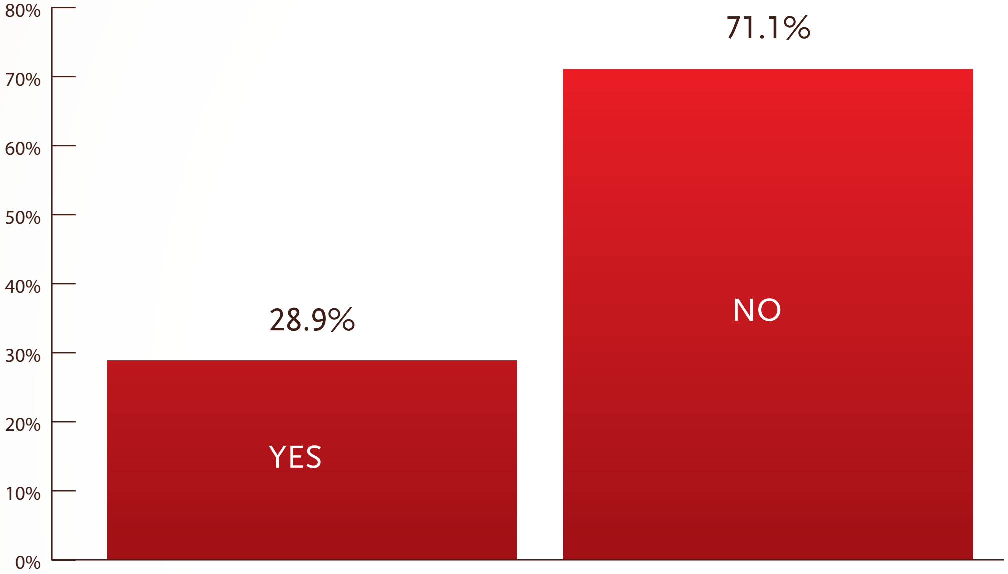
Over the past five years, the cancer health care community has shown a growing commitment to distress screening and integration of psychosocial care as professional organizations have formally recognized that screening, referral and follow-up for psychosocial concerns are critical to ensuring quality cancer care for the whole patient. Integrating psychosocial care into cancer care is associated with improved long-term health outcomes (Andersen et al., 2010) and improved cost outcomes (Carlson & Bultz, 2004).

A recent report on findings from CSC’s Cancer Experience Registry (Elevating the Patient Voice, 2014) demonstrates an ongoing need for coordinated care that integrates programs and services throughout the health care system. Indeed, findings from the “Elevating the Patient Voice” report showed that about half of respondents were never asked about distress by their health care team. Those who received all or part of their treatment in an academic or comprehensive cancer center were significantly more likely to be asked about distress compared to those receiving treatment anywhere else. Disturbingly, 21% of patients who were asked about distress never received any referrals and only 16% were referred to community-based organizations for treating their distress where their services are often provided at low or no cost. Further, while validating the CSC patient distress screening tool (CancerSupportSource™), CSC learned that patients with lower income were more likely to request help for their psychosocial needs and higher distress predicted the likelihood of wanting to talk to a staff person (Buzaglo et al., 2014).

Although the patients in this Access to Care Project reported good access to medical care, over 70% of the patients did not receive social and emotional support services including screening for distress. Among the 335 patients not receiving such support, 55% did not know where or how to get support (33%) or did not receive a referral (22%) for psychological and/or emotional support. This suggests a disparity between access to medical care compared to psychosocial care for these patients and affirms the need for continued collective efforts to improve distress screening and referral.

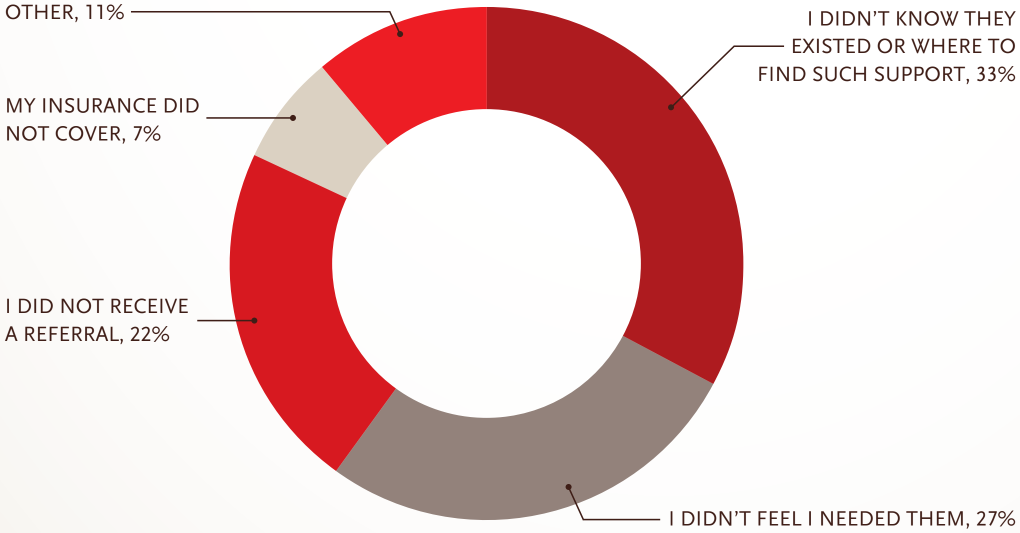
RECEIPT OF SOCIAL AND/OR EMOTIONAL SUPPORT SERVICES INCLUDING SCREENING FOR DISTRESS DURING CANCER CARE

(n=471)



IF YOU DID NOT RECEIVE EMOTIONAL SUPPORT OR COUNSELING, WHAT ARE THE REASONS YOU DIDN'T ACCESS THIS SUPPORT?

(n=335)



Cost of Health Care

Americans are certainly not absent of concern regarding health care costs. In the report, entitled "Too High a Price: Out-of-Pocket Health Care Costs in the United States," The Commonwealth Fund highlighted that having a lower income was associated with spending a higher share of income on uncovered health care costs. As might be expected, those in poorer health are also shown to spend more on health care than healthier individuals (The Commonwealth Fund, 2014). Greater cost sharing is believed essential toward reducing health spending and inflation. But, on the downside, adverse consequences might ultimately surface, such as delayed medical care and more advanced disease at the point of access—leading ultimately to greater spending.

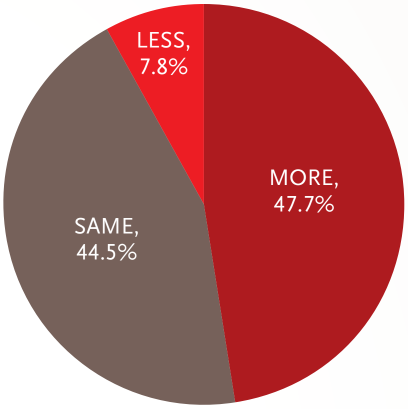
Cost of care continues to be a major concern for people facing cancer—with a wide range of impact on treatment and lives. These concerns stem directly from the costs of treatment and from indirect costs such as loss of work, costs of child care or transportation to and from treatment centers. As noted in the chart (top right), just under half of patients report paying more for health care over the past 12 months. The top reasons individuals in our sample indicated paying more for health care over the past year included:

- Paying more for insurance premiums
- Paying more for deductibles
- Paying more for treatment co-pays
- Paying more for co-insurance
- Needing more care

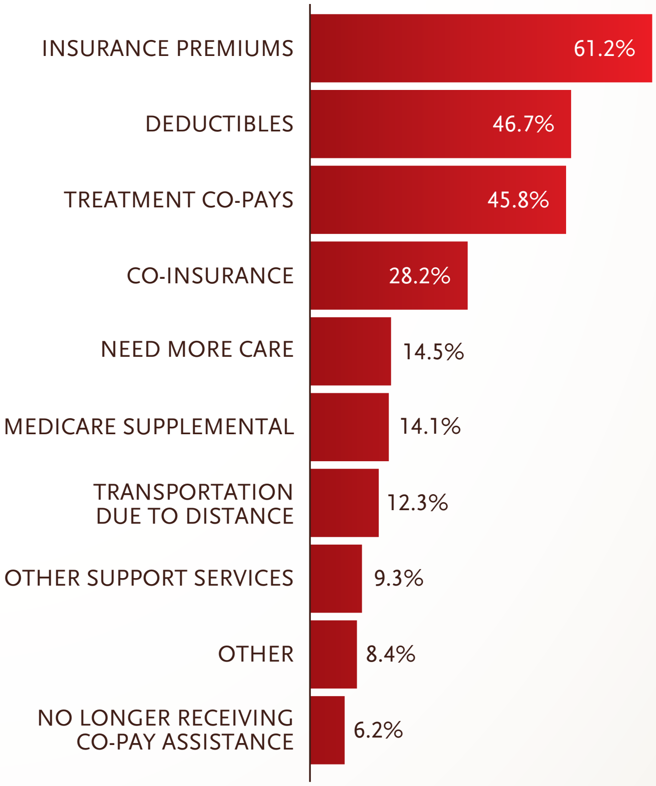
Patients were also asked about their concern for bankruptcy. Nearly 4 in 10 (37.1%, n=467) reported being seriously or very seriously concerned about bankrupting their family. A significantly higher proportion of patients age 18-44 (58.8%) reported being seriously or very seriously concerned about bankrupting their family compared to those aged 45-64 (40.9%) and those 65 or older (23.3%).

HAVE YOU NOTICED A CHANGE IN THE COST YOU PAY FOR YOUR HEALTH CARE OVER THE PAST 12 MONTHS?

(n=476)



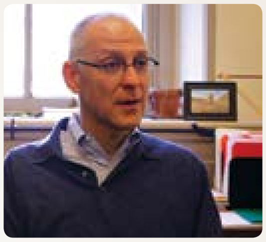
IF YOU ARE PAYING MORE OUT-OF-POCKET (n=227), ARE THE INCREASED COSTS RELATED TO (MULTIPLE RESPONSES)

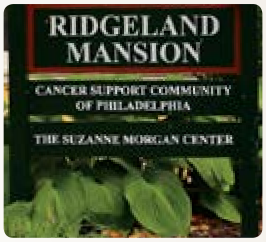


We also asked patients about their level of concern about specific out-of-pocket costs and responses for high concern are provided below.

PERCENT EXPRESSING HIGH CONCERN (SERIOUSLY, VERY SERIOUSLY CONCERNED) ABOUT OUT-OF-POCKET COSTS	PERCENTAGE
OUT-OF-POCKET COSTS FOR HOSPITAL STAYS (n=463)	38.0%
OUT-OF-POCKET COSTS FOR MEDICATIONS (n=469)	38.0%
OUT-OF-POCKET COSTS FOR LAB TESTS OR SCANS (n=468)	37.8%
THE COST OF THE MONTHLY PREMIUM YOU PAY FOR HEALTH INSURANCE (n=467)	36.8%
OUT-OF-POCKET COSTS FOR PHYSICIAN VISITS (n=464)	31.5%
OUT-OF-POCKET FOR PALLIATIVE AND SUPPORTIVE CARE (n=464)	26.3%
OUT-OF-POCKET COSTS FOR MEDICAL CARE (n=455)	24.8%
GETTING FINANCIAL ASSISTANCE AND/OR ASSISTANCE (n=467)	24.2%

The implications of these concerns will be important to monitor over time. For example, future efforts might explore if high concern for out-of-pocket costs for medication is associated with poorer adherence, especially poorer adherence to oral medication. Findings from the CSC Cancer Experience Registry Report indicate that the combination of high levels of distress and financial burden can significantly impact adherence among patients with chronic myeloid leukemia (Buzaglo et al., 2014). This might ultimately influence overall health outcomes and costs of care to the health system. Therefore, there may be great benefit in identifying those at highest risk, addressing their emotional and social concerns and providing access to financial assistance.





Summary and Future Direction

It is quite likely that this sample includes a particularly proactive and engaged subset of individuals, as many may be connected to the CSC community and were responsive to an online survey. For these patients, we note many areas of triumph with health care access. In particular, this sample was largely satisfied with their health insurance coverage and time with their health care team, while few reported delays in access to care. Further, these patients express engaging in discussion with their health care team about treatment-related issues, including voicing their own perspectives. Though low in number, some patients report having coverage despite a pre-existing condition, as well as access to insurance through the Health Insurance Marketplace. This might suggest that some patients are benefiting from the ACA, though more study is needed.

Yet, approximately 20% struggle with issues of access to care, including not receiving needed medical care or experiencing delays. We also illuminate other areas of concern for those included in this sample. Foremost concerns pertain to the direct and indirect costs for patients, with 37% reporting high concern about their illness bankrupting their family. Future research should explore this financial burden in terms of implication on health care use and outcomes over the long-term.

Importantly, although these patients with cancer report good access to medical care, we note that over 70% reported not receiving social and emotional support services, including screening for distress. Over half (55%) of those who did not receive services either did not know where or how to get support or did not receive a referral for psychological and/or emotional support. These findings affirm the need for collective efforts to incorporate distress screening and referral in cancer care and follow outcomes over time.

Insight from patients can inform future research and policy efforts. We recommend that the cancer community continues to prioritize understanding the experiences of patients in terms of access to quality cancer care. Priority areas must include:

- Monitoring the direct and indirect costs of cancer and related care for patients throughout the trajectory of disease
- Understanding the implications of cost burden in terms of a patient’s emotional health and use of health services over time
- Further exploring the impact of Health Insurance Marketplaces on financial and emotional burden of patients
- Identifying the subtleties of key elements of patient-centered care including quantity and quality of time spent with health care team and discussions on cost
- Evaluating the impact of psychosocial distress screening, referral and follow-up on patient care and costs

CSC is grateful for the patients who freely shared their time and voices so that others might learn. Our goal is to hear their voices, as well as continue to listen so that CSC, other advocacy organizations and health care stakeholders can shape efforts that are most meaningful to patients and the health care system as a whole.

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