

# Elevating the Patient Voice

CANCER EXPERIENCE REGISTRY INDEX REPORT 2013 - 2014



The mission of the Cancer Support Community is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.

The Cancer Experience Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families throughout the cancer journey.



A PROGRAM *of the* CANCER SUPPORT COMMUNITY 

## A Message from Kim Thiboldeaux



Every person who faces cancer has a story—a unique narrative. It’s important that those stories be told. The very act of doing so empowers both the teller and everyone who hears and shares that experience.

The individual testimony is strong and necessary, but in today’s world, people with cancer need to speak collectively, and to use that powerful, unified voice as the core of a transformative model of health care that puts the patient experience at its center.

At the Cancer Support Community, we have developed and are continuing to grow our Cancer Experience Registry as a vehicle for hearing what those impacted by cancer say about their issues, values, preferences and concerns. We are analyzing that data and sharing it. We use what we learn as the foundation for our programs, materials and interventions.

We know that people with cancer want transparency—to understand how and why decisions are being made about their treatment. They want to be able to view their health care records—but many of today’s electronic medical records are complicated, hard to use and limit interaction with the health care team. Insurance companies are increasingly putting clinical pathways that direct treatment decisions into place—but patients often do not know about or have access to these guidelines. People with cancer want to be able to make informed decisions about what is cost effective care, but the disconnect between the cost and benefit of cancer therapy remains wide, and largely unaddressed from the patient perspective.

People with cancer are living longer and with this comes an increased emphasis on quality of life. Patient input and the patient experience are essential today to designing and implementing clinical trials and to making decisions about how best to balance therapeutic effectiveness with both short- and long-term side effects. Perhaps most important, patients and their families want open, honest communication with their physicians and health care teams.

In this publication, the Research and Training Institute of the Cancer Support Community reports on the data we have gathered and analyzed in 2013-14 from the cancer patients who have enrolled in our Cancer Experience Registry. During the last year, we have significantly increased the number of participants, added three disease specific sub-registries and greatly expanded the data we report to the broader community. The extent of the data and the rigor that we bring to our analysis make the Cancer Experience Registry a critically important resource in the effort to create an authentically patient-centric system of health care delivery for cancer patients.

I want to personally thank our partners, supporters and sponsors. A key to generating a collective voice for cancer patients is real cooperation and collaboration among the organizations that represent them and the health care community at large that often drive research and progress.

I also want to thank the extraordinary members of our Advisory Councils, who provide such depth and breadth of expertise and wise guidance for the Cancer Experience Registry—and all of our programs.

Most of all, I want to thank the patients who take the time, make the effort—and the commitment to participate in the Cancer Experience Registry. By sharing their individual experience, they are truly contributing to an essential whole that will change the way we think about and deliver cancer care in this country.

A handwritten signature in black ink, appearing to read "K. Thiboldeaux".

## A Patient-Powered Research Network / Growing, Evolving, Deepening

“We hear over and over that patients feel uncomfortable bringing up their issues with their doctors. They don’t want to bother them, or be seen as a ‘bad patient.’ We put a lot of effort into asking questions that are sensitive to our population—and our respondents often tell us, ‘no one ever asked me that before.’” — Joanne Buzaglo, PhD, Cancer Support Community

The concept for the Cancer Experience Registry began in 2010, out of the Breast Cancer M.A.P. (Mind Affects Physical) Project, a novel registry open to breast cancer patients at all stages of the disease. The M.A.P. Project asked people with breast cancer to fill out an extensive survey identifying their treatment-related issues, as well as their emotional, psychological and physical concerns. The goal was to engage patients to share individual experiences to build a quantitative database that would serve as a unified voice, one that would reach health care teams, policymakers, organizations that support breast cancer patients and most importantly, the people facing the disease.

The M.A.P. Project recruited patients and generated a wealth of insightful, usable data on a wide range of issues. The results were summarized in the October 2011 Index Report, Cancer Survivor Registry: The Breast Cancer M.A.P. Project. The data was valuable in identifying gaps in care as well as in developing new programs and services to address those gaps.

The success of the M.A.P. Project led the Research and Training Institute of the Cancer Support Community to expand the scope of the effort to reach people with different cancers. In March 2013, the Cancer Experience Registry was opened. The Registry utilizes the same basic methodology to gather and analyze data on a wide range of issues.

“The work we did with the M.A.P. Project informed and inspired our decision to develop the Cancer Experience Registry,” says Joanne Buzaglo, PhD, Vice President, Research and Training, who directs the Registry. “We are committed to moving from a patient focused model to one that is truly patient-powered. We realize we are tapping into a deep vein of information and knowledge. Patients want to connect with other patients. They want to see how other people are responding to the same questions and to the same issues—and they want to be heard.”

As of September 2014, over 7,000 cancer patients have enrolled in the Cancer Experience Registry, representing more than 35 different cancer types. In 2014, the Cancer Support Community deepened and broadened the Registry, launching sub-registries for people with Multiple Myeloma, Chronic Myeloid Leukemia and Metastatic Breast Cancer, with plans to develop additional ones for cancer caregivers, Lung Cancer, Melanoma and Chronic Lymphocytic Leukemia in the next year. Each has an Advisory Council that includes experts in the clinical and psychosocial aspects of the cancer type, experts on policy, patient advocacy groups, industry representatives, as well as patients who are experts in living with that diagnosis.

“We see some consistent themes in what Registry participants are reporting across the various diagnoses,” says

### JOIN THE CANCER EXPERIENCE REGISTRY

Any person who is living with cancer can join the Cancer Experience Registry. Whether you have just been diagnosed, are currently in treatment or your treatment has ended, we encourage you to take the time to enroll and answer the survey questions. By sharing your experiences, you are helping to identify and advance the understanding of the emotional and social needs of people who have been impacted by this disease. All personal information you provide remains confidential and will be used only to support greater understanding of the needs of people living with cancer and develop programs and services that improve the quality of life for people affected by every type of cancer.

### TO JOIN, GO TO

[www.cancerexpericeregistry.org](http://www.cancerexpericeregistry.org)

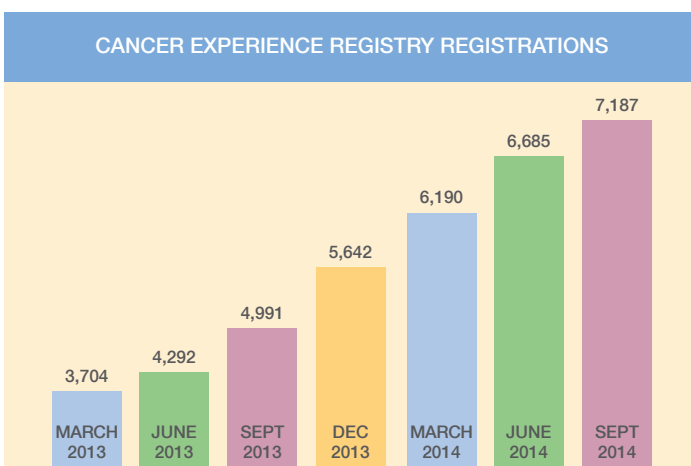


JOANNE BUZAGLO, PHD,  
VICE PRESIDENT, RESEARCH  
AND TRAINING

Buzaglo, “but we also realized that people with different kinds of cancer have issues that are more specific, or even unique to their diseases, and we need to provide a vehicle for identifying those concerns more precisely. That’s the purpose of the sub-registries.”

The mission and vision for the Cancer Experience Registry have remained focused on supporting a greater understanding of the social and emotional needs of people impacted by cancer. But experience with the Registry has also led to an evolving vision of what it can and should accomplish. There is an increased emphasis on disseminating data to the research community, health care providers, patient advocates and policymakers as a means of putting the patient voice and experience at the center of health care. The ultimate goal is to have patients control what data they report, with whom they share it and in what format—as a critical component in developing programs and services that improve the long-term quality of life for people facing cancer.

In analyzing the data from the Registry, certain themes emerged. These include: Managing Long-Term Side Effects, The Cost of Cancer Care and The Ongoing Need for Emotional Support. We explore these issues in separate sections of this report.



## AN EXTRAORDINARY PARTNERSHIP

A key goal for the Registry is to develop strategic relationships with other patient advocacy organizations. The registry for patients with Chronic Myeloid Leukemia (CML) is the result of a special partnership between the Cancer Support Community and The Leukemia & Lymphoma Society (LLS).

“This is an extraordinary collaboration,” says Gwen Darien, Executive Vice President, Programs and Services at the Cancer Support Community. “The joint effort with LLS has extended and improved every aspect of the CML Registry. This is a great example of what can be done when the organizations that serve people impacted by cancer work together.”

The LLS partnership has helped the CML Registry to identify and recruit key advisors as well as to develop a questionnaire specifically attuned to the issues that CML patients face. LLS also played a major role in reaching out to CML patients across the country, as well as in bringing other groups, including the Max Foundation and the National CML Society, into the program. “The Cancer Experience Registry for CML gives patients the opportunity to speak to other stakeholders in the CML community—oncologists, nurses, social workers, advocacy organizations,” says Clare Karten, MS, The Leukemia & Lymphoma Society, who adds, “It connects patients who might otherwise never meet another person living with CML. We have been very excited about our participation in this program.”

## Overview of Registry Findings

This annual update explores key findings from the Cancer Experience Registry, bringing to light critical issues and trends that our participants report across the cancer experience. It provides the opportunity to communicate these findings to the cancer community and others interested in ensuring patients have full access to comprehensive, quality cancer care.

In the year and half since its launch, it has become clear that people impacted by cancer are eager to share their experiences, that they value engaging each other and the health care teams who provide their treatment. From the data, we are able to draw out themes, some specific to people with certain types of cancer, others that apply across the spectrum of cancer diagnoses. Among the most prevalent and interesting findings are:

- There are a growing number of patients surviving for longer periods of time, some of whom are experiencing their cancers as a chronic condition. This trend means that people impacted by cancer have to manage both short- and long-term side effects over an extended duration. They are also confronted with treatment decisions that impact their quality of life as well as have to deal with an increased array of financial issues. For many, treatment never ends and brings with it higher levels of anxiety and uncertainty about the future. This redefining of the cancer experience has led some patients to take ‘drug holidays,’ or even discontinue treatment entirely—and represents an area that demands more study and better understanding.

- While many patients report that they understand the importance of clinical trials and have discussed this option with their doctors, some of the data indicates that myths and misconceptions about these studies are still very common and represent significant obstacles to increasing patient participation. This data is particularly significant in light of the movement to rethink and restructure clinical trials to make them more accessible and appealing to a broader range of both patients and physicians.

- A hallmark of the Registry is the opportunity it presents for people to respond to open-ended questions. Their answers and comments add depth and richness to what we learn across a wide variety of topics. One strong theme focuses on self-advocacy. Many patients speak to the value of becoming their own best advocates and of the necessity of becoming well-informed, engaged partners in their treatment. They often extend that benefit to advocating for others who are facing cancer, saying that

they believe that helping people is a strong factor in promoting their own healing and emotional well-being.

### METHODOLOGY

Upon registration, respondents have access to the website where they can complete core questions about their social and emotional experience. For those with a diagnosis that falls into a category in which a sub-registry exists, in particular, Metastatic Breast Cancer, Multiple Myeloma, and Chronic Myeloid Leukemia, they answer a series of questions identified as ‘gap’ areas in psychosocial research for their specific conditions. These ‘gap’ areas are informed by key advisors with expertise in the specific disease type in medical oncology, clinical research, advocacy, behavioral research, health care industry and policy as well as patient and caregiver representatives who are impacted by that cancer. Participation is completely voluntary. In addition, after completing their responses, participants can click an icon for each question and review how others have responded in aggregate.

### OUTREACH AND RECRUITMENT

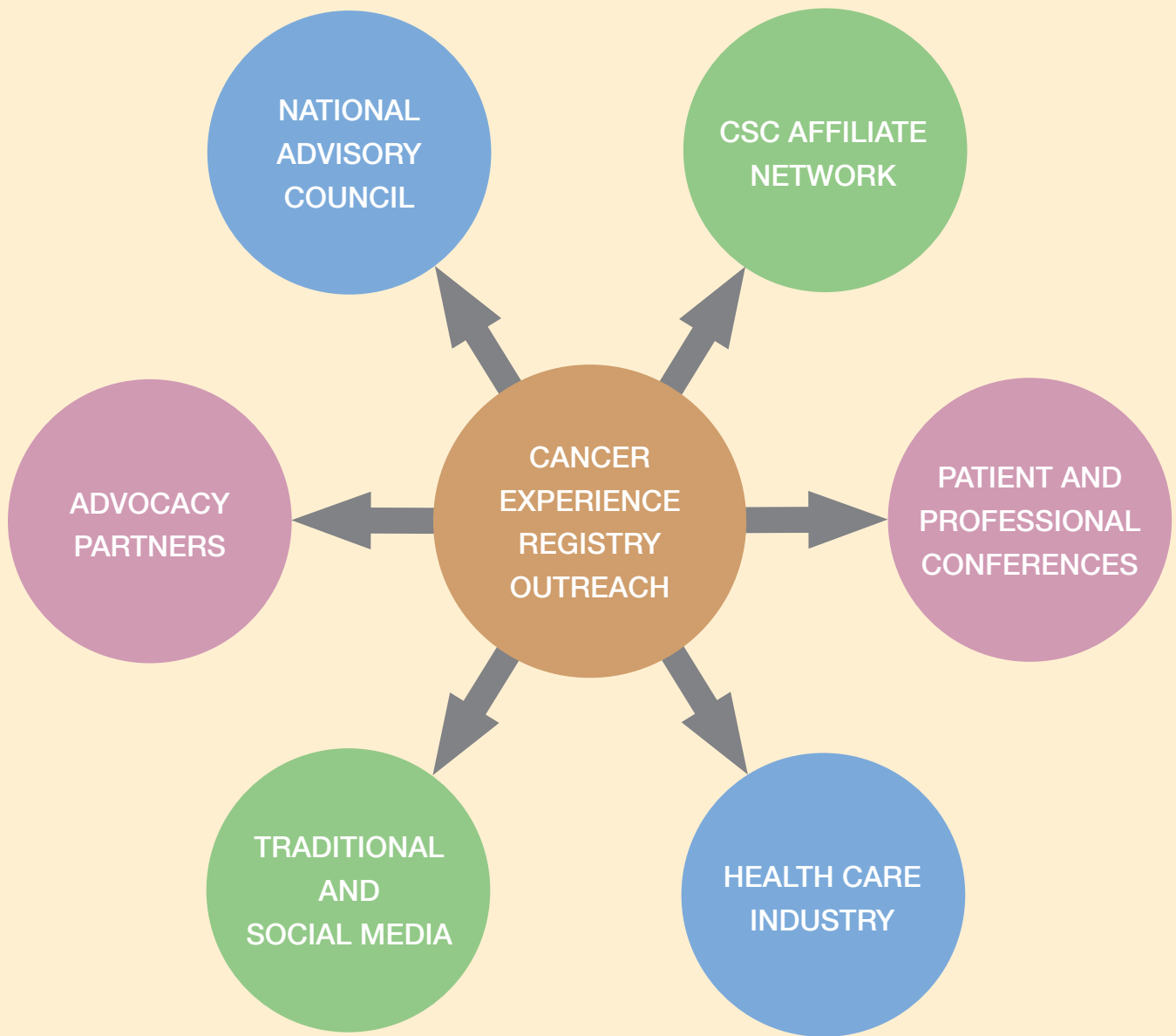
The Research and Training Institute developed a comprehensive outreach and recruitment strategy to reach a broad spectrum of people impacted by cancer and to encourage participation in the Cancer Experience Registry. Key elements of the strategy include leveraging the robust CSC affiliate network, online community and national helpline; working with CSC’s relationships with key advocacy organizations, our advisory councils and professional networks; as well as utilizing social and traditional media outlets; and the health care industry. Recruitment and outreach is ongoing with open enrollment.

### THE PARTICIPANTS IN THE CANCER EXPERIENCE REGISTRY

As of September, we have over 7,000 participants in the Registry. For this report, we have analyzed a subset of participants who joined between March 2013 and September 2014 and live in the United States. The participant characteristics for those participating in the General Cancer Experience Registry (GEN) and the three sub-registries for Metastatic Breast Cancer (MBC), Chronic Myeloid Leukemia (CML) and Multiple Myeloma (MM) are described in the table on the following page.

### CANCER-RELATED DISTRESS

In the Cancer Experience Registry, CancerSupportSource<sup>SM</sup> (CSS-25; Miller et al., 2014) is used to measure concerns related to distress and quality of life. CSS-25 is a validated instrument that is used to screen for distress as part of a larger community based distress screening program designed to



PARTICIPANT CHARACTERISTICS				
	GENERAL (GEN) (N=1195)	CHRONIC MYELOID LEUKEMIA (CML) (N=327)	METASTATIC BREAST CANCER (MBC) (N=599)	MULTIPLE MYELOMA (MM) (N=365)
<b>MEDIAN AGE</b>	56 YEARS (RANGE: 21-88)	59 YEARS (RANGE: 18-85)	56 YEARS (RANGE: 24-92)	64 YEARS (RANGE: 32-88)
<b>GENDER</b> FEMALE	83%	67%	99%	54%
<b>RACE AND ETHNICITY</b> CAUCASIAN BLACK OR AFRICAN-AMERICAN HISPANIC	88% 4% 4%	90% 3% 3%	93% 2% 3%	87% 10% 2%
<b>EDUCATION</b> COLLEGE DEGREE OR HIGHER	58%	51%	61%	56%

identify concerns and link patients to resources and referrals. The 25 items are based upon the Institute of Medicine's recommended areas of unmet psychosocial need (IOM, 2008), cover three critical domains (psychosocial, practical, physical) and include a four-item depression subscale. The items listed in the box to the right are consistently the top areas of concern across the Registry and sub-registries. For participants with Metastatic Breast Cancer, Multiple Myeloma, and Chronic Myeloid Leukemia, pain also becomes a top area of concern.

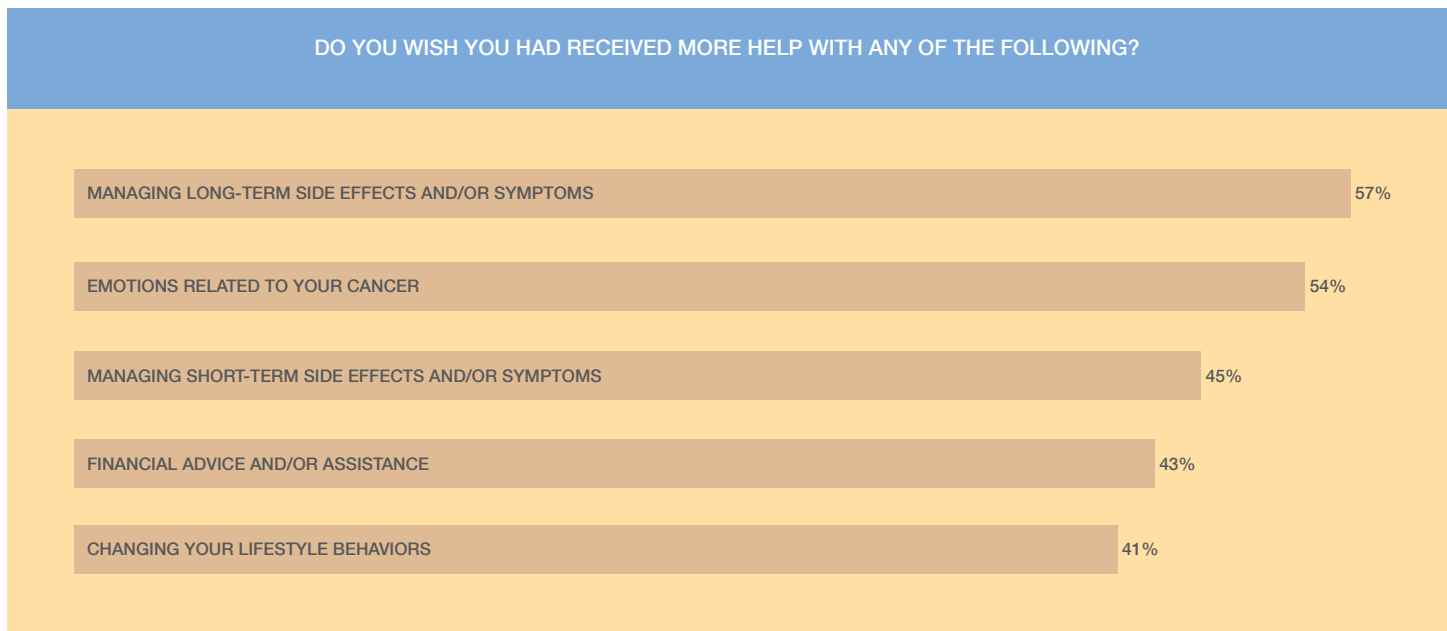
The top five concerns people want more help managing are: 1) long-term side effects, 2) the emotions related to cancer, 3) short-term side effects, 4) financial impact of cancer and 5) lifestyle changes, such as diet and exercise. More than half wished they had received more help with managing the long-term side effects and emotions related to cancer. As people are living longer after a cancer diagnosis, they want help in understanding the long-term implications of their disease and treatment in order to plan effectively for their future.

Over the past five years, there has been 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 (American College of Surgeons 2013; ASCO 2014, NCCN 2014).

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

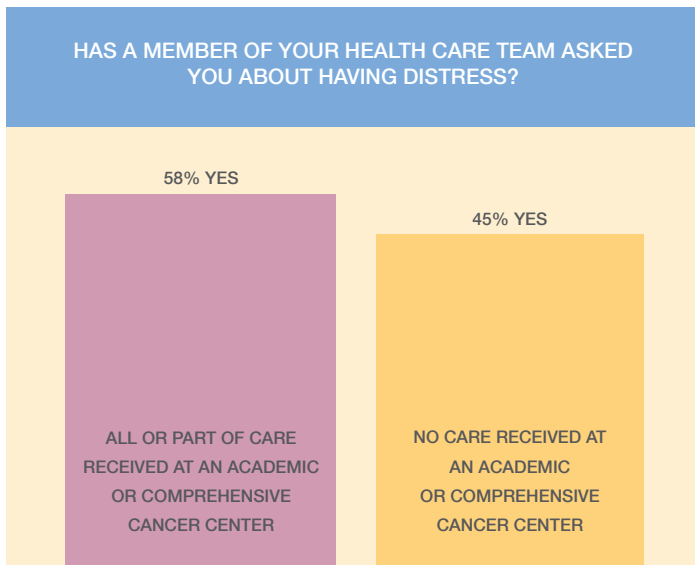
**TOP CONCERNS OF CANCER EXPERIENCE  
REGISTRY PARTICIPANTS**

- *Eating and nutrition*
- *Worrying about the future and what lies ahead*
- *Health insurance or money worries*
- *Feeling too tired to do the things you need or want to do*
- *Exercising and being physically active*
- *Worrying about family, children and/or friends*
- *Changes or disruptions in work, school or home life*
- *Thinking clearly (e.g., "chemo brain")*
- *Moving around (walking, climbing stairs, lifting, etc.)*
- *Body image and feelings about how you look*
- *Sleep problems*



PERCENTAGE OF GENERAL, CML, MBC, MM PARTICIPANTS WHO RESPONDED "YES"





PERCENTAGE OF GENERAL, CML, MBC, MM PARTICIPANTS

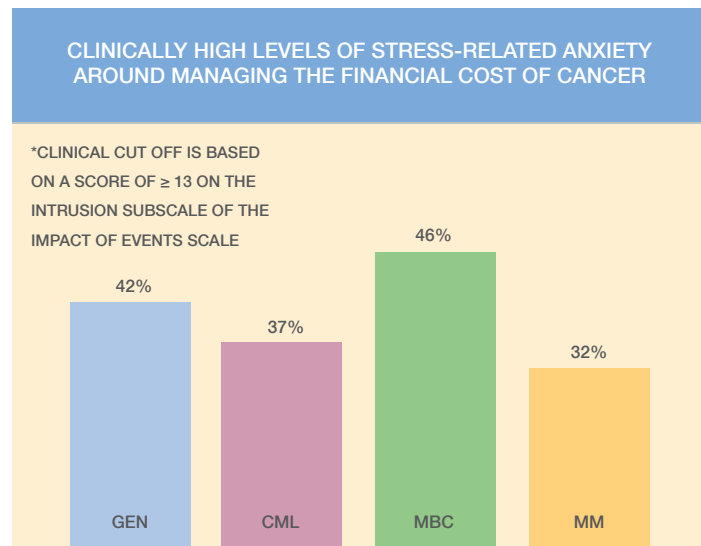
were significantly more likely to be asked about distress versus those receiving treatment anywhere else (58% vs. 45%, Disturbingly, 21% of patients who were asked about distress, never received any referrals, and only 16% were referred to community-based organizations for treating their distress where these services are often provided at low or no cost. These findings demonstrate that there is an ongoing need for coordinated care that integrates programs and services across health care systems, particularly for those seeking treatment in community-based practices.

### TREATMENT DECISION MAKING

When making cancer treatment decisions, there are often a number of options including chemotherapy, radiation, surgery and active surveillance/watchful waiting. With the movement toward patient-centered care, and the importance of engaging the patient in the treatment decision process, we asked a number of questions about the patient experience in making cancer treatment decisions. Nearly all (91%) reported receiving information about their cancer type before making a treatment

decision, and 76% received information about their treatment choices. While most patients reported receiving information about their treatment options, less than half report being knowledgeable about treatment options, and a significant proportion reported not having enough knowledge or support to fully engage in treatment decisions. A significant proportion felt minimally or not at all involved in the treatment decision-making process, and over half felt significantly unprepared to discuss treatment options with their doctor.

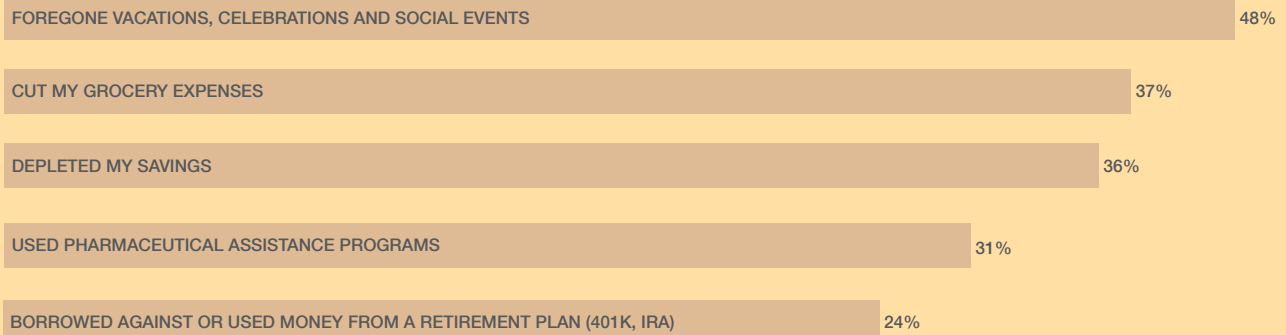
Among all registrants, 34% received treatment decision support prior to therapy, and 38% would have liked more support. Twenty-six percent reported they did not have enough time to make a treatment decision. Those who wrote down a list of questions prior to their first visit to discuss treatment options with their health care provider felt significantly more prepared to discuss their treatment options. Studies have shown that 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.



PERCEPTIONS ABOUT TREATMENT DECISION-MAKING PREPAREDNESS				
	GEN	CML	MBC	MM
KNOWLEDGEABLE ABOUT TREATMENT CHOICES	26%	41%	22%	33%
INVOLVED IN TREATMENT DECISION MAKING	15%	29%	12%	16%
PREPARED TO DISCUSS TREATMENT OPTIONS WITH A DOCTOR	52%	65%	52%	60%

PERCENTAGE OF PARTICIPANTS WHO RESPONDED "NOT AT ALL" OR "A LITTLE BIT"

## BECAUSE OF THE MEDICAL COSTS OF CANCER, I HAVE



PERCENTAGE OF GENERAL, CML, MBC, MM PARTICIPANTS WHO RESPONDED "YES"

### FINANCIAL COST OF CARE

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. The degree to which these concerns affect people's lives also varies significantly.

To assess the impact of the financial concern, we measured respondents' level of stress-related anxiety and asked them to what extent thoughts about managing the cost of care intrude into their thinking. Using the Impact of Events Scale (IES; Horowitz et al., 1979), we found that up to 46% of respondents are experiencing

significant levels of anxious thinking or intrusive ideation about managing the cost of care. Issues include, "having trouble falling asleep," "thinking about it when I didn't mean to," and "other things kept making me think about it." One-third to nearly one-half or more across sub-registries reported currently experiencing clinically high levels of stress-related anxiety ( $IES \geq 13$ ) about managing the financial cost of cancer.

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

## IN ORDER TO REDUCE THE COST OF CANCER, I...

	CML	MBC	MM
POSTPONE DOCTOR'S APPOINTMENTS	16%	12%	5%
POSTPONE FOLLOW-UP SCREENING AND/OR BLOOD WORK	12%	12%	5%
POSTPONE FILLING PRESCRIPTIONS	14%	12%	6%
DELAY FOLLOW UP ON RECOMMENDATIONS FOR COMPLEMENTARY TREATMENT (E.G. PHYSICAL THERAPY, OCCUPATIONAL THERAPY, NUTRITION COUNSELING)	17%	31%	14%
POSTPONE SEEKING PSYCHOLOGICAL COUNSELING OR SUPPORT	23%	34%	17%
SKIP DOSAGES OF PRESCRIBED DRUGS	10%	7%	5%

PERCENTAGE OF PARTICIPANTS WHO RESPONDED "SOMETIMES", "OFTEN" OR "ALWAYS"

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.

**CANCER CLINICAL TRIALS**

Nationally, the overall percentage of patients participating in clinical trials remains at 4%, a low figure which has remained unchanged for several decades. There are many reasons for this, including misconceptions by both patients and physicians about trials, lack of access and issues related to clinical trial structure and eligibility. Improving patient understanding of the importance of clinical trials and increasing engagement with these studies is critical to advancing cancer treatment.

There is a range of patient experience with respect to the extent to which the health care team speaks to patients about cancer clinical trials related to the specific cancer type. Overall, a significant proportion of participants report that no one spoke to them about a clinical trial and/or that they did not receive information about clinical trials before making a treatment decision. Notably, over 70% of participants indicate that they understand what a cancer clinical trial is; yet, 60% are uncomfortable with being randomly assigned to a treatment in a cancer clinical trial and 57% fear receiving a placebo. The prevalence and persistence of these myths about clinical trials are major barriers to increasing patient participation.

**PATIENT BELIEFS AND ATTITUDES IMPACT OUTCOMES AND ADHERENCE**

Patient beliefs, attitudes, values and goals can have a profound impact on overall health outcomes and behaviors.

For example, we learned from people living with Multiple Myeloma—a disease often characterized by alternating periods of remission and the need for more treatment—that their sense of control (how they will feel on a daily basis, and whether the treatment will get them back into remission) impacts their quality of life. Those who reported that they did not perceive control had significantly higher levels of anxiety, depression and fatigue and lower levels of physical function and satisfaction with participation in social roles. In addition, we learned from those living with CML, a disease that is generally managed with daily oral medication, that patient attitudes and beliefs can have a significant influence on adherence. CML participants who strongly agreed with the statement, “It is okay to miss a dose every now and then,” are 50 times more likely to miss a dose at least once a month compared to those who strongly disagreed with the statement. Future research and programs should examine whether enhancing perceived control over the course of disease and knowledge about the implications of non-adherence to therapeutic regimens through support and education can improve quality of life and health outcomes.

**CONCLUSION**

The depth and range of the data that we have collected and analyzed demonstrates the willingness of people impacted by cancer to share their experiences in both quantitative and qualitative formats. These findings are just the beginning. They suggest the need for ongoing engagement of people impacted by cancer and greater resources to understand and address the whole patient—the biology, the psychology and the social context in which we live and deliver health care. The Cancer Experience Registry is a powerful tool that is evolving into an important force in elevating the patient voice.

DOCTOR-PATIENT COMMUNICATION ABOUT CLINICAL TRIALS				
	GEN	CML	MBC	MM
MEMBER OF HEALTH CARE TEAM SPOKE TO ME ABOUT CANCER CLINICAL TRIALS	34%	33%	48%	64%
RECEIVED INFORMATION ABOUT CLINICAL TRIALS	33%	37%	42%	52%

PERCENTAGE OF PARTICIPANTS WHO RESPONDED “YES”

Linda P.

## Diagnosed with Breast Cancer 2010

“I was diagnosed two weeks after I started my new job—and that was after having been laid off for several months. I was in so much emotional distress. I cried all the time. I was so anxious and afraid. It was like nothing I had ever experienced. It made a huge difference when I told my manager what was happening and he told me that he was a Melanoma survivor. He said my job was safe and I should do whatever I needed to take care of my cancer. I signed up for the Cancer Experience Registry to give back to other women going through what I did, let them know they can get through it. I want to participate in the opportunity to support and talk to other women facing Breast Cancer.”





## Rick W. Diagnosed with Prostate Cancer 2008

“The first day was the worst. I knew my PSA had been going up, but I thought it was nothing. I felt fine. Prostate Cancer patients have to be advocates for themselves because there are a number of treatment options, and it’s up to you to decide which one fits your life. Other people might give you advice that is generically good, but not the best for you. My wife and I took our time, talked to a number of doctors, got as much information as we could and made the treatment choice that was right for us.”

## VOICES FROM THE REGISTRY

*We ask our Registry participants a number of open-ended questions. In this way, we hear their voices, telling us everything from what worries them most to what keeps them moving forward. These comments are a source of practical advice as well as inspiration and hope. We have included some of the actual quotes in this Report as Voices from the Registry.*

*“How do I stop worrying it will reoccur? How do I enjoy an active life?”*

*“I would hope that the primary physician would better prepare a patient for the possibility of a cancer diagnosis. I was sent to a hematologist without any indication that I might have Chronic Lymphocytic Leukemia (CLL). I hyperventilated when told the diagnosis.”*

# Chronic Myeloid Leukemia / Living with Cancer as a Chronic Disease

“The availability today of several oral therapies has dramatically changed survival outcomes for people diagnosed with chronic phase CML. The Cancer Experience Registry for CML helps tell the story of people living with CML, and the impact of taking daily oral medication to keep the cancer from progressing.”

— Clare Karten, MS, The Leukemia & Lymphoma Society

CML PARTICIPANT CHARACTERISTICS	
MEDIAN AGE IN YEARS	59 YEARS (RANGE 18-85)
GENDER	67% FEMALE 33% MALE
RACE	90% CAUCASIAN 3% BLACK OR AFRICAN-AMERICAN
EDUCATION	51% COLLEGE DEGREE OR HIGHER
EMPLOYMENT STATUS	43% FULL TIME 12% PART TIME 22% RETIRED
MEAN TIME SINCE DIAGNOSIS	5.2 YEARS

The Cancer Experience Registry opened its sub-registry for Chronic Myeloid Leukemia (CML) in October 2013. This year’s report is based on responses from 345 participants.

The world of CML divides into two distinct eras: pre and post 2001, the year the first oral therapy was approved. The drug, one of the first early success stories in the search for targeted therapies, turned chronic phase CML into a manageable chronic condition for most patients. Today, there are three drugs approved for newly diagnosed CML patients and two others for second line treatment. The patient experience with these therapies has raised complex and unprecedented questions about what it means to take cancer drugs indefinitely.

## PHYSICAL AND PSYCHOSOCIAL DISTRESS

A high percentage of CML survey respondents report physical and emotional distress.

- Fatigue is one of the most commonly reported problems, followed by muscle aches and cramps and sleep disturbances
- Skin problems are experienced by more than one-third
- Over 40% of patients also report “loss of concentration or memory”
- Close to 40% report problems with sexual or intimate relations
- Over 30% report anxiety, sadness or depression

Using the CancerSupportSource (CSS; Miller et al., 2014; Buzaglo et al., 2013) depression subscale, 51% of these patients are at risk for depression. Consistent with other sub-registries, only 41% say that their treatment teams asked them about experiencing distress. The percentage is significantly higher, 51% for those treated in comprehensive or academic cancer centers than for those treated in community settings, 35%.

TOP RATED SIDE EFFECTS OR SYMPTOMS	MEAN*	≥ 2 (SOMEWHAT, QUITE A BIT, OR VERY MUCH)
FATIGUE	2.2	70%
MUSCLE ACHES OR CRAMPS	1.9	59%
SLEEP DISTURBANCE	1.5	47%
LOSS OF CONCENTRATION OR MEMORY	1.5	43%
PROBLEMS WITH SEXUAL OR INTIMATE RELATIONS	1.2	38%
BONE PAIN	1.2	37%
ANXIETY	1.1	35%
RASH OR OTHER SKIN ISSUES	1.2	34%
SADNESS OR DEPRESSION	1.1	34%

\*ON A 0-4 SCALE, WITH 0="NOT AT ALL" AND 4="VERY MUCH"

The finding that most surprised many of the CML Advisory Council members was the high percentage (32%) of people who said they had trouble “thinking clearly.”

“The data shows this is a real issue—and representative of several lesser-known realities of living with CML,” Karten says, “which speaks to the importance of amplifying the patient voice.”

The CML sub-registry data also reveals that these patients face challenges in understanding how to evaluate their side effects when they do occur. While close to three quarters of respondents say their health care teams told them what side effects to expect, only about 40% know which ones to report to their doctors or how to manage them.



“People who are getting chemotherapy usually go to the doctor or cancer center on a regular basis and are asked by the health care team how they are feeling and whether they have any problems,” says Kay Johnson, a patient advocate on the CML Advisory Council. “That doesn’t happen if you are taking a pill once a day. You are more likely to have infrequent, brief visits to the doctor. You might not tell them what is happening—or they don’t ask.”

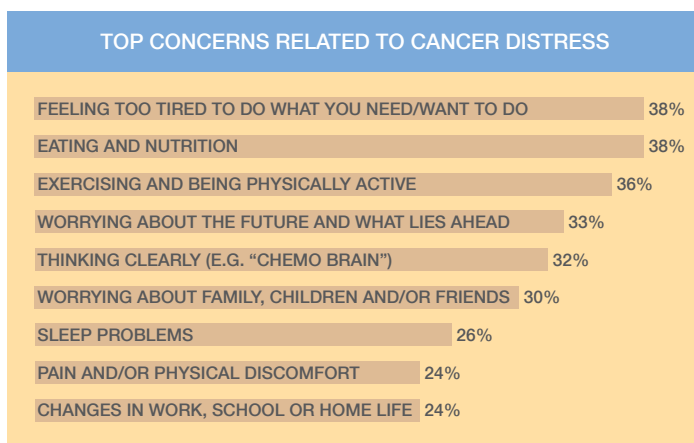
### ANSWERING KEY QUESTIONS ABOUT ADHERENCE

The long-term survival of CML patients on targeted therapies brings to bear another set of novel, complicated questions for both patients and their providers related to compliance with therapy.

“If you look at different patient populations,” says Joseph Greer, PhD, a Massachusetts General Hospital researcher, “you will find very different attitudes to taking their drugs. People with Metastatic Lung or Breast Cancer understand their prognosis and are very aware that their medications are keeping them alive. But CML patients, especially those who have been doing well for years, begin to question that. They are much more likely to become less adherent to their drug regimens.”

Kay Johnson agrees. “CML patients hear about clinical trials in which people are being taken off their medications—and then decide on their own to stop taking it—maybe for a vacation or special event, because of the expense of the drug or side effects. I’m afraid they don’t always understand the potential consequences.”

“We don’t know whether the people who stop their medications are cured or not,” says Greer. Some patients have relapsed after a year of being okay off meds—others appear to be cured. Any CML patient who chooses to stop treatment needs to have a discussion with the oncologist—and be very closely monitored. Doctors also have to ask their patients directly whether they are taking their medications and not just rely on lab reports.”



PERCENTAGE OF CML PARTICIPANTS “SERIOUSLY” OR “VERY SERIOUSLY” CONCERNED  
CancerSupportSource<sup>SM</sup>

Of CML Registry participants, 23% disagree or strongly disagree that they need to take every dose of their CML medication or it might not work. Thirty-three percent agree or strongly agree it is okay to miss a dose every now and then. Participants are significantly more likely to report missing a dose of their CML medication at least once per month if they agree that it is okay to miss a dose every now and then. Those participants who strongly agreed to the statement, “It is okay to miss a dose every now and then,” are 50 times more likely to miss a dose every now and then compared to those who strongly disagreed with the statement.

Progress in CML therapy is a great success story in terms of survival outcomes and quality of life. Yet, the data from the CML Registry and other sources tells us that the story is not over. More research is needed to continue to improve therapy and to bridge the current gaps in understanding and managing CML.

### KEY ISSUES FOR CML

**DIAGNOSIS**—Many people diagnosed with chronic phase CML do not have symptoms and the diagnosis is often made in the course of a routine physical examination or a check-up for another condition.

**ACCESS TO TREATMENT**—CML should be treated by hematologists/oncologists with specific experience and expertise in both treating the disease and managing its side effects.

**ADHERENCE**—Taking daily medication comes with challenges. The hope is that increased communication among all stakeholders in the CML community can help people taking CML oral therapy to better cope with these challenges. For example, since many patients take medication for years, and do not get their medication in clinical settings, how can their side effects be assessed and managed more effectively?

**LIFE-LONG THERAPY**—Today people living with CML must continue to take daily medication indefinitely. There are clinical trials to understand if patients, or a subset of patients can achieve treatment-free remission; research for a cure also continues.

**ORAL DRUG PARITY**—Although 33 states and the District of Columbia have now enacted oral chemotherapy parity laws, with six new laws passed to date in 2014, to achieve equal insurance coverage regardless of method of chemotherapy administration, more work is needed.

VOICES FROM THE  
REGISTRY

*“Find something to laugh about every day.”*

*“Ask questions. Don’t be afraid to speak up. You have to learn to be your own best advocate.”*

*“I would make sure every patient had some sort of aftercare—that they were given resources on support groups in their area, the “real” long-term side effects of chemo, and most importantly, how to mentally handle being a survivor.”*

*“Over and over, I hear from single patients that their mail (and bills) are overwhelming. ‘I can work and take treatment and get a meal on the table, but I am too tired to manage my mail and finances.’ ”*

**Kelly D.**  
**Diagnosed with Triple Negative Breast Cancer 2011**

“I didn’t get involved with cancer—it got involved with me. I was living my life.

The diagnosis almost took me down.

I almost went over the deep end. The emotional support I got from the Cancer Support Community allowed me to draw positive energy from people who were going through what I was going through, and am still going through. It became a safe haven for me, a place filled with kindred spirits. I can’t see how I could help someone else if I couldn’t find the strength to help myself.”



Maria B.

Diagnosed with Lung Cancer, 2010

“The diagnosis was devastating.  
I asked how long people with my disease  
lived and the answer was about a year—  
but I’m still here. There are times when  
I feel down, or afraid, but I would tell anyone  
facing this disease, that no matter what  
the difficulty, they should try to stay positive.  
Learn to relax, even in the trying times.  
Whatever you enjoy doing, do it, and  
if there are people in your life who are  
negative, you need to let go of them.  
I find when my essence is peaceful,  
everything goes better.”



# Metastatic Breast Cancer / Living with Uncertainty

“I know some people don’t like the metaphor, but having Metastatic Breast Cancer is like being in a war zone you can never leave. You never know when your disease will progress, or whether there will be a treatment for it.” – Shirley Mertz, Patient Advocate

People with Metastatic Breast Cancer (MBC) share one thing in common, they have a disease that cannot be cured. However, more treatment options, targeted therapies for many types of breast cancer, better understanding of the biology and genetics of these diseases have all contributed to improved survival, which for some people means living for many years with the disease. The Cancer Experience Registry explored the issues that these patients, the overwhelming majority of them women, face in dealing with Metastatic Breast Cancer.

MBC PARTICIPANT CHARACTERISTICS	
MEDIAN AGE IN YEARS	56 YEARS (RANGE 24-92)
GENDER	99% FEMALE 1% MALE
RACE	93% CAUCASIAN 2% BLACK OR AFRICAN-AMERICAN
EDUCATION	61% COLLEGE DEGREE OR HIGHER
EMPLOYMENT STATUS	31% FULL TIME 10% PART TIME 22% RETIRED
MEAN TIME SINCE DIAGNOSIS	3.7 YEARS

## TOP CONCERNS RELATED TO CANCER DISTRESS

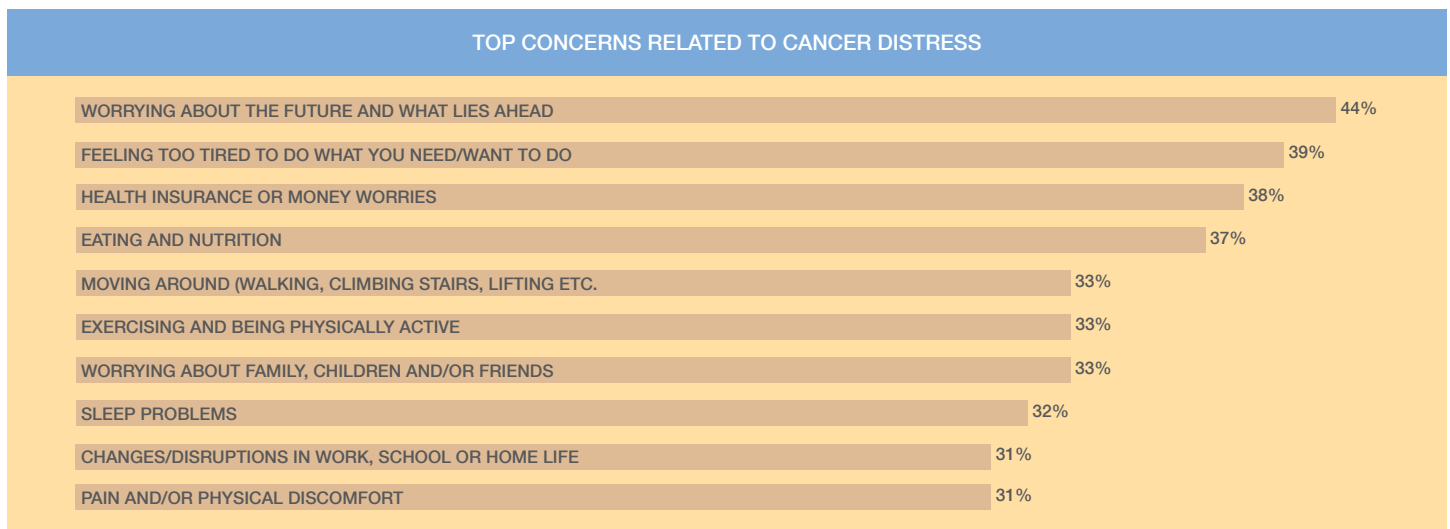
Not surprisingly, the concern most frequently cited was “worried about the future” (44%), with “worried about family” (33%) also identified as a major issue.

“There is no doubt why this anxiety is so high,” says Shirley Mertz. “You have to think about the roles these women serve in a larger society. They are the mothers, wives, partners. They are caring for aging parents or small children.”

Findings also reveal deep concerns about recurring fatigue, feeling too tired to do the things they care about, being able to move and exercising, all reported by more than 30% of respondents. Issues related to nutrition and sleep problems also were prevalent with more than 30% of the survey participants.

The cost of care and the impact of ongoing treatment on work status are major issues for people with Metastatic Breast Cancer. Nearly half reported losing their jobs as a result of their breast cancer (45%), and 46% stated they had experienced a decline in their ability to work as a result of their MBC and its treatment.

“Breast cancer hits so many women at a vulnerable age,” says Patricia Robinson, MD, a member of the MBC Advisory Council. “For some, they are at the peak of their careers. Others are young, just starting out and trying to prove themselves. They not only have to deal with their disease, but also with employers who are asking, ‘Can you handle the job? Will you even be here?’”



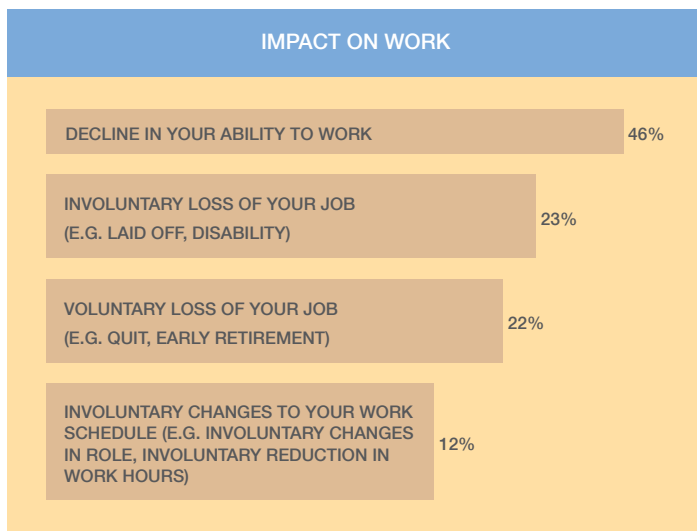
In addition to the impact on the work environment, the cost of treatment, both direct and indirect, takes its toll. These costs range from choosing a less effective treatment based on the price of the drug to depleted savings, downsized living quarters, or even foreclosures, and foregoing vacations or other personal activities. Furthermore, 34% reported delaying seeking psychological counseling or support and 31% reported delaying follow-up on recommendations for complementary treatment such as physical therapy, occupational therapy, or psychological support.

In a world in which treatment doesn't end, patients also have to make choices about the types and levels of side effects they are willing to tolerate.

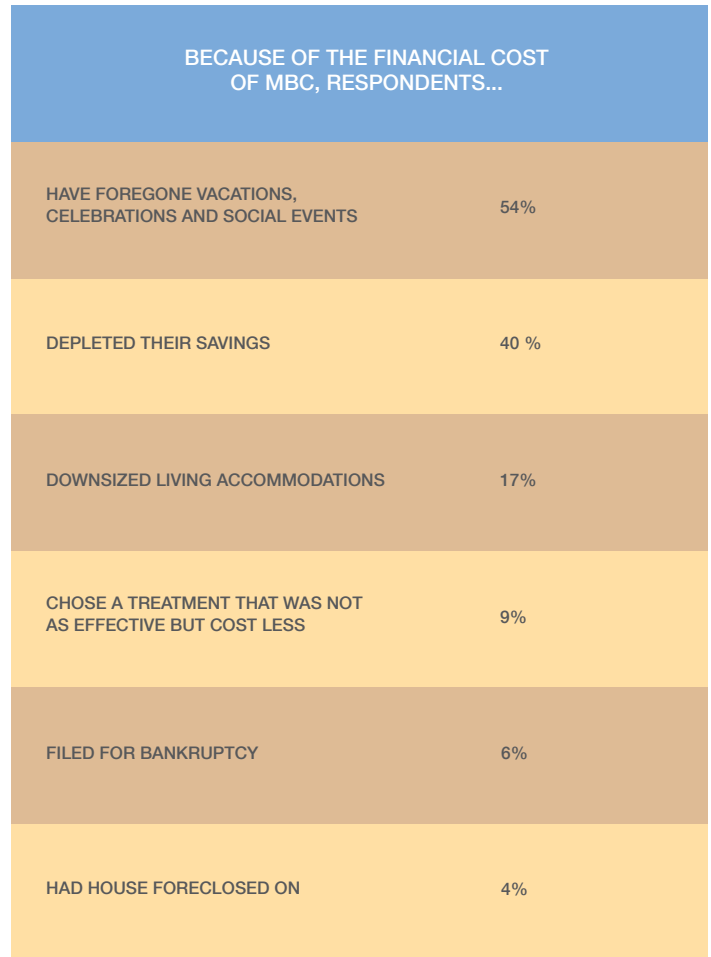
"In the metastatic setting, quality of life is really important," says Dr. Robinson. "Fatigue and low energy can be serious problems, and we don't have great strategies for dealing with them. I also have patients who choose drugs that do not cause hair loss. They say to me, 'If I only have a few years to live, I want to look good during that time.' As doctors, we are trained to use the therapies that work, but we need to take the time to ask our patients what matters to them."

Mertz agrees. "Clinicians can't just attend to the treatment side. They need to deal with the whole person, not divorce the emotional or quality of life issues from the next treatment."

Dr. Robinson views the Cancer Experience Registry as one critical tool in achieving that goal. "The Registry provides an excellent quantitative base that helps move from the anecdotal to evidence based. That is essential in having the patient voice heard."



PERCENTAGE OF MBC PARTICIPANTS WHO RESPONDED "YES"



PERCENTAGE OF PARTICIPANTS WHO RESPONDED "YES"

## KEY ISSUES FOR METASTATIC BREAST CANCER

**AWARENESS**—The focus has been so strongly on early breast cancer and its treatment that MBC is often not well understood.

**LOOKING GOOD ON THE OUTSIDE WHILE DEALING WITH A SERIOUS ILLNESS**—Many people with MBC "look fine," but experience a full range of disease and treatment-related issues.

**FINANCIAL COSTS/WORK ISSUES**—The ongoing and uncertain nature of MBC has a heavy impact on a wide spectrum of financial and work-related areas.

**MANAGING SIDE EFFECTS**—It is critical to balance treatment efficacy with quality of life issues.

## Multiple Myeloma / New Hope, New Challenges

“Many people have never heard of Multiple Myeloma until they are told they have it. It’s a real challenge to change both the awareness and perception of this disease. We have an important story to tell. This is no longer a hopeless condition.”

— Craig Cole, MD, University of Michigan

In recent years, new understanding about Multiple Myeloma (MM) has opened the doors to a number of new treatment options—treatments that are matched to both the type and stage of the disease, and to the lives of the people who have it.

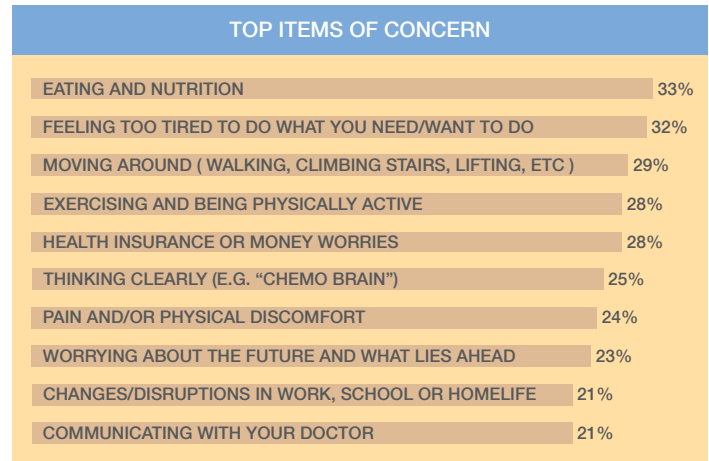
Craig Cole, MD, a member of the Multiple Myeloma Advisory Council, believes that more options and better outcomes increase the importance of patients being informed, active participants in the process. “The Myeloma world has become very complex. We see more distress when patients are not able to engage in conversations about their disease and physicians are not able to educate them. That leads to fear and lack of empowerment which contributes greatly to anxiety.”

Leo Dierckman, the patient advisor to the Council, agrees. “Having Multiple Myeloma really demands that you become more assertive about your own health care, ask assertive questions, challenge your doctors.”

The Multiple Myeloma sub-registry, begun in 2013, provides people with this disease with a forum for identifying and discussing the issues that affect their treatment decision making and their lives.

The Cancer Experience Registry opened its sub-registry for Multiple Myeloma in July 2013 with a total of 544 enrollees as of September 2014. This year’s report analysis is based on 365 U.S. respondents.

MM PARTICIPANT CHARACTERISTICS	
MEDIAN AGE	64 YEARS (RANGE 32-88)
GENDER	54% FEMALE 46% MALE
RACE	87% CAUCASIAN 10% BLACK OR AFRICAN-AMERICAN
EDUCATION	56% COLLEGE DEGREE OR HIGHER
EMPLOYMENT STATUS	20% FULL TIME 7% PART TIME 42% RETIRED
MEAN TIME SINCE DIAGNOSIS	5.3 YEARS



PERCENTAGE OF MM PARTICIPANTS “SERIOUSLY” OR “VERY SERIOUSLY” CONCERNED  
CancerSupportSource<sup>SM</sup>

### KEY FINDINGS

Findings indicate that for many people, issues related to fatigue, energy levels and the ability to move and exercise rank very high. Concerns over health insurance and money worries follow closely behind with worries about the future.

In terms of specific side effects and symptoms, the most commonly reported problems were peripheral neuropathy (55%), fatigue (51%), sleep disturbances (33%) and pain (32%). GI disturbances, mood swings and infections were also noted. Of all the reported problems, fatigue was cited most often as interfering with daily activities (40%).

Most people with Multiple Myeloma receive steroids as part of their treatment regimen at some point. These agents produce a range of side effects. In the survey, the most commonly reported issues were sleep disturbances (58%), weight gain (46%), mood swings (41%) and edema (swelling in the limbs) (39%). Despite the high prevalence of these side effects, 36% said they rarely or only sometimes report these issues to their health care teams, with the primary reason being they “don’t think anything can be done about them.”

A relatively high percentage of the sub-registry respondents say that their health care teams prepared them for possible side effects and symptoms (62%), and even higher number (80%) feel that



IN THE PAST SEVEN DAYS, HOW MUCH HAVE THE FOLLOWING SYMPTOMS AFFECTED YOU?			
	OFTEN OR ALWAYS	INTERFERE WITH DAILY LIFE	INTERFERE WITH DAILY ACTIVITIES
PERIPHERAL NEUROPATHY	55%	22%	16%
FATIGUE	51%	40%	24%
SLEEP DISTURBANCE	33%	21%	95%
PAIN	32%	22%	16%
GI TOXICITY	26%	16%	8%
MOOD SWINGS	13%	10%	3%
INFECTION	6%	5%	4%

PERCENTAGE OF MM PARTICIPANTS WHO RESPONDED “YES”

their health care teams understand the side effects and symptoms of Multiple Myeloma treatment. And yet only half (51%) feel that their family members understand their side effects and symptoms.

Dr. Cole believes it is important that patients understand that treatments can often be aligned with a patient’s goals. “We have choices and we can often wrap our treatment around a person’s life and lifestyle.”

The PROMIS Profile 29-item short form (v 2.0) was used to measure physical, mental and social health. There are seven domains that include: physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with participation in social roles and pain interference. Compared to the U.S. general population, PROMIS scores were significantly different for MM survivors in the following domains: physical function, fatigue, sleep disturbance and satisfaction with social roles; they did not differ in levels of anxiety, depression and pain interference. Half (49.6%) of MM survivors felt they had ‘no control at all over the course of their MM (that is, whether their MM will come back, get worse, or they will develop a different type of cancer). Those who reported no perceived control had significantly higher levels of anxiety, depression and fatigue and lower levels of physical function and satisfaction with participation in social roles.

According to the CancerSupportSource<sup>SM</sup> depression subscale (Miller et al., 2014), 41% of this group are at risk for depression. A total of 56% say that they were asked by their health care team about experiencing distress. As with other subsets, that number is significantly higher for those patients treated in academic centers than in community settings, 64% to 48%.

## MINORITY REPRESENTATION

Multiple Myeloma strikes African-Americans at a rate twice as high as in any other ethnic or racial group in the United States, but only 9% of the survey participants are black.

“We need to work harder to engage African-Americans in registries, online communities, support groups or clinical trials,” says Dr. Cole. “In terms of Myeloma, there’s an overall lack of awareness about the disease. It is still something of a mystery and that is a challenge for us.

“The great thing about the Cancer Experience Registry is that it really gives substance to the patient voice. For decades, we as providers have thought we knew what our patients were thinking, but the Registry has turned that around. We are learning things that we never anticipated. That gives our patients more power and our health care providers better tools.”

## KEY ISSUES FOR MULTIPLE MYELOMA

**PROMPT DIAGNOSIS**—Many people are diagnosed only after they break a bone or are suffering from serious back pain.

**ACCURATE STAGING**—Myeloma can occur in different forms and at different stages—from very slowly progressing to more aggressive forms of the disease. Accurately characterizing and staging is critical to making treatment decisions.

**EDUCATION AND AWARENESS**—Myeloma is not well known, especially among minority communities.

**ACCESS TO TREATMENT**—With the availability of new treatment options and better outcomes, it is critical that all patients have access to state-of-the-art treatment.

**OVERCOMING THE AGE BIAS**—In the past, older patients were often under-treated. New options make it more possible to provide optimal treatment to all age groups.

**SIDE EFFECT AND SYMPTOM MANAGEMENT**—Both the symptoms of Myeloma and the side effects of treatment can be complex and challenging. Patients need to work closely with their health care teams to monitor and manage these conditions.

VOICES FROM THE  
REGISTRY

*"I would like a more holistic approach for the next patient, including nutrition and exercise, spirituality, and mental health support and education."*

*"It is not the end, it is the beginning of a new you, your new normal will open many new doors."*

*"Better communication between the oncologist and the patient. I was only told what kind of treatment I would be receiving. I was never told if there were different treatment options, I still do not know if the reason I was not given an option was because none exists or if the doctor decided that was my best option."*

**Barbara B.**  
**Diagnosed with Breast Cancer 2012**

"I meet so many women with breast cancer who end up going through the experience by themselves. I ask them why they want to do that and they say they don't want to be a burden to anyone else. I had a great support team in my family and it made a big difference. The first time I went for chemo, I was kind of sick because of my nerves, but they were all there with me. You would have thought we were having a party. I would also tell people going through this to take someone with you to your appointments because that person is going to hear things that you don't."





Lloyd K.  
Diagnosed with Lung Cancer 2012

“Before my diagnosis, I didn’t know anything about cancer. Now, I have met so many people with so many different kinds of cancer experiences—and I really go back to the idea that no one should ever have to go through cancer alone. I have gained so much from the Cancer Support Community’s mindfulness program. It’s something that will be with me all my life. I don’t understand why more men don’t get involved in support programs. Maybe it’s just the nature of the beast, but you end up getting support in areas you might not even be aware exist.”

**Ruth A., Caregiver;  
Partner: Ken, Diagnosed with  
Ocular Melanoma 2011 and Bladder Cancer 2014**

“I think the most important thing to know about emotional support is that you have to ask for it. Ken has been treated for two different cancers in two different hospitals and no one ever asked him about distress or offered a referral for emotional support. I think that doctors don’t always know how to provide that support in the medical context, but they do know where to find those resources.”







**Linda C.**  
**Diagnosed with Breast Cancer 1994**

“Right after I got my diagnosis, I didn’t tell anyone for a long time. I was going through a tough divorce and I just didn’t want to go public with it. Then, I realized that keeping quiet wasn’t helping anyone including myself. My true healing started happening when I started helping other people. I got involved with the Cancer Support Community and the Linda Creed Foundation. I’ve been on a dragon boat team of breast cancer survivors. I have met so many courageous women. The more I do, the better I feel. I think that today you really do have to be your own advocate, have your plan of attack. There’s no such thing as too much information.”

*VOICES FROM THE  
REGISTRY*

*“Look for a social worker, psychologist, or someone like that to involve your loved ones, for both you and for them. Be prepared to ask questions, and bring someone with you who will ask questions. Record each appointment, because you will be in a fog.”*

*“Communicate back to your medical team about everything you are feeling in regards to your treatments. They can adjust your treatment to help with any side effects that you may experience.”*

*“When chemo ends, the hard works begins. Integrating back to ‘normalcy’ without the safety net of chemo can be very hard and overwhelming.”*

## The Growing Reality of Long-Term Side Effects

“MBC patients are dealing with a treatment that never ends. We really need to identify the concerns and needs of this group that are not being met in the clinic—give them a voice. Health care teams don’t always ask about distress. They focus on whether the treatment is working, not on whether you are sleeping, how you are feeling, can you do the things you enjoy. If they don’t have the time or resources, they need to refer patients to other resources. People with Metastatic Breast Cancer never have time to recoup from treatment. They never have the opportunity to let their whole body try to get back to normal.”

— Shirley Mertz, Diagnosed with Metastatic Breast Cancer in 2003

In a very real way, the issues associated with long-term side effects of cancer and treatments are part of a major success story. They reflect the growing number of people, an estimated 13 million in this country alone, who are either cured of their cancers or live with their disease for extended periods of time. Today, 79% of childhood cancer patients and 64% of adults with cancer will survive for at least five years. New agents, targeted therapies, better use of existing drugs, more precise approaches to radiation and surgery, and novel therapies such as immunotherapy are all contributing to longer survival while placing increased emphasis on the patient experience and quality of life.

The reality of long-term side effects is not new. For decades, patients and doctors have known that even successful cancer treatment can take its toll. At least 50% of cancer survivors experience treatment-related side effects, including physical, psychosocial, cognitive and sexual problems. Many of these last for months or years, and some are life threatening. They encompass a wide range of issues, including depression and anxiety, weight gain and severe cardiac toxicity. An estimated 16% of all primary cancers occur in people who have already been treated for one cancer.<sup>(1)</sup>

“The strongest support for people facing cancer is usually during the period of diagnosis and active treatment,” says Patricia Robinson, MD, of Loyola University. “After that, people do not get the same level of concentrated attention. They may experience a wide range of long-term side effects, or be dealing with other conditions or health issues. So often, they end up asking ‘where do I go from here, or who do I call about these problems?’ ”

The Cancer Experience Registry (CER) data demonstrates growing importance of recognizing and dealing with long-term side effects. Respondents report high levels of problems with sleep, nutrition, energy levels, fatigue and inability to exercise or perform their normal activities.

Two groups of patients represented in the CER sub-registries illustrate the specific issues that have emerged for people with cancer whose disease requires them to undergo treatment for as long they live. For many subsets of Metastatic Breast Cancer patients, the prognosis has improved significantly over the past decade. Those patients whose tumors are hormone dependent or who respond to targeted therapies often live for many years. For some, this amounts to having a chronic condition. Metastatic Breast Cancer patients, however, live with high levels of uncertainty about how long their treatments will work, and what will happen when they stop being effective. They must also contend with an array of life-altering side effects, and make treatment decisions that balance effectiveness with these side effects.

“In the metastatic setting,” Dr. Robinson says, “quality of life is really important. As doctors, we are trained to find therapies that work with acceptable toxicity. As we deal with more patients who have chronic disease, we have to take the time and room to ask them about the issues that are affecting how they live, what is important to them, their goals.”

Dr. Robinson notes that she frequently hears from her patients that they have problems with concentrating, “chemo fog or chemo brain,” as it is sometimes called. “I don’t see anything in the literature that says this should be an ongoing problem for

my patients, but this is what they are telling me. We need to know more about this phenomenon and the multiple variables that influence it—sleep issues, anxiety, fatigue, problems with relationships. We have heard those voices and we are starting a cognitive deficit clinic to address this issue for our patients.”

People with Chronic Myeloid Leukemia (CML) also face years of ongoing treatment. Targeted therapies have turned CML into a truly chronic condition—but have also raised questions related to adhering to treatments.

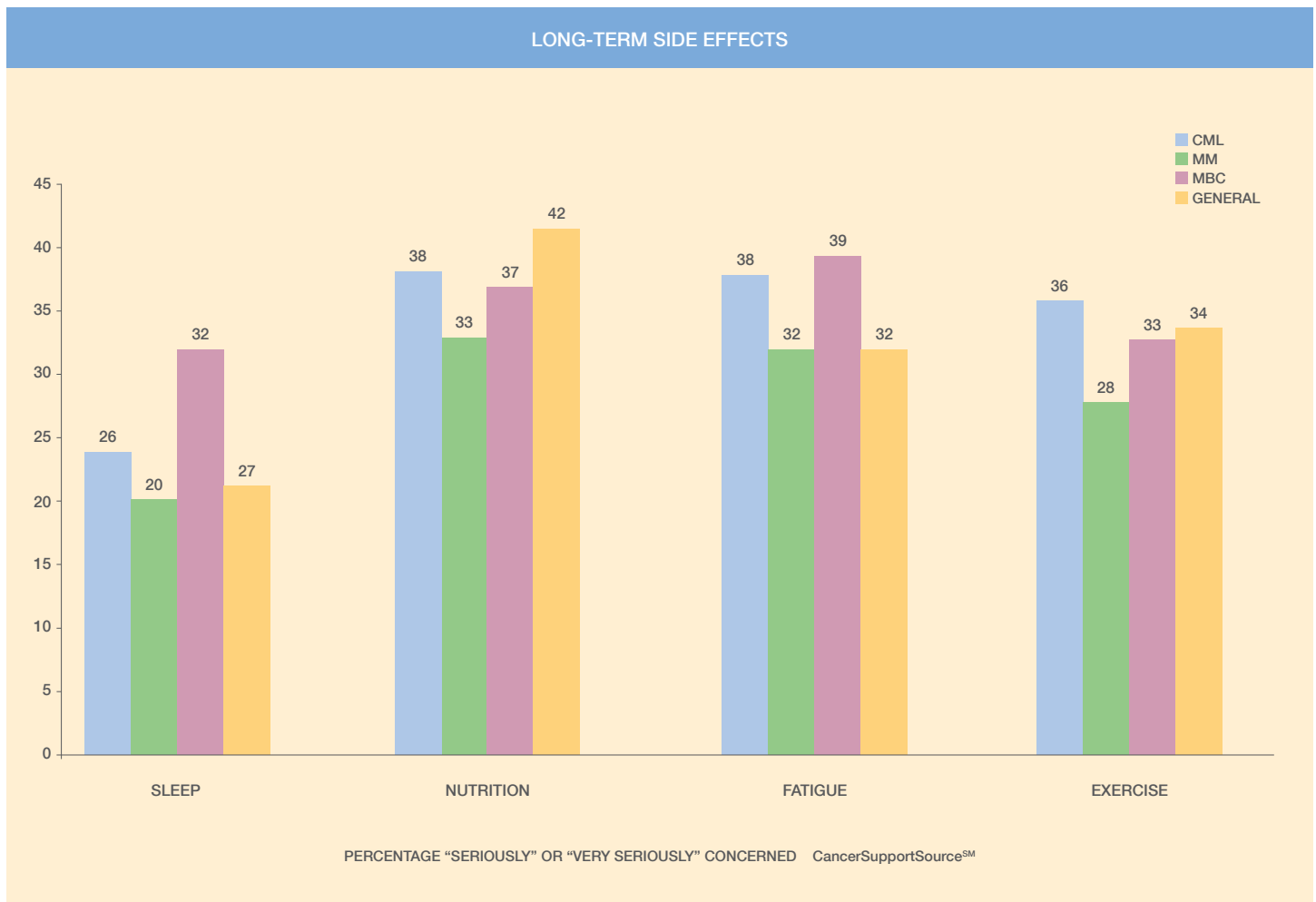
“People with CML often don’t feel sick because of their disease,” says Joseph Greer, PhD, of Massachusetts General Hospital, “but they do have side effects—fatigue, pain, gastrointestinal problems and rashes. After a while, they start to say, ‘If I’m okay, why do I have to keep taking these drugs that are causing problems?’”

According to both patient reports and studies such as those conducted by Greer, it is not uncommon for people with CML to take drug holidays or to stop taking their medicines

altogether. The reasons for making this decision range from avoiding side effects for a specific event, for example a vacation or wedding, to wanting to become pregnant and to questioning the need for continued therapy. A number of clinical trials are also underway to determine which CML patients can safely stop treatment.

“Many CML patients are really not clear about their treatment plan,” says Greer. “They don’t get their treatment in the clinic, so they are not always asked about their side effects or the problems they are encountering. We need to develop a system of communication that delivers feedback to the treatment team and triage a lot of issues. These patients should not feel abandoned. They need to be heard.”

1. All statistics from: Cancer Survivors in the United States: A Review of the Literature and a Call to Action, Valdivieso, M, Kujawa, AM, Jones T, Baker LH, International Journal of Medical Sciences, 2012; 9(2): 163-173; [www.medsci.org/v09p0163.htm](http://www.medsci.org/v09p0163.htm)



## VOICES FROM THE REGISTRY

*"It's possible to manage the anxiety, medical treatments and sense of loss of control. Many patients get through it and survive to return to a new normal."*

*"Now that I am in remission how do I plan for a future when I have terminal cancer and know that it can return at any time?"*

*"Find a safe person or group that you don't have to be 'strong' in front of. Take advantage of support groups so you don't feel so alone. Deal with depression and anxiety before AND after treatment, preferably through a professional or other objective party."*

## **Gloria P.** **Diagnosed with Uterine Cancer 2013** **Recurred 2014**

"I was told that my cancer has an 80% chance of returning—and I decided that I need to live in the 20%. You live your life through advocating positively for yourself and others. The more I become involved with the cancer community, the more inspired I am to do more. I am choosing not to work right now, and to spend more time volunteering. It is so important to balance the medical needs with the emotional ones and to exude compassion and care for people."



**Lori B.**  
**Diagnosed with Neuroendocrine Tumor 2012**

“People tend to get very philosophical about having cancer—look for the deeper meaning. I would tell anyone to take a deep breath, if you have to cry, then cry, and then put your thinking cap on and get to work. The sooner you confront it, the sooner you can get back to life. The Cancer Experience Registry provides the opportunity to connect with people who are going through what you are. You can read something and say, ‘I’m not crazy,’ or ‘They’re scared too.’ It humanizes the disease, gives you insight.”



# The Ongoing Need for Emotional Support

In 2008, Barbara Andersen, PhD, of Ohio State University, published her seminal study demonstrating that breast cancer patients who received a social and emotional support intervention had lower rates of recurrence and longer life expectancy than those who do not. Andersen’s study provided evidence for what every person facing cancer knows. Having cancer is not just a physical experience—it is one that affects, and often transforms, a person’s entire life.

Data from the Cancer Experience Registry reinforces the critical importance of making emotional and psychosocial support an integral component of treatment, rather than an adjunct to it, or an area that is disregarded entirely. The analysis shows that patients report high levels of anxiety related to worrying about the future, finances and the family. Approximately 55% of patients being treated in community settings say they have never been asked about distress. That number is lower for those treated in academic centers, about 42%, but still represents a substantial number of people whose emotional needs are never assessed, or met.

“Doctors often do not ask patients about distress,” says Shirley Mertz, an 11-year survivor of Metastatic Breast Cancer (MBC). For women with MBC, anxiety about the future is a huge issue. Doctors in both small practices and large centers need to read these results and understand that quality of life is crucial to long-term survival. They need to take the time to ask people, ‘are you sleeping, do you do the things you enjoy?’ ”

Oncologist Craig Cole, MD, of the University of Michigan, specializes in blood cancers and Multiple Myeloma, and also does research on patient distress in hematological cancers. He sees the increasing complexity of cancer treatment as contributing to the problem of patient distress—even as advances in treatment have helped lengthen people’s lives.

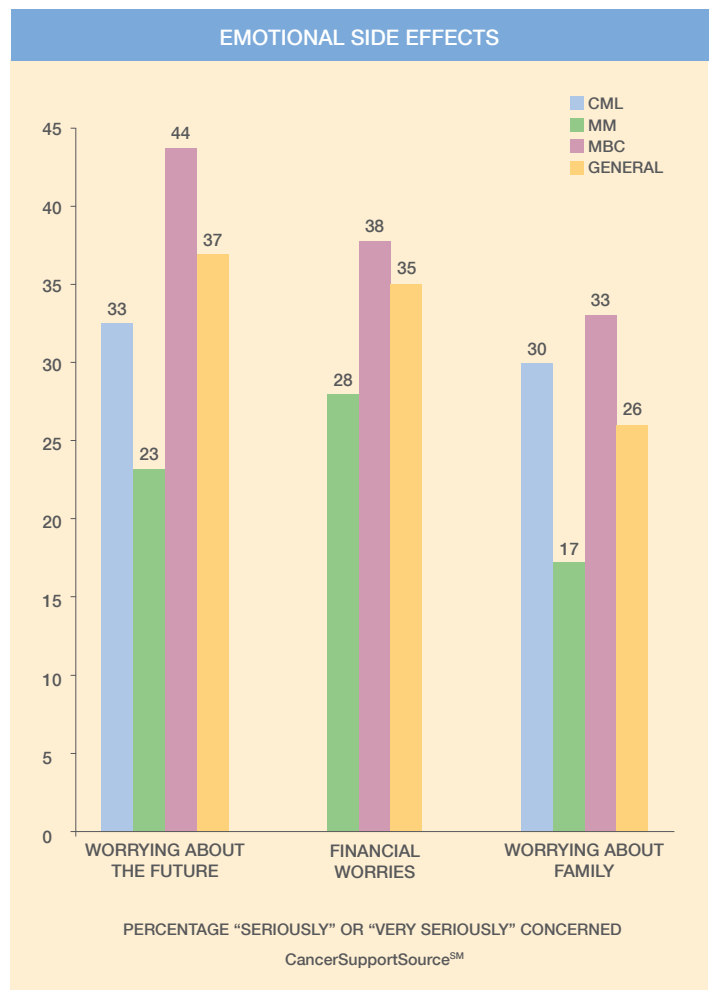
“For many people,” he says, “more options can equal more distress. If you look at myeloma, for example, there used to be two regimens and the choice was to treat or not treat. Today, we are asking people to make choices about very complex options—choices that directly affect their lives in so many ways. We need to make sure that we are able to provide people with both the education to make these decisions and the counseling and support to help them get through the treatment process.”

Aziza Shad, MD, who co-directs the pediatric oncology program at MedStar Georgetown University Hospital, says, “You cannot treat a child successfully, unless you take care of

the whole person, and the family. It’s not just about medical care. We have to focus on emotional and psychosocial care as part of the total treatment program. We do our jobs as doctors better when we provide treatment in the context of a program that is centered on addressing these issues.”

Dr. Shad’s program assigns a dedicated team that includes a social worker, art therapist, child life specialist and nutritionist for each child. She notes that despite this intensive approach, she still sees patients who suffer from post-traumatic stress disorder, especially among those diagnosed in adolescence or early adulthood.

Regardless of the time of life when an individual faces cancer, the diagnosis, treatment and long-term challenges of living with the disease impact every aspect of that person’s emotional life. In both their personal statements and their collective voices as demonstrated through the Cancer Experience Registry, people with cancer have made it clear that these issues not only continue to be important, but are becoming increasingly so as cancer treatment evolves and advances.





## The Cost of Cancer Care

“Life in general has not gotten easier for cancer patients in the workforce. If your boss has had a personal experience with cancer, he or she is much more likely to be supportive, but other factors such as age and gender don’t seem to make much difference.”

— Hester Hill Schnipper, LICSW, BCD, OSW-C, Beth Israel Deaconess Medical Center

The cost of cancer care is not a simple issue. There are many ways to measure costs and all of them apply to people facing cancer. The costs can be directly related to the delivery of care itself—the actual price of the drugs, the co-pays and deductibles for treatment that mount up even for people with good insurance plans—the crushing avalanche of bills for those who do not. There are indirect costs involved in getting to treatment, gas and parking fees, finding child care, lost time at work and jobs lost entirely. The financial impact of a cancer diagnosis and treatment is something that few people can anticipate, a factor that can add significantly to the anxiety and stress of managing the disease.

“I talk to people all the time who tell me that they cannot afford their medication,” says Kay Johnson, a CML patient and advocate. “They are taking the pills every other day or missing a month—and the reasons are completely financial. It’s heartbreaking.”

The Cancer Experience Registry data demonstrates how deep and broad financial issues are for people facing cancer. Respondents report that the impact ranges from having to delay a vacation or special event to having their homes foreclosed. Nine percent also say they have made a treatment decision based on the cost of the drug, opting for a less expensive and potentially less effective therapy.

“Drug costs are becoming an increasing concern for patients,” says Kim Thiboldeaux, President and CEO of the Cancer Support Community. “The new targeted agents tend to be very expensive. The changes in the health care delivery system are also putting more pressure on patients to make choices based on costs.”

One area in which the cost of cancer care is felt deeply is on a patient’s work life. Regardless of age or job status, cancer treatment often leads to interrupted careers, missed opportunities, reduced income, lost insurance coverage or losing or having to leave a job. This impact results both from the actual physical and emotional challenges of dealing with cancer, and from the ways in which people are perceived in the workplace.

“The diagnosis hit me like a brick wall,” says Leo Dierckman, a four-year survivor of Myeloma. “These are real-life concerns. Who is going to support my family if I am too sick to work, or not here? For me, as a man, one source of calm is to know that I can be a good provider and when you’re told you have cancer, all your plans are blown away.”

Dierckman’s smoldering Myeloma has not yet required treatment, but many people with cancer are faced with the choice of trying to work through treatment, take time off or leave their jobs.

“There are so many factors that influence the work situation,” says Hester Hill Schnipper, LICSW, BCD, OSW-C. “Women in high paying, high pressure jobs may find themselves unable to keep pace for a period of months or even longer, while women in lower-paying jobs usually are not paid at all if they miss work, or lose their jobs if they take time off. The results can be devastating financially and emotionally.”

Financial resources can also influence the decisions that people with cancer make about their work and personal lives. Hill Schnipper notes, “In addition to all the other issues cancer patients confront, they often have to think about priorities. For some that means continuing to work, but others choose to move away from the workplace—if they have the financial ability to do so.”

“The diagnosis hit me like a brick wall. These are real-life concerns. Who is going to support my family if I am too sick to work, or not here? For me, as a man, one source of calm is to know that I can be a good provider and when you’re told you have cancer, all your plans are blown away.”

—Leo Dierckman, a four-year survivor of Myeloma

## Elevating the Patient Voice



The data that we gather and analyze through the Cancer Experience Registry makes it clear that people facing cancer are very aware of the need to become their own best advocates. We want our voices to be heard, not just by other patients, but also by our health care teams. The rise of the informed and engaged patient is a major driver for a significant change occurring in the health care system—the movement to a more patient-centered and patient-driven system of care. —Gwen Darien, Cancer Support Community

When we say that our goal is to elevate the patient voice, what does that actually mean? How do you turn what sounds like a noble and necessary goal into a reality? How does the model of patient-centered care translate into the reality of a revitalized approach that genuinely informs the future of cancer research and care? As advocates and survivors, we are often asked to provide input, data and advice, to sit on panels, fill out questionnaires, to evaluate clinical trials and to participate in studies—or sign up for registries, but how can we be sure that those voices are heard?

In today's world, it begins by recognizing the patient as an expert, and giving that unique, special expertise primacy in the decision-making process that impacts treatment and life. That in turn relies on seeing patients as fully embodied, multidimensional people with diverse values, experiences and desires, with lives that extend far beyond the clinic and their diagnosis.

It also means being able to hear—and measure—both the individual voice, and the collective one. Every patient has a story, and every story adds value to the whole. We need to engage patients in open, transparent discussions that allow them to express the issues that are important to them on a personal level. At the same time, we must also be aware of the greater community that exists, and the complex ways in which the individual experience builds on itself to impact and influence society. A fundamental value of the Cancer Experience Registry is to honor that individual experience while creating a community of understanding that extends to the entire health care delivery system.

In our first year of the Cancer Experience Registry, we have seen what a powerful driver these voices are for the medical community as well as to the patients themselves. One of the most striking aspects of the Registry data is the feedback that we receive from physicians and health care providers telling us how much they learn from the data that we report. When doctors hear the patient voice, it allows them to move beyond defining value only in terms of therapeutic efficacy, and deepen their understanding of how patients define value in their lives.

For many patients, regardless of diagnosis, that value is measured in a compelling variety of ways. They tell us about the concerns they have, the anxiety and ongoing physical and emotional issues they confront, but they also speak of the healing that they experience by advocating for others, of the ways in which they redefine their priorities in life, of how much they learn from other members of the cancer community, and how powerful it is to be empowered to speak up, to tell and share their stories.

The Cancer Experience Registry has taught us how much we still have to learn about the individual and the community. We can take what we learned, and what we haven't even discovered yet, and continue to grow, evolve and deepen our ability to hear—and to elevate the patient voice. That is our plan—and our vision for the future.

— GWEN DARIEN,  
EXECUTIVE VICE PRESIDENT, PROGRAMS AND SERVICES  
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## **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 more than 50 licensed affiliates, more than 100 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 helps CSC provide a seamless flow of program delivery 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 2013, CSC delivered nearly \$48 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. So that no one faces cancer alone®

## **ABOUT THE RESEARCH AND TRAINING INSTITUTE**

In 2008, the Cancer Support Community launched the Research and Training Institute – the first institute of its kind – dedicated to psychosocial, behavioral, and survivorship research and training in cancer. The Institute examines the critical role of social and emotional support for those living with cancer, and studies the distinctive needs of survivors and caregivers throughout each phase of the cancer experience and beyond. The Institute brings scientific rigor, evidence-based research, and established and novel educational and training methods together to evaluate, refine, and disseminate the programs, services and support that the Cancer Support Community provides to people affected by cancer.

For more information, please visit [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

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