PATIENT INSIGHTS

2020 CANCER EXPERIENCE REGISTRY REPORT

JUNE
2020

CANCER SUPPORT
COMMUNITY

GILDA'S CLUB
WORLDWIDE

TABLE OF CONTENTS

CANCER EXPERIENCE REGISTRY: KEY HIGHLIGHTS

SOLID TUMOR CANCERS

BLOOD CANCERS

A MESSAGE FROM KIM THIBOLDEAUX

It is an honor to share with you a report from our Research and Training Institute that illustrates the Cancer Support Community's commitment to **putting the voices of patients and caregivers at the center of the conversation about cancer**.

Since 2013, thousands of patients, caregivers, and survivors have generously given their time to share their experiences through our Cancer Experience Registry®. These individuals have provided valuable insights that have influenced health-related policy initiatives, informed health professionals of ways to improve communication with patients, and guided programs, such as nutrition and survivorship, to become even more effective and innovative.


Kim Thiboldeaux, Chief Executive Officer

As a result of what these patients and caregivers have told us, we are launching groundbreaking research on important topics, such as clinical trial participation and the cost of care. This unique research will uncover a deeper, more personal account of what challenges, choices, and changes face individuals dealing with a cancer diagnosis. What's more, this perspective underscores a core reality: behind every diagnosis is a real person, a family, and a team of caregivers invested in the best possible outcomes.

As you read through this report, please know that we are here to act and build on these latest findings. The results presented here were collected and analyzed before the COVID-19 pandemic occurred. In response to the unprecedented public-health crisis, we are capturing the patient and caregiver experience and will release those findings in subsequent reports. We welcome your ideas and collaboration to enact new programs and expand research that will further benefit the patient and caregiver as the health care environment evolves.

Our belief is that Community is Stronger than Cancer™. To our community, we extend our deepest gratitude – to our Registry participants who have taken the time to share your experiences and make critical contributions for better care and to our dedicated donors, advisory board members, and corporate and advocacy partners for your unwavering support. You have all made the Cancer Experience Registry and its contributions to cancer care possible.

All my best,

Kim Thiboldeaux
Chief Executive Officer

INTRODUCTION

Patient-centered care has been a major driver of change for cancer care in the 21st century.[1] Care that is truly patient-centered goes beyond monitoring clinical and biomedical factors around disease status; it also considers the concerns and needs of cancer patients, survivors, and their loved ones regarding their cancer experience. Insights gathered from the psychosocial experiences of individuals touched by cancer lead to superior care that enhances shared treatment decision-making, enables better access to required and desired services, improves quality of life, and may lengthen life.

Along with our broad community of stakeholders, the Cancer Support Community (CSC) harnesses and communicates these insights from patients and caregivers in order to advocate for key policy initiatives, develop educational programming and resources, and provide an integrative support system for **all** people impacted by cancer.

THE CANCER EXPERIENCE REGISTRY®

To help document and convey the totality of the patient experience, the Cancer Experience Registry (the Registry) was developed by CSC's Research and Training Institute. Since its launch in March 2013, the Registry has been recognized as a unique resource in the cancer community. It provides:

- A **vehicle for individuals and their loved ones** who have current or past experiences with cancer to share their voices about issues that matter to them and ensure that their experiences are communicated to the broader cancer community
- A **data source for research** that highlights the physical, emotional, social, practical, and functional aspects of the cancer experience from the patient and caregiver perspective
- An **opportunity for stakeholders** to identify and address unanswered questions and ultimately to contribute to data-driven solutions to improve care and quality of life

The Registry is comprised of:

- The **General Registry**, a core survey that all cancer patients are encouraged to complete and that addresses a wide range of issues that patients face, regardless of the nature of their diagnosis
- **Specialty Registries**, where, in addition to the core survey, individuals with select cancer types are asked additional questions tailored to address the unique issues of their disease experience
- A **separate survey for cancer caregivers** that examines the specific experiences of being a family or informal caregiver to someone living with cancer±

± A caregiver is anyone who provides physical, emotional, financial, spiritual, or logistical support to someone affected by cancer. Caregivers can include partners, spouses, adult children, siblings, and non-family members.

REGISTRY PARTICIPATION AND OVERSIGHT

For our General, Specialty, and Caregiver Registries, participation is voluntary. Our General Registry is open to anyone diagnosed with any cancer type at any point along the care continuum. Our Specialty Registries are open to anyone who self-identifies as a patient/survivor with the specific cancer type. And, our Caregiver Registry is open to anyone who self-identifies as a cancer caregiver. Participants must be 18 years of age or older at the time of enrollment and may register at cancerexperienceregistry.org to join the study and answer questions about their cancer experiences. The complete list of our registries is as follows:

- **General Registry**
- **Solid Tumor Cancer Specialty Registries**
  - Breast Cancer – non-metastatic
  - Metastatic Breast Cancer
  - Lung Cancer
  - Melanoma
  - Ovarian Cancer
  - Prostate Cancer
  - Stomach Cancer
  - New Initiative: Liver Cancer*
- **Blood Cancer Specialty Registries**
  - Acute Myeloid Leukemia
  - Chronic Lymphocytic Leukemia
  - Chronic Myeloid Leukemia
  - Multiple Myeloma
- **Caregiver Registry**

> "It feels so nice to take part in the Cancer Experience Registry knowing that the info I share will help so many others. Not only in that it will help other cancer patients, but also that it will help physicians, caregivers, AND cancer research."
>
> **– Anne, Board Member, CSC Research and Training Institute**

Registry surveys were developed in collaboration with expert advisors in oncology, clinical research, advocacy, psychosocial and behavioral research, the health care industry, policy, and, most importantly, the patient and caregiver communities. CSC's Research and Training Institute (RTI) continues to collaborate with advisors to develop new specialty registries and surveys, incorporating learnings from existing registries. All study procedures and materials for the Cancer Experience Registry have been reviewed and approved by an independent Institutional Review Board (IRB).

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*New registry launched in September 2019

REGISTRY OUTREACH AND RECRUITMENT

CSC uses an ongoing and comprehensive strategy to recruit participants that includes: leveraging CSC's robust affiliate network, online community, and national helpline; partnering with national advocacy and professional membership organizations; enlisting help from members of our advisory councils, the health care industry, and hospital networks; and using social and traditional media and word-of-mouth.

As of June 2020, more than **14,700 patients, survivors, and caregivers,** representing more than **50 cancer types,** have joined the Registry. CSC is committed to expanding that number each year. Outreach to racial and ethnic minority populations, rural and urban populations, sexual and gender minority populations, and other underrepresented populations continues to be a critical goal.

> "The Cancer Experience Registry is a vital source for ensuring the voice of people with cancer is driving clinical development, compassionate care, health policy change, and educational needs."
>
> **– Ellen, Board Member, CSC Research and Training Institute**

IMPACT OF THE REGISTRY

Information from the General Registry is used to identify commonalities and differences across all types of cancer. Findings from the Specialty Registries delineate the unique themes and experiences of living with a particular cancer. The insights gathered from the Registries have informed CSC's educational services and programming, resource materials, and policy initiatives, which in turn have been shared with the patient, survivor, and caregiver communities.

Learn more about the Cancer Experience Registry and the RTI's research and publications at www.CancerSupportCommunity.org/our-research

THE 2020 CANCER EXPERIENCE REGISTRY REPORT

The 2020 Cancer Experience Registry Report is a valuable resource for all stakeholders in the health care community, including clinicians, researchers, advocates, policymakers, patients, caregivers, and others who are interested in patient, survivor, and caregiver perspectives about living with cancer.

This report can be found at www.CancerSupportCommunity.org/2020CancerExperienceRegistryReport

Previous reports and research results can be found at www.CancerSupportCommunity.org/publications-presentations

The findings shared here highlight the physical, emotional, social, practical, and functional aspects of the cancer experience in an era of:

- More complex treatment decision-making, a by-product of treatment innovations for many types of cancer
- Ongoing shifts in health care coverage and payment
- Evolving models of clinical trial design
- Greater appreciation for and focus on patient-centered care that takes patient perspectives and priorities into account alongside more traditional clinical outcomes

The General Registry portion of this 2020 report presents a snapshot of key survey results from 2,569 patients and survivors living in the U.S. or U.S. protectorates who joined the Registry between January 1st, 2016 and June 30th, 2019 and who provided basic demographic information. In our Specialty Registry sections, for reasons related to sample robustness, we present results from participants who joined the Registry from March 21st, 2013 to June 30th, 2019. In both the General Registry and Specialty Registry samples, non-U.S. participants were excluded due to significant variations in health care delivery. Note that enrollment is continuing in all of our registries.

In this 2020 report, our overall findings are presented in the Executive Summary, which is followed by data highlights for each of the Registries. These highlights include:

- Key findings on topics including treatment decision-making, side effects and symptom management, and financial impact
- Socio-demographics and select clinical history information
- Quality of life experiences of respondents compared to national averages
- Top cancer-related distress concerns

We conclude this report with a list of CSC resources – free to patients, survivors, and caregivers – that are designed to address many of the issues raised by the findings in this report.

> "Particularly for patients who have had or are living with a rare form of cancer, it's important to share their experiences in a way that can amplify their voices. The pooled, blinded data...can shed light on patient experiences and impact policies, perceptions, and coverage/benefits."
>
> **– Anonymous, Board Member, CSC Research and Training Institute, and rare cancer survivor**

EXECUTIVE SUMMARY

While much progress has been made in the diagnosis and treatment of cancer, our results show that the disease presents significant emotional, financial, and psychosocial challenges to patients and caregivers alike. Principal learnings in this 2020 report are as follows:

1. Across cancer types, a substantial number of our patients experience **anxiety and depression**. One-half of our General Registry participants were at risk for clinically significant anxiety and 4 out of 10 were at risk for clinically significant depression. Managing the long-term emotional effects of cancer will become paramount as survival rates increase and cancer becomes more of a chronic condition.

2. **Anxiety** is a prominent issue among our caregiver participants, as well: one-half of caregiver respondents reported anxiety levels that were substantially worse than the national average. The emotional demands on caregivers can be overwhelming, and supporting caregivers is an ongoing health care need.

3. Many patients and caregivers are also **fearful of the disease progressing** and worried about **what the future will hold** – over one-half of all General Registry participants and 7 out of 10 Caregiver Registry participants reported substantial concern about illness progression or recurrence.

4. Our patients are quite concerned about aspects of daily living and well-being. **Eating and nutrition and exercise/physical health** were among the most salient concerns among our patients – at least one-half of General Registry participants reported moderate to very serious concern about these topics.

5. Caregivers, too, had substantial worries about the **patient's eating and nutrition,** as well as the **patient's pain or physical discomfort** – 6 out of 10 reported moderate to very serious concern for each.

6. Our results suggest that, despite advances in patient-centered care, there remain notable gaps in **doctor-patient communication**. As an example, nearly one-third of our breast cancer participants tell us they have held back from sharing side effects and symptoms with their health care team. Among this same participant group, three-quarters said their health care team never asked about sexual problems, but 6 out of 10 would be open to discussing the topic with their provider.

7. Similarly, our results suggest gaps in **shared treatment decision-making**. Many patients and caregivers report they are involved in treatment decision-making, but notably fewer felt prepared to discuss treatment options with their doctor. If unaddressed, this gap has the potential to grow as the treatment landscape becomes increasingly complex.

8. A large majority of our patients said no one from their health care team talked to them about the **cost of their care**, yet many of our patients are spending $500 or more in monthly out-of-pocket cancer care costs.

   Our research also shows patients exhibit considerable distress over **finances**. As an example, three-quarters of chronic myeloid leukemia participants reported being moderately to very seriously concerned about health insurance or money worries. The consequences can be real: for cancer types involving oral treatments, some patients reported they were not filling prescriptions, a decision which can negatively impact recovery or survival.

9. Many of our patients reveal they are reluctant to join **clinical trials**, most notably due to fears about the randomization of treatment and the belief that they could receive an inactive placebo. At least one-half of our General Registry participants expressed these concerns. Addressing patients' concerns early and often may increase participation, which can benefit their health, as well as advance knowledge of the disease overall.

10. It is well-known that quality **caregiving** can lead to better patient outcomes; however, our caregivers tell us they received little preparation for the tasks and responsibilities of providing care for their cancer patient. Some caregivers in our Registry reported providing over 100 hours of care per week, and many reported a decline in their own personal health. Additionally, over one-half want help understanding the patient's medical condition and treatment and managing health benefits and financial services. Finding additional ways to provide caregivers with much-needed medical skills training, disease and treatment information, emotional support/coaching, and financial counseling is likely to benefit both the caregiver and, ultimately, the patient.

GENERAL REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**49%** were at risk for clinically significant levels of anxiety **38%** were at risk for clinically significant levels of depression	**51%** were moderately to very seriously worried about exercising and being physically active	**56%** were moderately to very seriously concerned about eating and nutrition
SIDE EFFECT AND SYMPTOM MANAGEMENT	**4 out of 10** felt inadequately prepared to manage side effects of treatment	**4 out of 10** did not recall receiving information about long-term side effects of treatment	**1 out of 3** held back from telling their health care team about side effects and symptoms
TREATMENT DECISION-MAKING	**9 out of 10** rated quality of life as a very important factor when weighing treatment options	**1 out of 3** were not satisfied with how much they participated in making the treatment decision	**1 out of 2** did not feel prepared to discuss treatment options with their doctor
CLINICAL TRIALS	**14%** thought logistical barriers like lack of transportation would stop them from participating in a clinical trial	**20%** believed that insurance would not cover clinical trial costs	**51%** feared receiving a placebo in a cancer clinical trial **54%** were uncomfortable with random assignment of treatment
FINANCIAL IMPACT	**1 out of 10** postponed filling prescriptions to reduce cost	**7 out of 10** reported that no one from their health care team talked to them about the cost of their care	**1 out of 3** depleted savings or used money from retirement to cover treatment costs
PRACTICAL CONCERNS	**41%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**40%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**13%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 1,390 to 2,087.

1. GENERAL REGISTRY HIGHLIGHTS

1.1 GENERAL REGISTRY: INTRODUCTION AND KEY FINDINGS

Cancer survival rates have steadily improved since the mid-1970s for many of the most common cancers, including breast, prostate, and lung cancers. Progress has been especially rapid for specific childhood cancers and certain blood cancers, such as chronic myeloid leukemia and chronic lymphocytic leukemia due primarily to improved diagnostics and testing, new treatments, lifestyle changes, and vaccines.[2]

Nevertheless, cancer remains a significant health care burden: the American Cancer Society estimates there will be 1.8 million newly diagnosed cases of cancer in the United States in 2020.[3] Moreover, as more people are successfully treated, doctors and researchers are becoming more focused on helping people deal with the lingering side effects in the years following treatment.[4] The need for palliative care and psychosocial support can extend after medical treatment has ended, as well.[5]

> "People with serious illnesses have stress in different ways. We need to understand what individuals are going through and focus on the physical, emotional, and spiritual quality of life our patients want."
>
> **– Hunter, MD, Medstar Georgetown Washington Hospital Center**

To capture the psychosocial experiences of those who are living with or are beyond cancer of any type, the General Registry portion of the Cancer Experience Registry was launched in March 2013. In this section, we report on 2,569 patients and survivors living in the U.S. or U.S. protectorates who enrolled between January 1st, 2016 and June 30th, 2019 and who provided basic demographic information for the core survey. (As noted previously in the Introduction, for reasons of sample robustness, our Specialty Registry samples include participants who joined the Registry from March 21st, 2013 to June 30th, 2019.)

1.2 GENERAL REGISTRY: WHO IS IN THE REGISTRY

FIGURE 1A. GENERAL REGISTRY DEMOGRAPHICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
Age	Average: 57 yrs	18 to 97 yrs
18-44	397	15%
45-64	1,353	53%
65 and older	705	27%
Female	1,852	72%
Race		
White	2,151	84%
Black or African American	164	6%
Other	125	5%
Multiple	50	2%
Non-Hispanic Ethnicity	2,252	88%
Education		
High school or less	405	16%
Associate degree or some college	872	34%
Bachelor's degree	651	25%
Graduate degree or higher	575	22%
Region		
Urban	954	37%
Suburban	863	34%
Rural	519	20%
Employment Status		
Full-time	833	32%
Part-time	240	9%
Retired	706	27%
Not employed due to disability	480	19%
Not employed (reason not specified)	208	8%
Annual Income		
$<40K	665	26%
$40–59.9K	319	12%
$60–79.9K	276	11%
$80–99.9K	223	9%
$100K+	479	19%
Prefer not to share/Don't know/Missing	607	24%

* Total number of participants = 2,569. Percentages may not total to 100% due to missing data.

> "A cancer diagnosis often raises huge issues surrounding work and career. People want to know if they can continue to work, or how it will affect their relationships. It is a very real and often overlooked area of concern."
>
> **– Hester, LICSW, OCW-C,**
> **Beth Israel Deaconess Medical Center**

FIGURE 1B. CANCER TYPES AMONG GENERAL REGISTRY PARTICIPANTS

CANCER	NUMBER OF PARTICIPANTS*	PERCENT
Breast (Metastatic and Non-Metastatic)	888	35%
Gynecologic (Ovarian, Endometrial, Cervical, Other)	216	8%
Prostate	216	8%
Lung	202	8%
Leukemia (AML, CML, CLL, Other)	164	6%
Lymphoma	157	6%
Colorectal	131	5%
Head and Neck	66	3%
Multiple Myeloma	62	2%
Melanoma	59	2%
Stomach	35	1%
Kidney	31	1%
Esophageal	21	1%
Gastrointestinal Stromal Tumor (GIST)	6	<1%
Other	315	12%

*Total number of participants = 2,569.

FIGURE 1C. GENERAL REGISTRY SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
Time Since Diagnosis	Average: 4.2 yrs	<1 to 54 yrs
Less than 1 year	431	17%
1 to less than 2 years	592	23%
2 to less than 5 years	669	26%
5 or more years	674	26%
Recurrence		
Experienced recurrence	508	20%
Never experienced recurrence	1,753	68%
Don't know	126	5%
Metastatic Status		
Ever metastatic	636	25%
Not metastatic	1,628	63%
Don't know	131	5%

* Total number of participants = 2,569. Percentages may not total to 100% due to missing data.

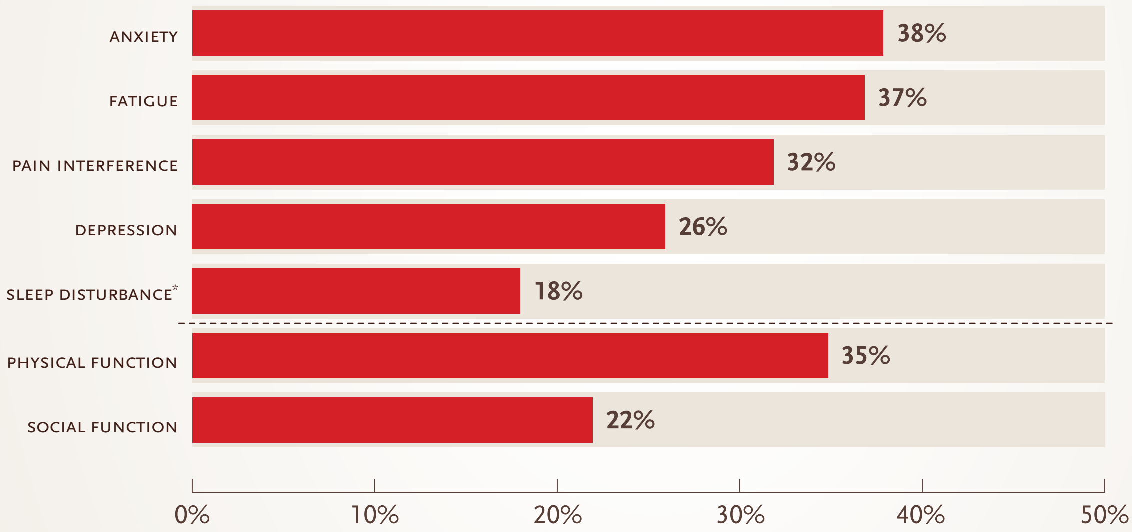
1.3 GENERAL REGISTRY: QUALITY OF LIFE

As more cancer patients live longer with their disease and the focus shifts from survival to survivorship, the issue of maintaining or improving physical, emotional, and social quality of life has taken on greater significance.

The General Registry incorporates the PROMIS®-29 v2.0 (Patient Reported Outcome Measurement Information System) – a scale that examines how participants' ratings of their quality of life compare to the estimated U.S. general population average in five symptom realms: anxiety, depression, fatigue, pain interference, and sleep disturbance, as well as two function realms: physical and social.[6±]

According to the PROMIS-29 data, among our General Registry sample, anxiety and fatigue were the most prominent issues – nearly 4 out of 10 participants reported symptoms that were substantially worse than the national average (38% and 37%, respectively; Figure 1D).

FIGURE 1D. PERCENT OF GENERAL REGISTRY PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 2,142 to 2,189.

± Physical function is defined as "one's ability to carry out various activities that require physical capacity." Social function is defined as "involvement in and satisfaction with one's usual social roles in life's situations and activities."[6]

1.4 GENERAL REGISTRY: CANCER-RELATED DISTRESS

Cancer patients—from the newly diagnosed to patients who are multiple years out from a diagnosis—experience varying levels of distress related to physical, psychological, social, and financial concerns. High levels of distress can negatively impact patient outcomes.

The General Registry survey measures cancer-related distress using CancerSupportSource® (CSS) – a validated set of distress screening questions that examines, via a 5-point scale, concepts related to 25 psychosocial, practical, and physical needs of cancer patients and survivors.[7] In addition to the 25 CSS items, the survey also includes 4 recently-added cancer-related exploratory distress items (totaling 29 items). The 10 items out of the 29 that received the highest ratings are shown in Figure 1E. These top-ranked concerns reveal areas of critical unmet need.

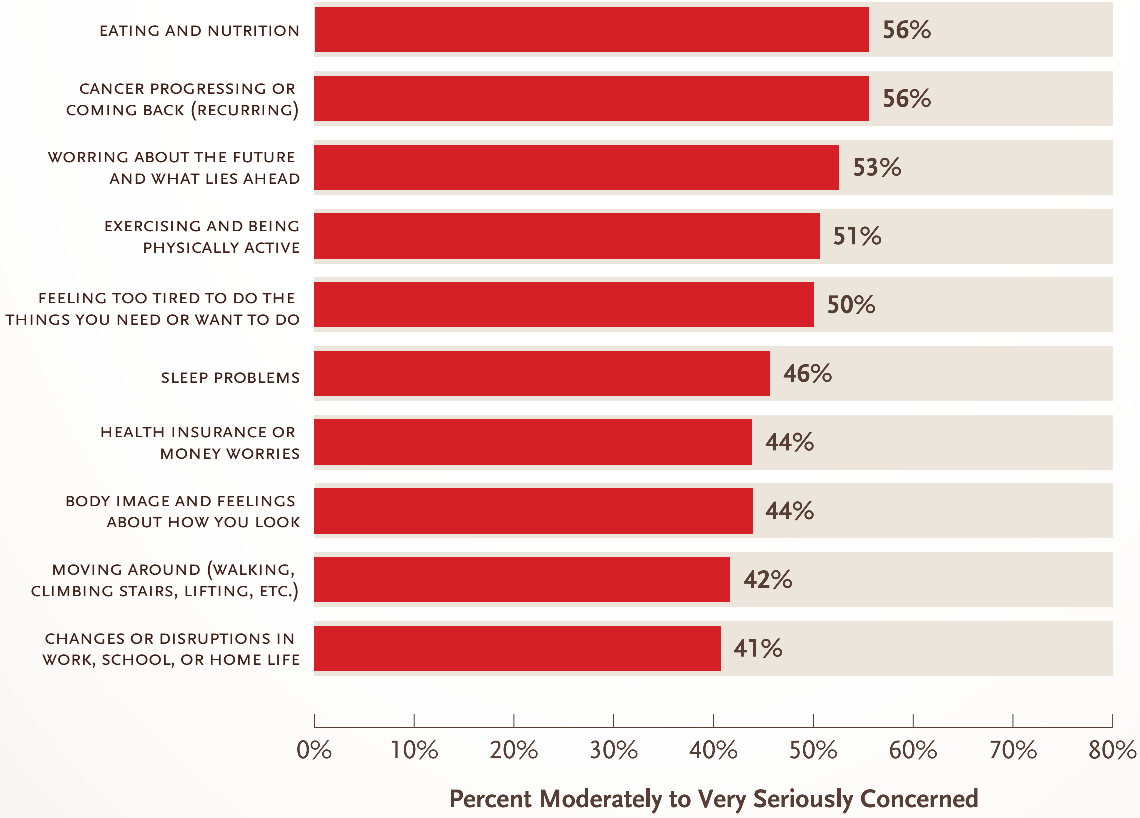
Among our total sample of participants, the most salient concerns were either physical or future-oriented in nature.

With regard to physical well-being, at least one-half of respondents reported being moderately to very seriously concerned about eating/nutrition (56%), exercising/being physically active (51%), and feeling too tired to do the things they need or want to do (50%).

With regard to the future, over one-half were moderately to very seriously concerned about their cancer progressing/coming back (56%) and worrying about the future/what lies ahead (53%).

Finances were also among the top ten concerns: more than 4 out of 10 (44%) were moderately to very seriously concerned about health insurance or money worries – a topical issue in the current cancer care landscape.

FIGURE 1E. TOP 10 CONCERNS AMONG GENERAL REGISTRY PARTICIPANTS



Sample sizes range from 2,071 to 2,089, except for the recently added exploratory item, "Cancer progressing...," where the sample size is 1,104.

BREAST CANCER REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**48%** were at risk for clinically significant levels of anxiety **39%** were at risk for clinically significant levels of depression	**62%** were moderately to very seriously concerned about eating and nutrition **55%** were moderately to very seriously concerned about exercising and being physically active	**1 out of 2** were moderately to very seriously concerned about sleep problems **1 out of 3** said their health care team never asked about sleep problems
SIDE EFFECT AND SYMPTOM MANAGEMENT	**40%** reported they experience neuropathy, the numbness and pain caused by nerve damage from chemotherapy	**56%** indicated fatigue was somewhat to very disruptive to their daily life	**31%** held back from telling their health care team about side effects and symptoms
DOCTOR-PATIENT COMMUNICATION & DECISION-MAKING	While **76%** were involved in treatment decision-making, only **48%** felt prepared to discuss treatment options with their doctor	**45%** did not recall receiving information about long-term side effects of treatment	**74%** said their health care team never asked about sexual problems, yet **61%** would be open to discussing sexual concerns
SOCIAL IMPACT & BODY IMAGE	**31%** were moderately to very seriously concerned about feeling lonely or isolated	**44%** said their diagnosis had a negative impact on their sexual life	**52%** were moderately to very seriously concerned about body image
FINANCIAL IMPACT	**7 out of 10** reported that no one from their health care team talked to them about the cost of their care	**4 out of 10** were moderately to very seriously concerned about health insurance or money worries	**1 out of 3** reported having forgone job opportunities or career advancement
PRACTICAL CONCERNS	**40%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**43%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**9%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 607 to 1,028.

2. BREAST CANCER [NON-METASTATIC] REGISTRY HIGHLIGHTS

2.1 BREAST CANCER REGISTRY: INTRODUCTION AND KEY FINDINGS

About 3.6 million individuals are living with breast cancer in the U.S. today.[8] Breast cancer is one of the cancers that has a high degree of awareness and that touches a high number of people who surround the patient, including family, friends, and co-workers. With the 5-year survival rate for localized breast cancer at 99%,[8] there are multiple chapters to the breast cancer patient's journey. This makes it even more important to understand the unique psychosocial experiences associated with this type of cancer. CSC has learned through the Cancer Experience Registry and other research that patients with breast cancer are not only able to document experiences with diagnosis, shared decision-making, treatment, and early post-acute care survivorship, they have considerable insights to share with the community about survivorship, late-stage symptoms and side effects, impact to job, and other factors of living in a post-cancer world long-term. These findings are helpful not only for people impacted by breast cancer, but may be helpful in establishing programs and services for other types of cancers.

> "There is a surprising validation in reading questions that no one has ever asked you before that reflect an important part of your experience of living with cancer. The Registry questions made me feel as if I were not alone."
>
> – **Joanne, breast cancer survivor**

Our Breast Cancer Registry, which includes questions uniquely relevant to people living with breast cancer, was launched in March 2013. The Breast Cancer Registry is a survey for breast cancer patients and survivors who indicated they did not have metastatic disease at the time of enrollment. In this 2020 Registry Report, we refer to these participants simply as "breast cancer" patients. Results for patients who indicated they had metastatic breast cancer can be found in the Metastatic Breast Cancer Registry Highlights section of this report.

In this section, we present results on 1,342 breast cancer participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with breast cancer are represented in the results of the Caregiver Registry.

2.2 BREAST CANCER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 2A. BREAST CANCER REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 56 yrs	18 to 89 yrs
Female	1,328	99%
White	1,145	85%
Non-Hispanic Ethnicity	1,217	91%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 4.1 yrs	<1 to 46 yrs
Stage at Diagnosis		
0–I	489	43%
II–III	555	49%
Other/Don't know	90	8%
Experienced Recurrence	98	9%

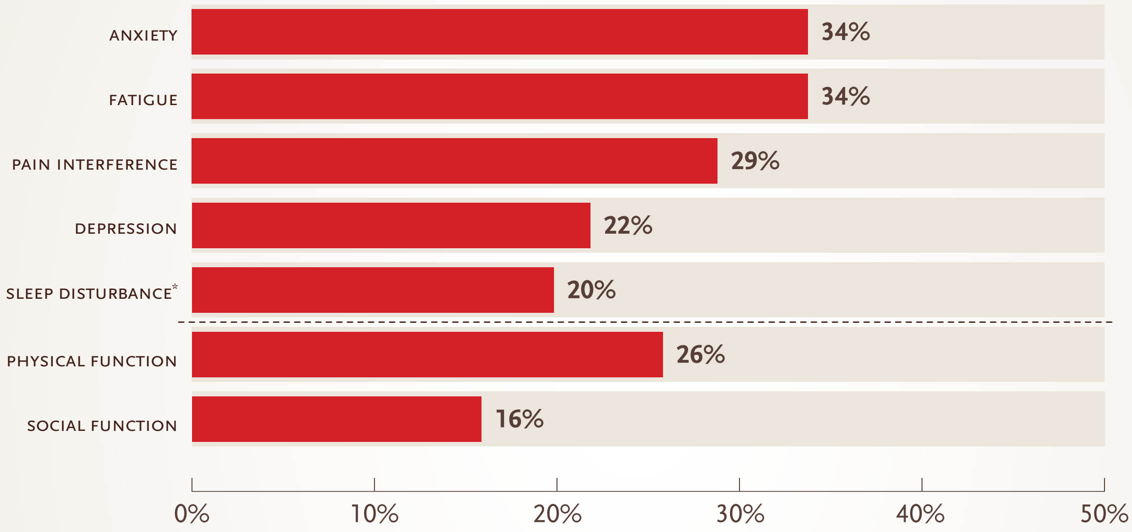
*Total number of participants = 1,342. Sample sizes for Select Clinical Characteristics range from 1,128 to 1,136.

2.3 BREAST CANCER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Among breast cancer participants, fatigue and anxiety were the most prominent quality of life issues: one-third of participants (34%, each) reported symptoms that were substantially worse than the national average – both consistent with the anxiety and fatigue issues noted in the Key Findings (Figure 2B).

FIGURE 2B. PERCENT OF BREAST CANCER PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 706 to 724.

2.4 BREAST CANCER REGISTRY: CANCER-RELATED DISTRESS

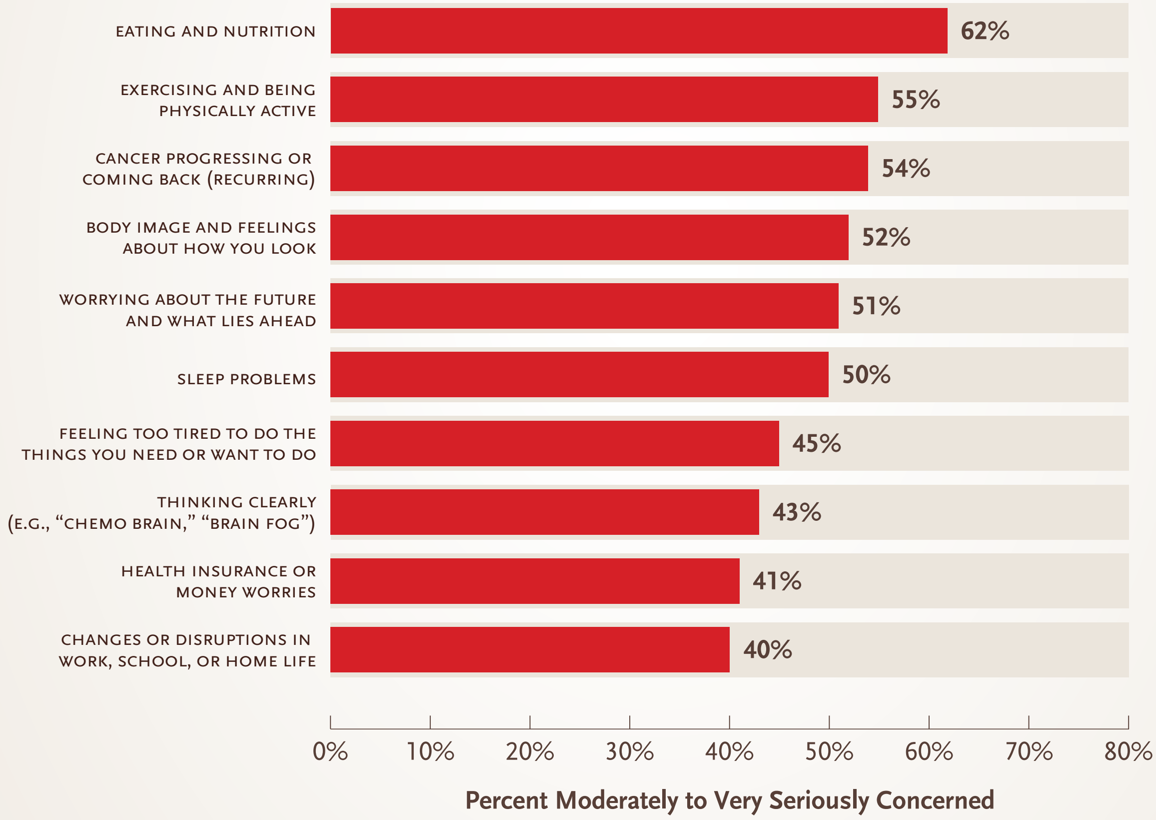
As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Among breast cancer respondents, the most prominent concerns were primarily physical or future-focused.

As noted in the Key Findings, more than one-half of breast cancer respondents (62% and 55%, respectively) reported being moderately to very seriously concerned about eating/nutrition and exercising/being physically active.

With regard to the future, more than one-half (54%) were concerned about their cancer progressing/returning and one-half (51%) were worried about what lay ahead for them.

As noted previously, body image was also a prominent concern (at 52%) among our breast cancer participants (Figure 2C).

FIGURE 2C. TOP 10 CONCERNS AMONG BREAST CANCER PARTICIPANTS



Sample sizes range from 1,013 to 1,028 except for the recently added exploratory item, "Cancer progressing...," where the sample size is 261.

METASTATIC BREAST CANCER REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**61%** were at risk for clinically significant levels of anxiety **46%** were at risk for clinically significant levels of depression	**44%** reported substantially worse fatigue than the national average	**31%** rated their overall health as poor or fair
SIDE EFFECT AND SYMPTOM MANAGEMENT	**57%** reported they experience neuropathy, the numbness and pain caused by nerve damage from chemotherapy	**37%** indicated neuropathy was disruptive to their daily life	**39%** held back from telling their health care team about side effects and symptoms
DOCTOR-PATIENT COMMUNICATION & DECISION-MAKING	While **68%** were involved in treatment decision-making, only **35%** felt prepared to discuss treatment options with their doctor	**35%** did not recall receiving information about long-term side effects of treatment	**76%** said their health care team never asked about sexual problems, yet **53%** would be open to discussing sexual concerns
SOCIAL IMPACT & BODY IMAGE	**36%** were moderately to very seriously concerned about feeling lonely or isolated	**56%** said their diagnosis had a negative impact on their sexual life	**50%** were moderately to very seriously concerned about body image
FINANCIAL IMPACT	**7 out of 10** reported that no one from their health care team talked to them about the cost of their care	**3 out of 10** spent over $500 in monthly out-of-pocket costs to cover cancer care **1 out of 2** reported having forgone job opportunities or career advancement	**1 out of 2** were moderately to very seriously concerned about health insurance or money worries
PRACTICAL CONCERNS	**50%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**52%** were moderately to very seriously concerned about thinking clearly (“chemo brain” or “brain fog”)	**14%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 242 to 733.

3. METASTATIC BREAST CANCER REGISTRY HIGHLIGHTS

3.1 METASTATIC BREAST CANCER REGISTRY: INTRODUCTION AND KEY FINDINGS

About 168,000 women and men in the U.S. are living with stage IV or metastatic breast cancer (MBC), a number estimated to have grown by 31% since 2010.[9] In 2011, CSC issued *Cancer Survivor Registry: The Breast Cancer M.A.P. (Mind Affects the Physical) Project* which clearly identified that patients living with metastatic breast cancer have entirely different feelings and a different experience living with their cancer than those living with non-metastatic breast cancer.[10] Due to these differences, CSC developed different surveys to assess the experiences of these two distinct patient groups. In the current MBC Registry, a number of unique issues are explored with patients, including the chronicity of the disease, life decisions made as a part of their planning, family and work tradeoffs, financial implications, and perceptions about clinical trials. As was mentioned in the Introduction, additional publications on this topic can be found at www.CancerSupportCommunity.org/publications-presentations.

The MBC Registry was launched in March 2013. In this 2020 Registry Report, we present results on 984 MBC participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with MBC are represented in the results of the Caregiver Registry.

> "Recently, I went back and read my journal entry from the beginning. I was really, really scared, and I'm scared now. And even though my doctors and others could say that there is life after the diagnosis, I wish somehow emotionally I could have felt that a little sooner. But again, it's that unknowing-ness of it...I think it's just part of living with metastatic breast cancer."
>
> **– Ruth, diagnosed with MBC**

3.2 METASTATIC BREAST CANCER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 3A. MBC REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 55 yrs	18 to 91 yrs
Female	966	98%
White	874	89%
Non-Hispanic Ethnicity	882	90%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 7.1 yrs	<1 to 52 yrs
Stage at Diagnosis		
0–I	50	15%
II–III	167	51%
IV	96	29%
Other/Don't know	17	5%
Experienced Recurrence	383	50%

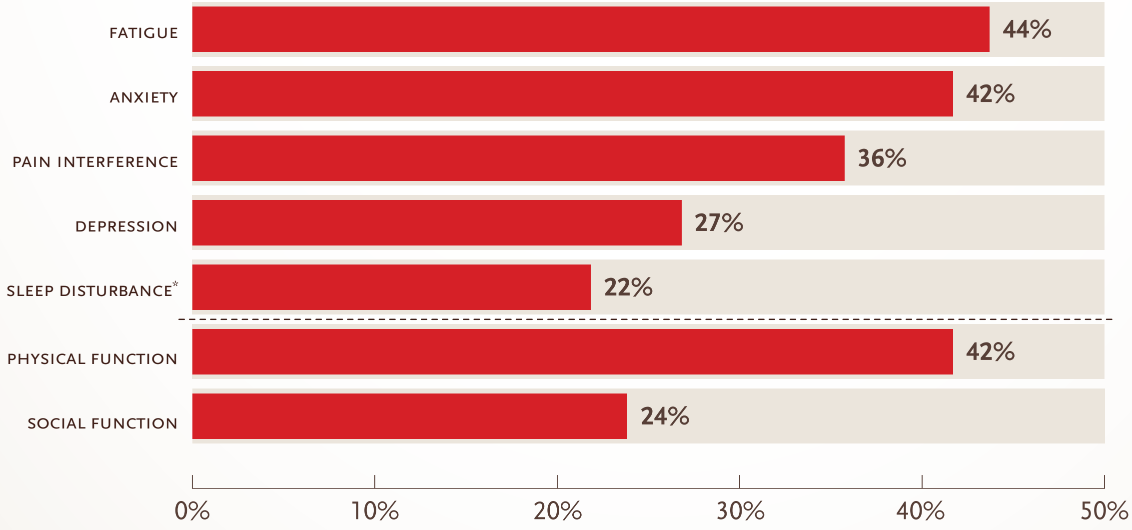
*Total number of participants = 984. Sample sizes for Select Clinical Characteristics range from 330 to 773.

3.3 METASTATIC BREAST CANCER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

The PROMIS-29 data suggest that fatigue, anxiety, and physical functioning are all prominent issues among MBC participants. Slightly more than 4 out of 10 MBC participants (44% and 42%, respectively) reported fatigue and anxiety levels that were substantially worse than the national average for each. A similar number (42%) reported levels of physical functioning that were substantially worse – consistent with the side effect and symptom management issues noted in the Key Findings (Figure 3B).

FIGURE 3B. PERCENT OF MBC PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 300 to 307.

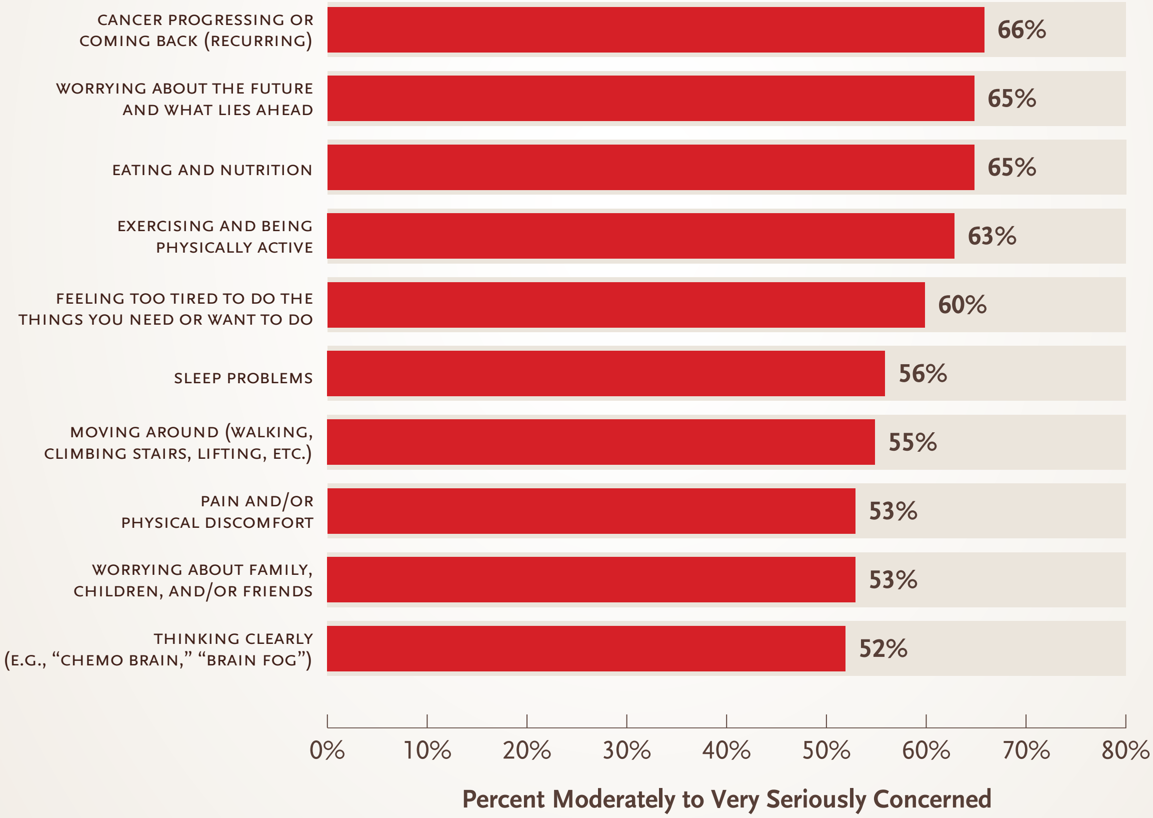
3.4 METASTATIC BREAST CANCER REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Among MBC participants, the most prominent concerns were primarily future-oriented and/or physical in nature.

The future weighed quite heavily among these respondents: more than 6 out of 10 reported being moderately to very seriously concerned about their cancer progressing or coming back (66%) and/or concerned about worrying about the future and what lies ahead (65%).

With regard to physical well-being, at least 6 out of 10 participants were moderately to very seriously concerned about eating and nutrition, exercising/being physically active, and/or feeling too tired to do the things they wanted or needed to do (65%, 63%, and 60%, respectively). In addition, many MBC respondents expressed concerns about moving around as well as about pain/physical discomfort (55% and 53%, respectively; Figure 3C).

FIGURE 3C. TOP 10 CONCERNS AMONG MBC PARTICIPANTS



Sample sizes range from 719 to 736, except for the recently added exploratory item, "Cancer progressing...," where sample size is 100.

LUNG CANCER REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**52%** were at risk for clinically significant levels of anxiety **42%** were at risk for clinically significant levels of depression	**53%** reported substantially worse physical functioning than the national average **38%** reported substantially worse fatigue than the national average	**44%** rated their overall health as fair or poor
TREATMENT DECISION-MAKING	While **65%** were involved in treatment decision-making, only **39%** felt prepared to discuss treatment options with their doctor	**93%** in second-line therapy or later felt more knowledgeable than they did during first-line therapy	**53%** reported not having their tumor tested for biomarkers
PSYCHOSOCIAL IMPACT	**37%** believed others think having lung cancer is their fault	**57%** were moderately to very seriously worried about the future and what lies ahead	**37%** reported feeling guilty because of their diagnosis
FINANCIAL IMPACT	**3 out of 4** reported that no one from their health care team talked to them about the cost of their care	Nearly **1 out of 2** were moderately to very seriously concerned about health insurance or money worries	**1 out of 4** spent over $500 in monthly out-of-pocket costs to cover cancer care
PRACTICAL CONCERNS	**44%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**42%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**17%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 27 to 240.

4. LUNG CANCER REGISTRY HIGHLIGHTS

4.1 LUNG CANCER REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 558,000 Americans are currently living with a diagnosis of lung or bronchus cancer.[8] There are two main types of lung cancer: small cell lung cancer (SCLC), which makes up about 15% of cases, and non-small cell lung cancer (NSCLC), which makes up about 85% of cases. Past learnings from the Lung Cancer Registry include the finding that lung cancer patients' experiences, including those related to perceptions of stigma and health care team communication, can vary by cancer type. Other CSC work has explored the degree to which patients' feelings of stigma and concerns with health care team communication, relationships and intimacy, and symptom burden/impact predict risk for clinically significant anxiety and depression.[11,12] With recent advances in lung cancer early detection, biomarker testing, and personalized care planning, patients are experiencing very different journeys than ever before, making it even more important to better understand the patient and caregiver experience as a part of immediate, short-term, and long-term survivorship.

> "I had many challenges from my treatment at the very beginning. The original chemo was very tough to handle. My relationship with my health care team grew over time. At the beginning, I didn't know what to expect…through time, I came to realize that they're phenomenal. I learned that it's okay to ask. It's better than okay. It's necessary."
>
> **– Elaine, lung cancer patient**

The Lung Cancer Registry, which includes questions uniquely relevant to people living with lung cancer, was launched in December 2014. In this 2020 Registry Report, we present results on 299 lung cancer participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with lung cancer are represented in the results of the Caregiver Registry.

4.2 LUNG CANCER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 4A. LUNG CANCER REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 61 yrs	18 to 86 yrs
Female	202	68%
White	249	83%
Non-Hispanic Ethnicity	265	89%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 3.1 yrs	<1 to 50 yrs
Stage at Diagnosis		
0–I	51	20%
II–III	83	32%
IV	85	33%
Other/Don't know	39	15%
Ever Metastatic	98	38%
Experienced Recurrence	62	24%

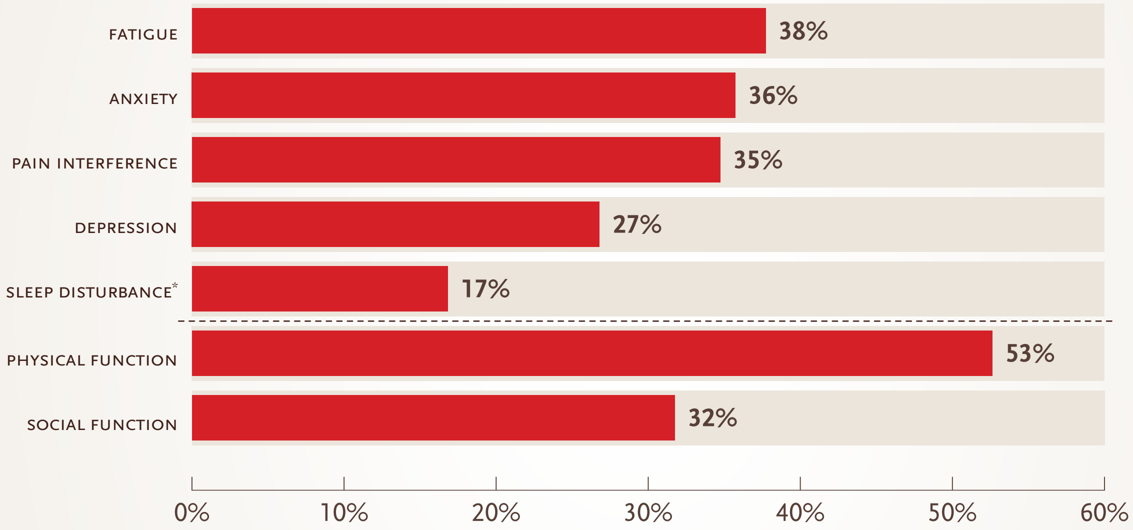
*Total number of participants = 299. Sample sizes for Select Clinical Characteristics range from 250 to 258.

4.3 LUNG CANCER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data, the most salient issue was physical functioning: more than one-half (53%) of lung cancer participants reported physical function levels that were substantially worse than the national average. On a related note, nearly 4 out of 10 (38%) lung cancer participants reported fatigue levels that were worse. These findings are consistent with our participants' ratings of their overall health, as noted in the Key Findings (Figure 4B).

FIGURE 4B. PERCENT OF LUNG CANCER PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 194 to 201.

4.4 LUNG CANCER REGISTRY: CANCER-RELATED DISTRESS

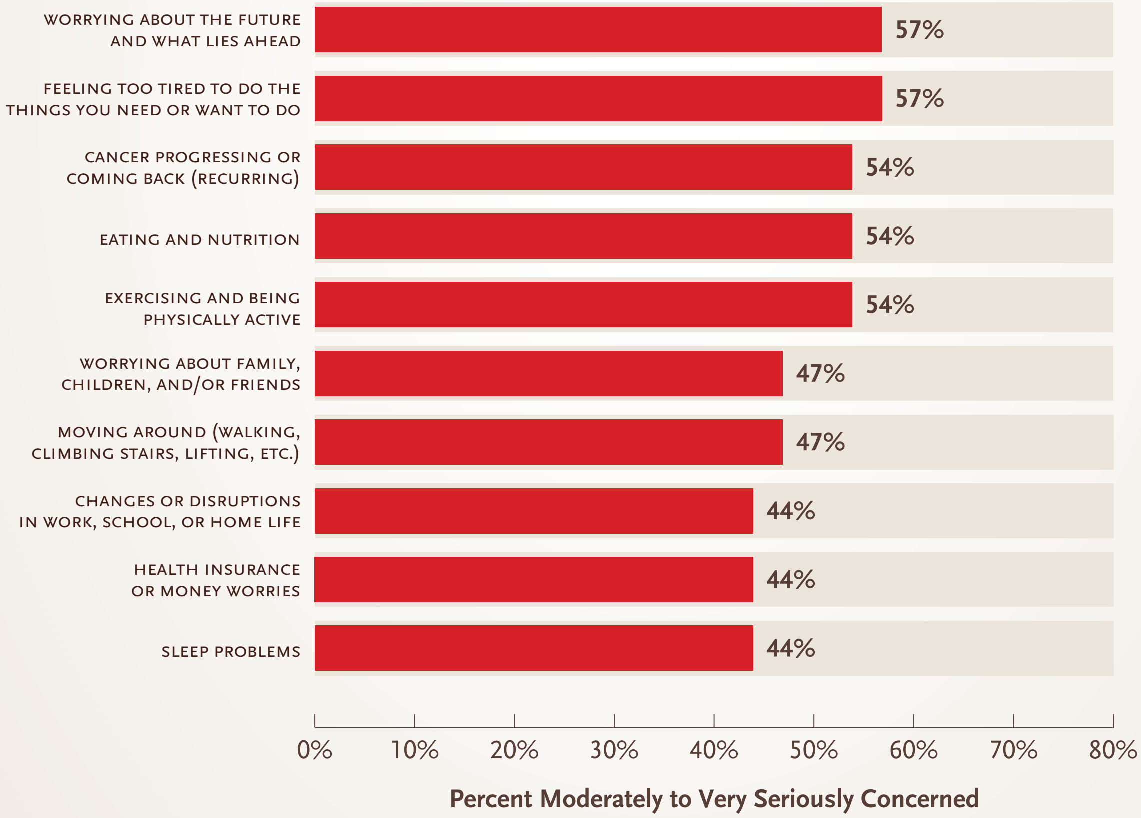
As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15).

Among lung cancer participants, the most prominent concerns were future-focused or physical in nature. Nearly 6 out of 10 (57%) reported being moderately to very seriously concerned about worrying about the future/what lies ahead. Nearly as many (54%) were moderately to very seriously concerned about their cancer progressing/coming back.

With regard to physical well-being, nearly 6 out of 10 (57%) lung cancer participants reported feeling too tired to do the things they needed or wanted to do. Over one-half (54%, each) were moderately to very seriously concerned about eating/nutrition and exercising/being physically active. These findings are consistent with the physical functioning issues experienced by our lung cancer participants, as highlighted in the previous section.

Worries about family, children, and/or friends was also a notable concern among lung cancer participants, at 47% (Figure 4C).

FIGURE 4C. TOP 10 CONCERNS AMONG LUNG CANCER PARTICIPANTS



Sample sizes range from 236 to 240, except for the recently added exploratory item, “Cancer progressing...,” where the sample size is 98.

MELANOMA REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**56%** were at risk for clinically significant levels of anxiety **47%** were at risk for clinically significant levels of depression	**53%** were moderately to very seriously concerned about exercising and being physically active **49%** were moderately to very seriously concerned about eating and nutrition	**22%** rated their overall health as poor or fair
TREATMENT DECISION-MAKING	While **64%** were involved in treatment decision-making, only **34%** felt prepared to discuss treatment options with their doctor	**45%** indicated that they make decisions about medical care together with their loved ones	**57%** did not feel knowledgeable about treatment options prior to making their treatment decision
SOCIAL IMPACT & BODY IMAGE	**25%** were quite a bit or very much dissatisfied with appearance of a scar	**26%** felt quite a bit or very much less physically attractive as a result of melanoma and treatment	**13%** avoided people quite a bit or very much because of the way they feel about their appearance
FINANCIAL IMPACT	**2 out of 3** reported that no one from their health care team talked to them about the cost of their care	Nearly **3 out of 10** spent over $500 in monthly out-of-pocket costs to cover cancer care	Nearly **1 out of 2** depleted savings or used money from retirement to cover treatment costs
PRACTICAL CONCERNS	**35%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**30%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**18%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 42 to 92.

5. MELANOMA REGISTRY HIGHLIGHTS

5.1 MELANOMA REGISTRY: INTRODUCTION AND KEY FINDINGS

Skin cancer is the most common cancer in the U.S. Melanoma makes up 1% of skin cancers; over 1.2 million people in the U.S. are living with melanoma of the skin today.[8] Both in the U.S. and globally, the number of people developing melanoma continues to grow, despite expanding awareness and prevention activities.[13] Previous learnings from the Melanoma Registry have found that the melanoma patient's experience can be impacted by stigma, body image, financial concerns, and shared decision-making.[14,15,16] Significant medical advances in the areas of screening, diagnosis, disease profiling, and treatment have resulted in changes in the patient experience across the spectrum.

> "The most challenging time for me was the initial diagnosis. I recommend taking someone with you to the appointments to help digest information, to take notes on different treatments. It tends to be overwhelming and you just don't hear very much."
>
> **– Matt, melanoma survivor**

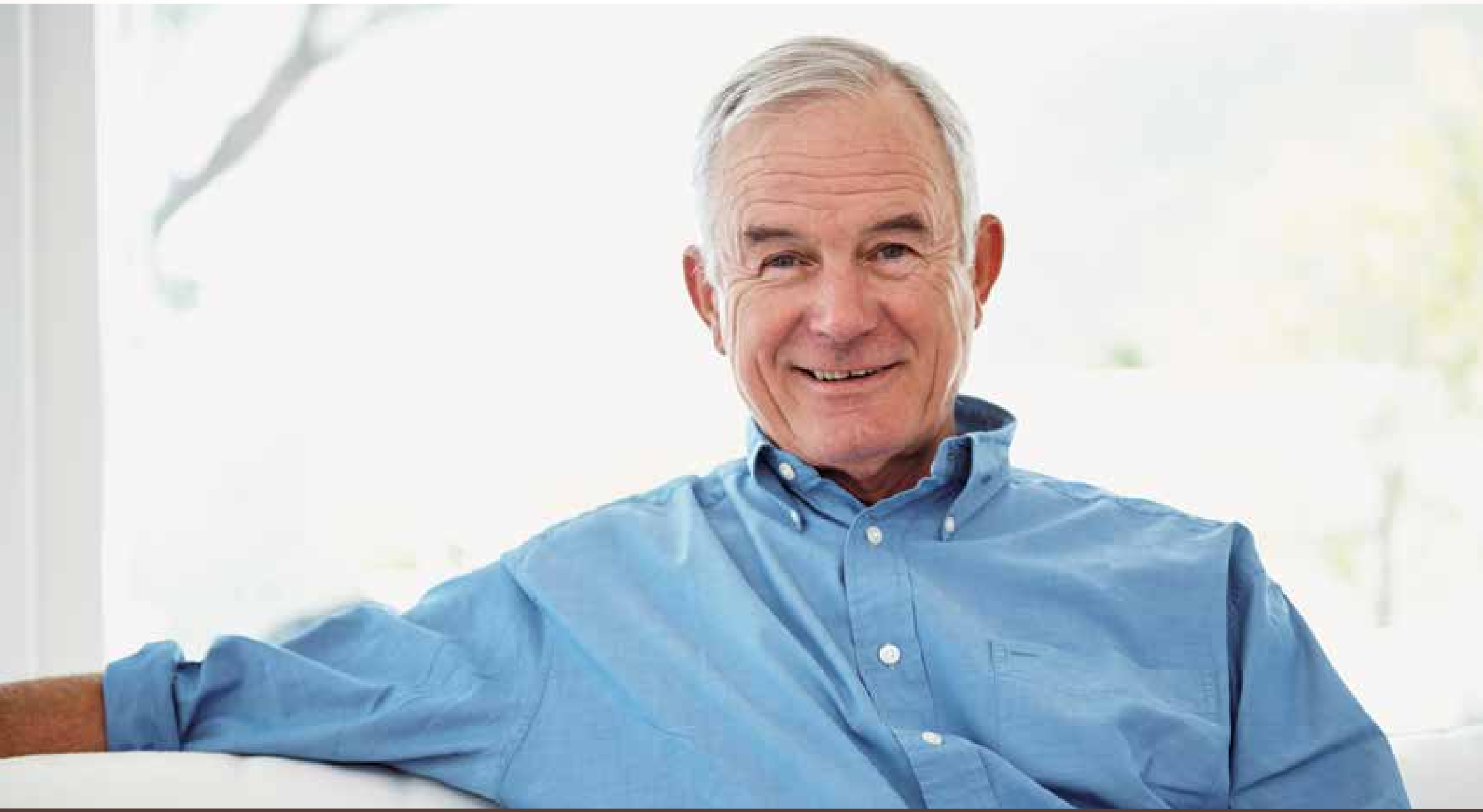
The Melanoma Registry, which includes questions uniquely relevant to people living with melanoma, was launched in December 2014. In this 2020 Registry Report, we present results on 106 melanoma participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with melanoma are represented in the results of the Caregiver Registry.

5.2 MELANOMA REGISTRY: WHO IS IN THE REGISTRY

FIGURE 5A. MELANOMA REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 56 yrs	24 to 82 yrs
Female	74	70%
White	99	93%
Non-Hispanic Ethnicity	99	93%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 5.0 yrs	<1 to 52 yrs
Stage at Diagnosis		
0–I	22	23%
II–III	42	44%
IV	25	26%
Other/Don't know	7	7%
Ever Metastatic	55	57%
Experienced Recurrence	33	34%

*Total number of participants = 106. Sample sizes for Select Clinical Characteristics range from 96 to 97.

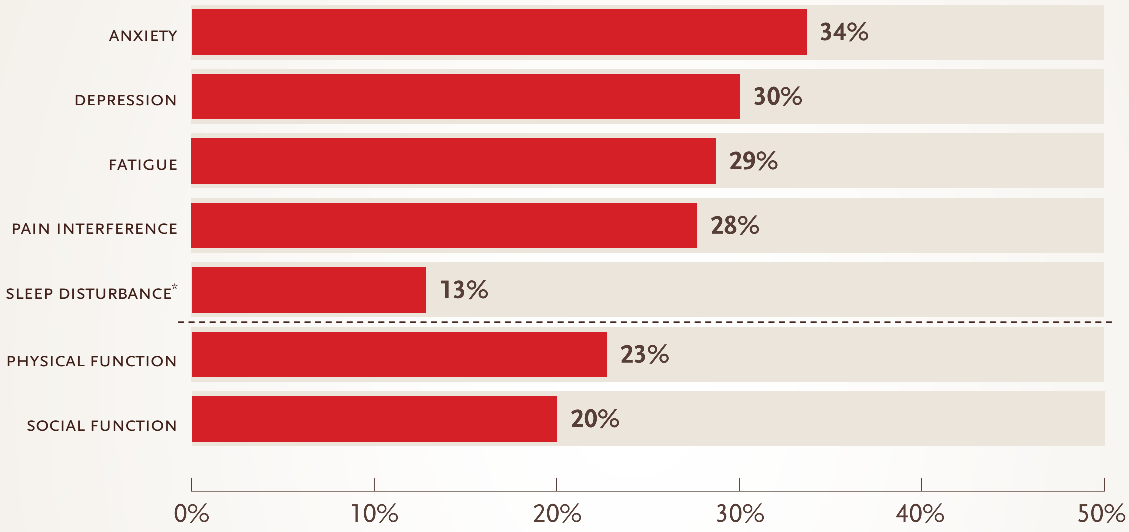


5.3 MELANOMA REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data on melanoma participants, anxiety was the most notable issue: one-third (34%) reported anxiety symptoms that were substantially worse than the national average – consistent with the clinical anxiety risk noted in the Key Findings (Figure 5B).

FIGURE 5B. PERCENT OF MELANOMA PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 75 to 76.

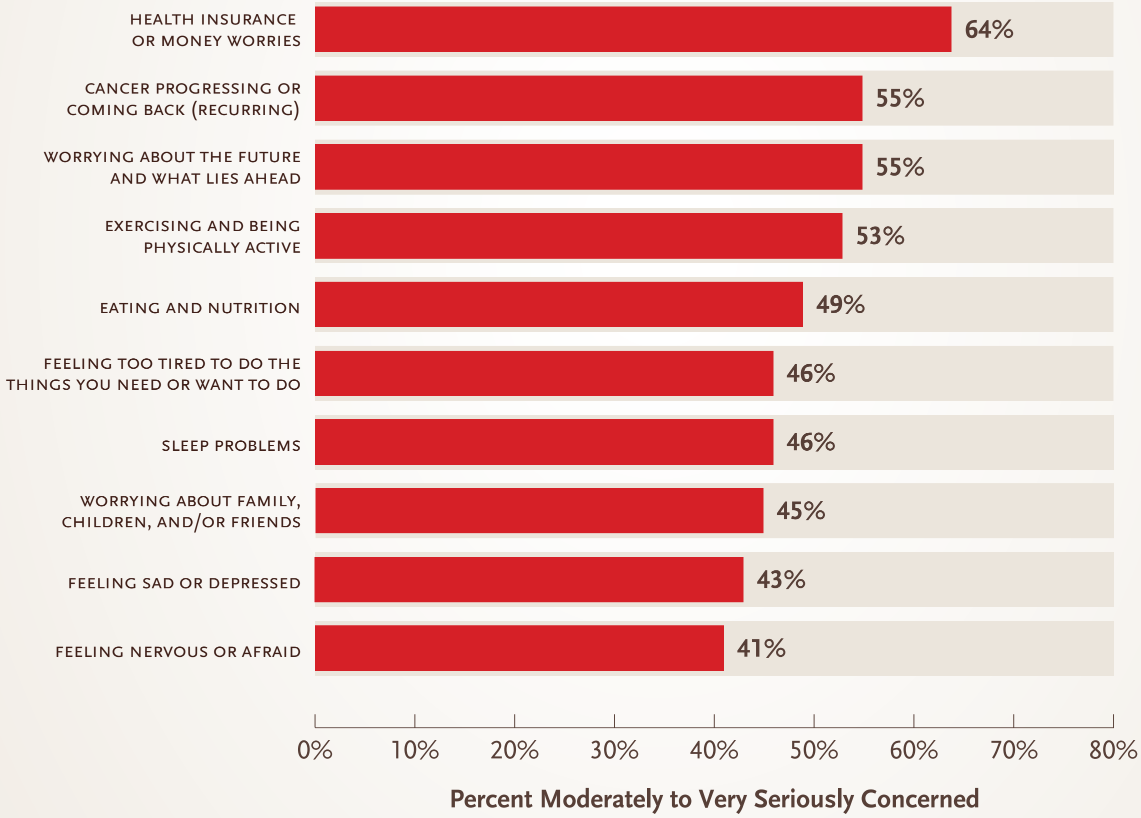
5.4 MELANOMA REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Among melanoma participants, the highest rated concerns included financial and future-focused issues.

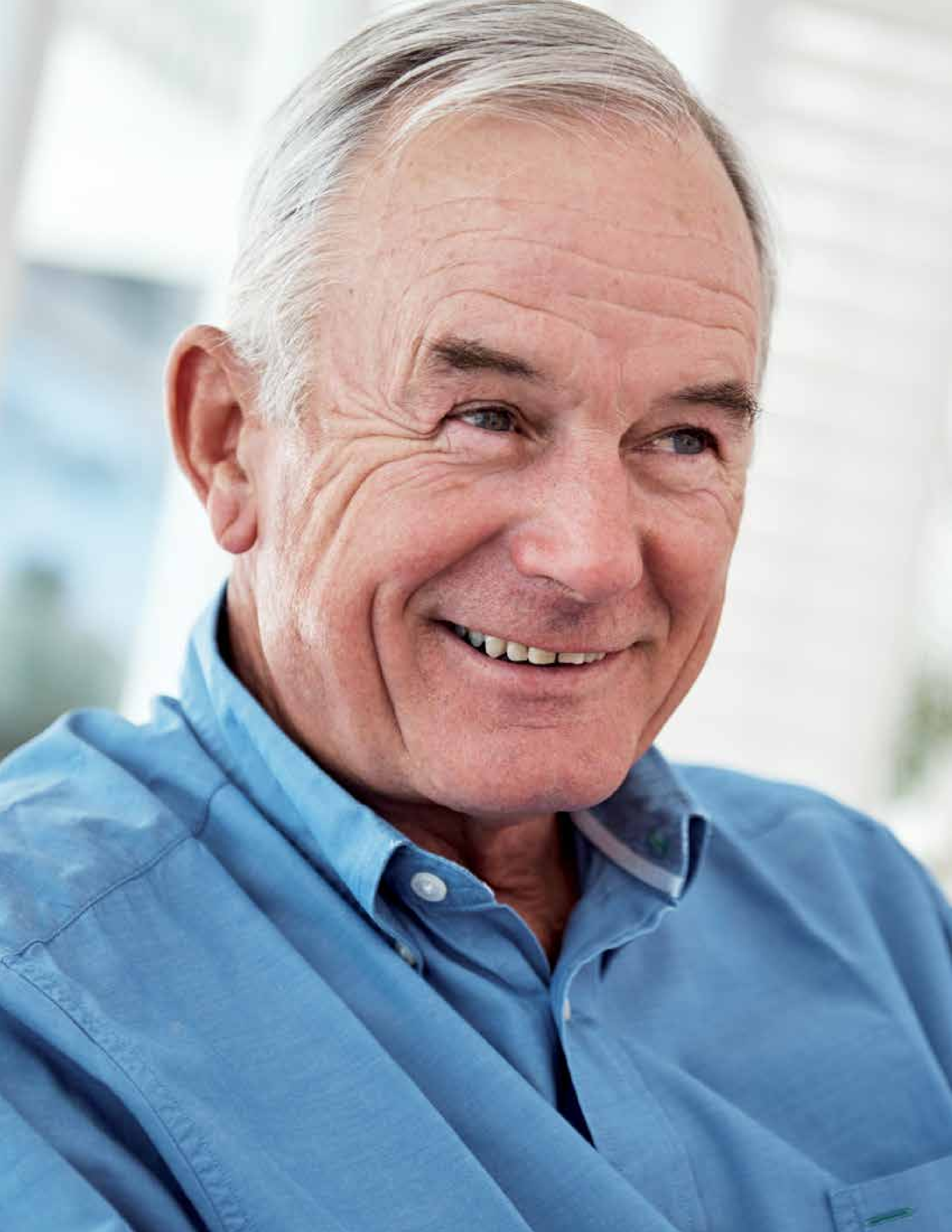
With regard to finances, more than 6 out of 10 respondents (64%) reported moderate to very serious concerns about health insurance and money worries. As noted in the Key Findings, some melanoma patients are spending a substantial sum of money monthly on cancer care – a situation that can extend for years.

With regard to the future, over one-half reported moderate to very serious concerns regarding their cancer progressing/coming back and worrying about the future/what lies ahead (55%, each; Figure 5C).

FIGURE 5C. TOP 10 CONCERNS AMONG MELANOMA PARTICIPANTS



Sample sizes range from 89 to 92, except the recently added exploratory item, "Cancer progressing…," where the sample size is 29.



OVARIAN CANCER REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**51%** were at risk for clinically significant levels of anxiety **39%** were at risk for clinically significant levels of depression	**65%** were moderately to very seriously concerned about eating and nutrition **53%** were moderately to very seriously concerned about exercising and being physically active	**29%** rated their overall health as poor or fair
SIDE EFFECT AND SYMPTOM MANAGEMENT	**35%** felt inadequately prepared to manage side effects of treatment	**44%** did not recall receiving information about long-term side effects of treatment	**37%** held back from telling their health care team about side effects and symptoms
TREATMENT DECISION-MAKING	While **56%** were involved in treatment decision-making, only **34%** felt prepared to discuss treatment options with their doctor	**1 out of 3** indicated that they make decisions about medical care together with their loved ones	**44%** were not satisfied with how much they participated in making the treatment decision
CLINICAL TRIALS	**20%** thought logistical barriers such as transportation would stop them from participating in a clinical trial	**24%** believed that insurance would not cover clinical trial costs	**54%** feared receiving a placebo in a cancer clinical trial **53%** were uncomfortable with random assignment
FINANCIAL IMPACT	**7 out of 10** reported that no one from their health care team talked to them about the cost of their care	Nearly **1 out of 2** spent over $250 in monthly out-of-pocket costs to cover cancer care	Nearly **1 out of 2** were moderately to very seriously concerned about health insurance or money worries
PRACTICAL CONCERNS	**40%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**49%** were moderately to very seriously concerned about thinking clearly (“chemo brain” or “brain fog”)	**8%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 99 to 164.

6. OVARIAN CANCER REGISTRY HIGHLIGHTS

6.1 OVARIAN CANCER REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 233,000 women in the U.S. are living with a diagnosis of ovarian cancer.[8] The patient experience is typically marked by delays in diagnosis, multiple treatment options and stages, and a number of lifestyle decisions. Additionally, advances in both genetic and genomic science have allowed for personalization in prevention and treatment that require additional levels of understanding. Previous Ovarian Cancer Registry work by CSC has revealed that ovarian cancer patients' concerns about communication with their health care teams are associated with risk for clinically significant anxiety and depression, and (among younger patients) concerns about sexuality and relationships are associated with risk for clinically significant anxiety.[17] As the 5-year survival rate continues to improve, one would expect the number of patients living with ovarian cancer to also increase. As such, continuing to understand all aspects of the experience will grow in importance in order to provide patients and families comprehensive solutions to improve their quality of life.

> "As an ovarian cancer survivor, research is important to me. Participating in CSC's Cancer Experience Registry was my way to give back by sharing my personal experiences which will benefit others going through cancer in the future."
>
> – **Marcia, ovarian cancer survivor and CSC employee**

The Ovarian Cancer Registry, which includes questions uniquely relevant to women living with ovarian cancer, was launched in October 2018. In this 2020 Registry Report, we present results on 204 ovarian cancer participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with ovarian cancer are represented in the results of the Caregiver Registry.

6.2 OVARIAN CANCER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 6A. OVARIAN REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 57 yrs	27 to 85 yrs
White	180	88%
Non-Hispanic Ethnicity	184	90%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 4.3 yrs	<1 to 38 yrs
Stage at Diagnosis		
0–I	35	19%
II–III	109	60%
IV	27	15%
Other/Don't know	10	6%
Ever Metastatic	58	32%
Experienced Recurrence	59	33%

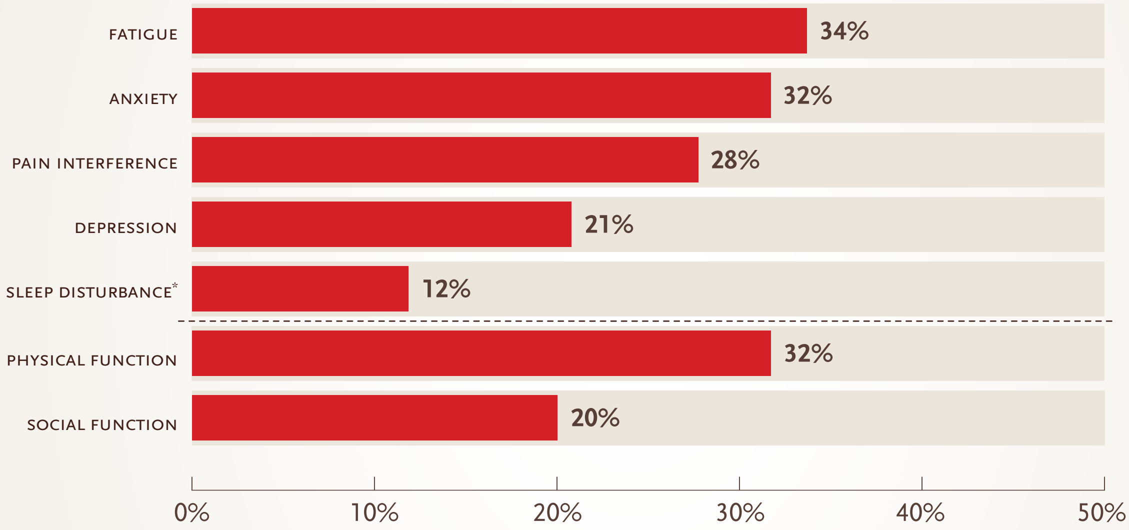
*Total number of participants = 204. Sample sizes for Select Clinical Characteristics range from 179 to 181.

6.3 OVARIAN CANCER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data, fatigue, anxiety, and physical functioning were the most notable quality of life issues among ovarian cancer participants: about one-third of participants reported fatigue and anxiety symptoms that were substantially worse than the national average (34% and 32%, respectively). A similar number (32%) reported physical function symptoms that were substantially worse, consistent with the previously noted health-related issues experienced by our ovarian cancer participants (Figure 6B).

FIGURE 6B. PERCENT OF OVARIAN CANCER PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 122 to 127.

6.4 OVARIAN CANCER REGISTRY: CANCER-RELATED DISTRESS

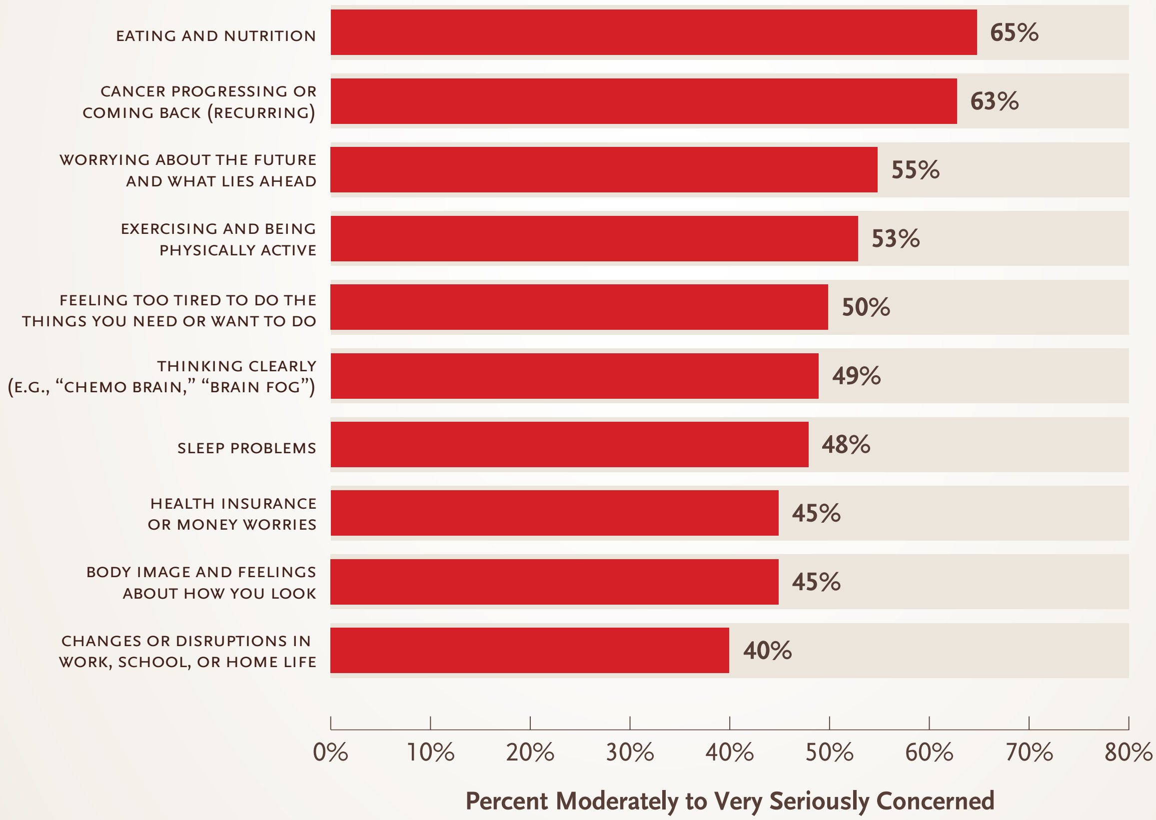
As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Ovarian cancer respondents' predominant concerns were physical or future-oriented.

As noted in the Key Findings, nearly two-thirds (65%) of respondents were moderately to very seriously concerned about eating and nutrition.

The future weighed heavily among our ovarian cancer participants: more than 6 out of 10 (63%) were moderately to very seriously concerned about their cancer progressing or coming back. Relatedly, more than one-half (55%) reported moderate to very serious concerns regarding worrying about the future and what lies ahead.

Thinking clearly ("chemo brain") was also a notable concern in this participant group, at 49% (Figure 6C).

FIGURE 6C. TOP 10 CONCERNS AMONG OVARIAN CANCER PARTICIPANTS



Sample sizes range from 161 to 165, except for the recently added exploratory item, "Cancer progressing…," where the sample size is 52.

PROSTATE CANCER REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**37%** were at risk for clinically significant levels of anxiety **33%** were at risk for clinically significant levels of depression	**50%** were moderately to very seriously concerned about eating and nutrition **44%** were moderately to very seriously concerned about intimacy, sexual function, and/or fertility	**32%** live quite a bit/very much in fear that their PSA* level will rise
SEXUAL INTIMACY	**73%** have experienced erectile dysfunction since diagnosis and/or treatment	**22%** said they did not feel comfortable speaking with anyone about sexual side effects	**34%** felt they were not given enough information about erectile dysfunction prior to treatment
TREATMENT DECISION-MAKING	While **88%** were involved in treatment decision-making, only **60%** felt prepared to discuss treatment options with their doctor	**41%** indicated they make decisions about medical care together with their loved ones	**58%** discussed the impact of cancer and treatment on work, but **66%** of those were not satisfied with the discussion
FINANCIAL IMPACT	**2 out of 3** reported that no one from their health care team talked to them about the cost of their care	**1 out of 3** were moderately to very concerned about health insurance or money worries	**4 out of 10** spent over $250 in monthly out-of-pocket costs to cover their cancer care
PRACTICAL CONCERNS	**32%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**20%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**8%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 97 to 235.

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*PSA = prostate-specific antigen

7. PROSTATE CANCER REGISTRY HIGHLIGHTS

7.1 PROSTATE CANCER REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 3.2 million men in the U.S. are currently living with prostate cancer. The 5-year survival rate is 98%, and the cancer is often curable if caught early.[8] The patient and survivor experience with prostate cancer is highly unique to the patient across a number of dimensions including multiple and complex treatment options with vastly different side effects, feelings of loss of privacy, impact on intimacy, and concerns regarding disease recurrence or progression. Learnings from the Prostate Cancer Registry include the finding that, not surprisingly, quality of life is an important consideration for prostate cancer patients in treatment decisions.[18] This finding and others demonstrate the need to understand these very personal experiences in order to inform the most meaningful solutions possible for patients.

> "Prostate cancer can strike fear in those who receive this diagnosis. Understanding the experiences of living with prostate cancer – ranging from "scanxiety" to intimacy-related side effects – can enhance person-centered care and improve overall well-being."
>
> **– Michael, prostate cancer survivor and retired physician**

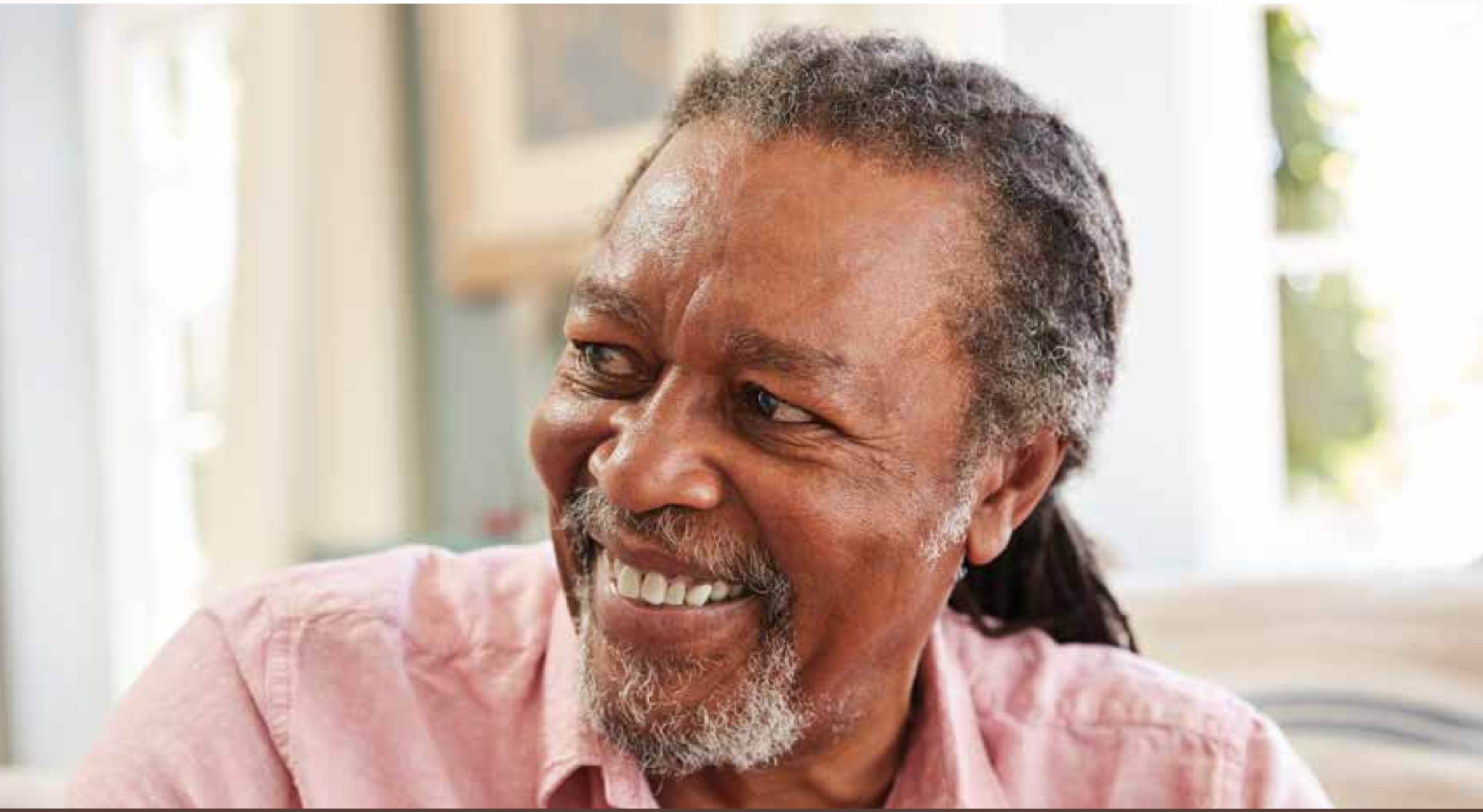
The Prostate Cancer Registry, which includes questions uniquely relevant to men living with prostate cancer, was launched in April 2015. In this 2020 Registry Report, we present results on 292 prostate cancer participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with prostate cancer are represented in the results of the Caregiver Registry.

7.2 PROSTATE CANCER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 7A. PROSTATE CANCER REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 66 yrs	18 to 88 yrs
White	261	89%
Non-Hispanic Ethnicity	262	90%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 4.5 yrs	<1 to 33 yrs
Stage at Diagnosis		
0–I	68	26%
II–III	80	30%
IV	44	17%
Other/Don't know	74	28%
Ever Metastatic	69	26%
Experienced Recurrence	66	25%

*Total number of participants = 292. Sample sizes for Select Clinical Characteristics range from 265 to 269.

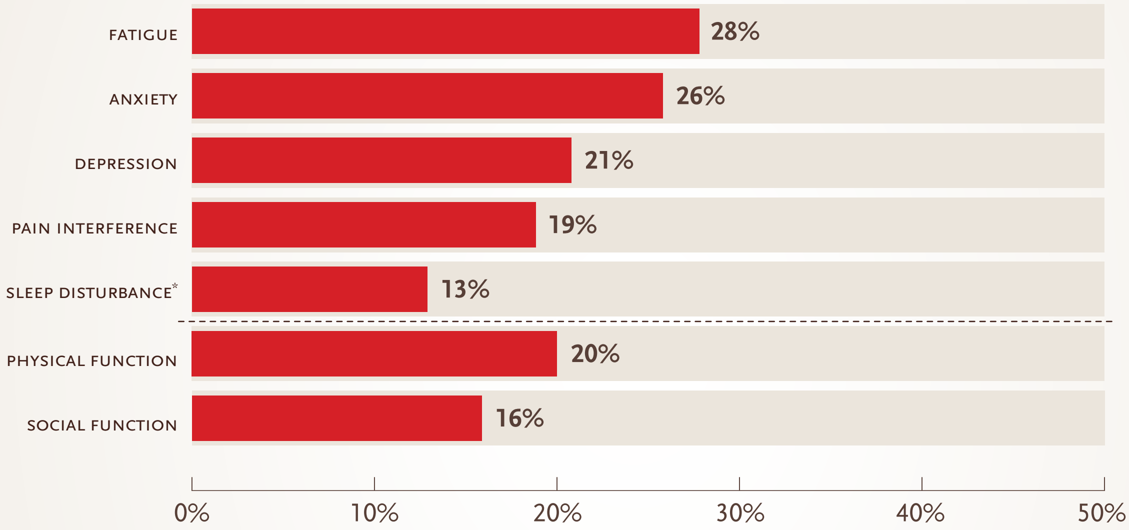


7.3 PROSTATE CANCER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data for our prostate cancer respondents, fatigue and anxiety were the most notable issues. Nearly 3 out of 10 (28%) of our prostate cancer participants reported fatigue symptoms that were substantially worse relative to the national average. Nearly as many (26%) reported anxiety levels that were substantially worse than the national average (Figure 7B).

FIGURE 7B. PERCENT OF PROSTATE CANCER PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 209 to 214.

7.4 PROSTATE CANCER REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15).

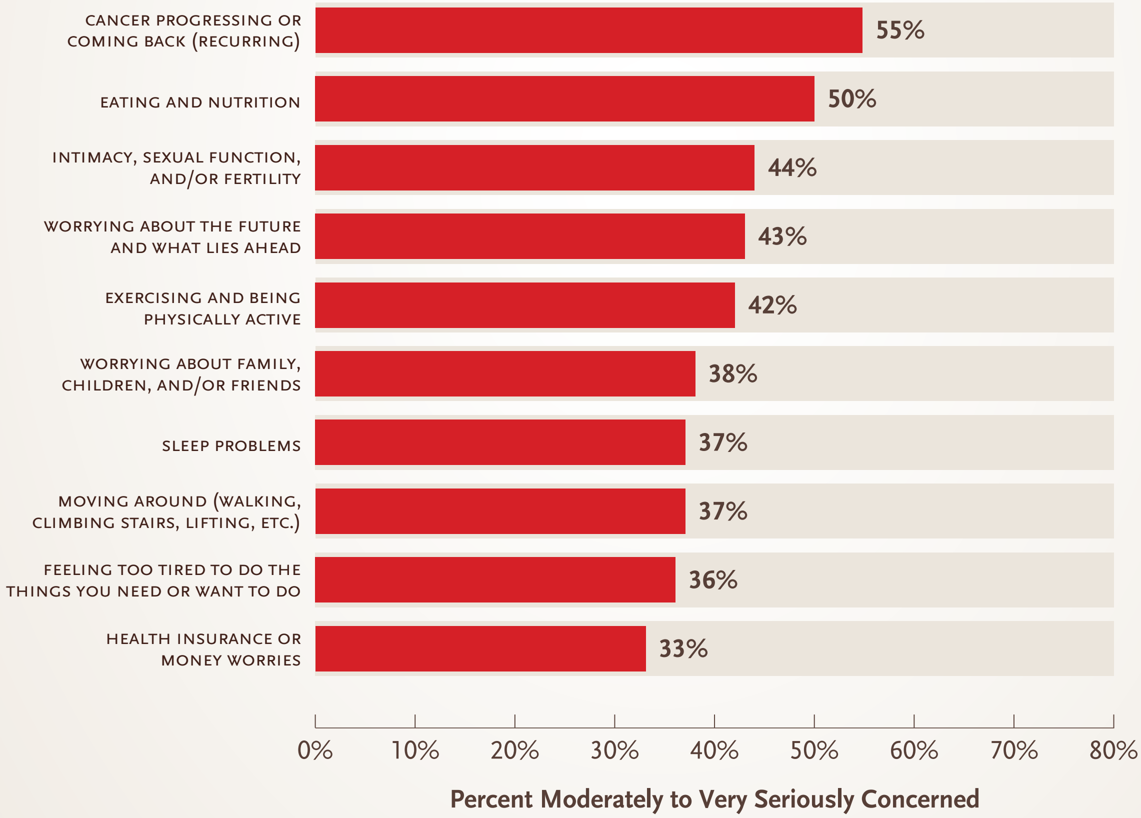
Among prostate cancer participants, the most prominent concerns were future-oriented or physical/intimacy-related.

More than one-half (55%) reported moderate to very serious concern about their cancer progressing or coming back.

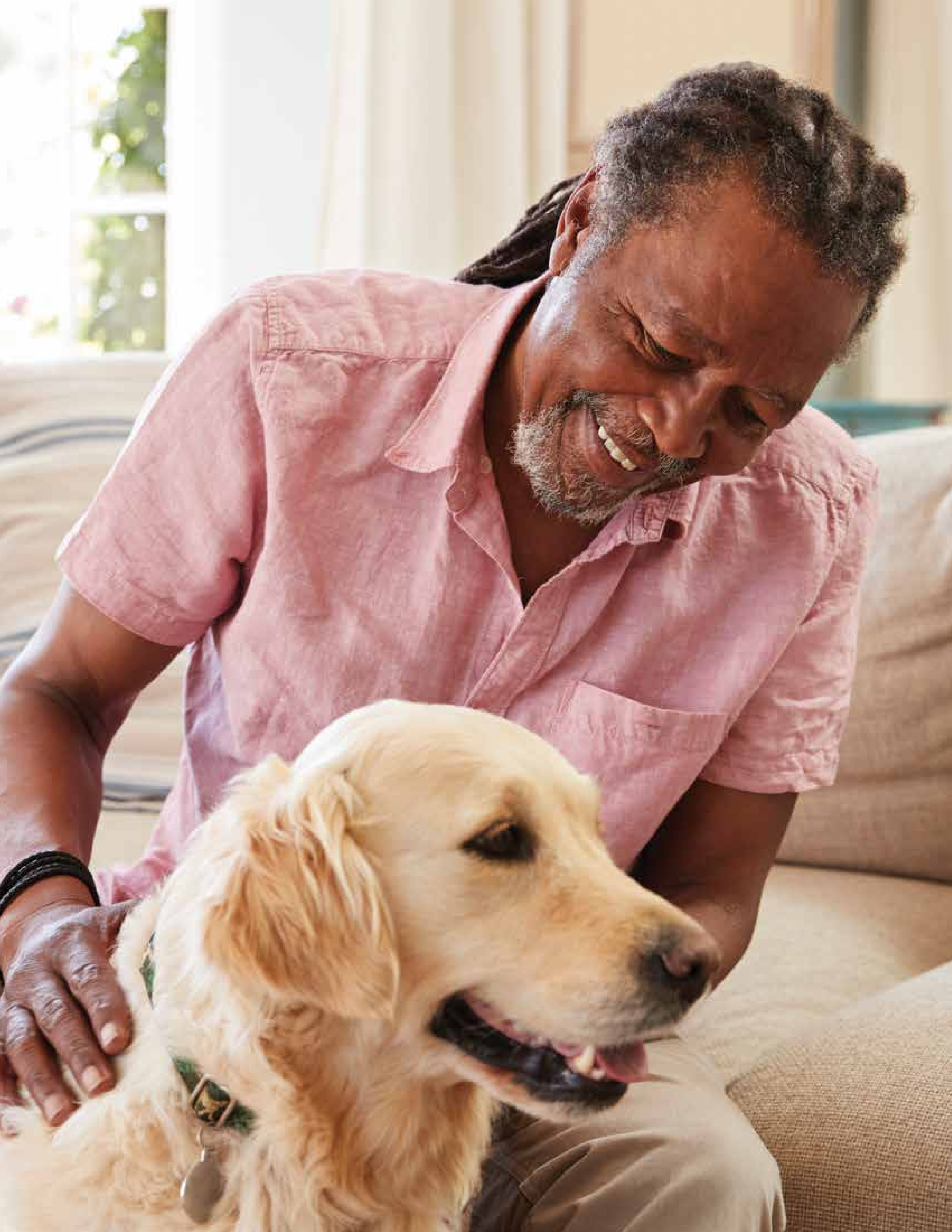
With regard to physical and intimacy health worries, one-half were moderately to very seriously concerned about eating and nutrition. And, as noted in the Key Findings, over 4 out of 10 (44%) were moderately to very seriously concerned about intimacy, sexual function, and/or fertility.

Worries about family, children, and/or friends was also a relatively strong concern among prostate cancer participants, at 38% (Figure 7C).

FIGURE 7C. TOP 10 CONCERNS AMONG PROSTATE CANCER PARTICIPANTS



Sample sizes range from 231 to 235, except for the recently added exploratory item, "Cancer progressing…," where the sample size is 100.



STOMACH CANCER REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**69%** were at risk for clinically significant levels of anxiety **50%** were at risk for clinically significant levels of depression	**59%** were moderately to very seriously concerned about feeling too tired to do the things they need/want to do	**29%** rated their overall health as poor or fair
SIDE EFFECT AND SYMPTOM MANAGEMENT	**68%** were moderately to very seriously concerned about eating and nutrition	**45%** reported physical function that was substantially worse than the national average	**33%** did not recall receiving information about long-term side effects of treatment
TREATMENT DECISION-MAKING	While **72%** were involved in treatment decision-making, only **52%** felt prepared to discuss treatment options with their doctor	**29%** indicated that they make decisions about medical care together with their loved ones	**1 out of 2** did not feel knowledgeable about treatment options prior to making their treatment decision
FINANCIAL IMPACT	About **6 out of 10** reported that no one from their health care team talked to them about the cost of their care	**1 out of 2** were moderately to very seriously concerned about health insurance or money worries	**1 out of 2** spent over $250 in monthly out-of-pocket costs to cover cancer care
PRACTICAL CONCERNS	**45%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**43%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**19%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 18 to 35.

8. STOMACH CANCER REGISTRY HIGHLIGHTS

8.1 STOMACH CANCER REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 117,000 people in the U.S. are living with stomach cancer.[8] Often, a diagnosis of stomach cancer brings with it a sense of urgency that must be acknowledged as a key part of the patient experience. The impact of this can be felt across activities of work, family, and school life. Findings from the Stomach Cancer Registry highlight the importance of incorporating quality of life and family impact considerations when engaging in shared treatment decision-making.[19] Delineation of the psychosocial factors that arise when undergoing treatment for stomach cancer has led to the development of patient services such as online communities, but the research is just emerging, and further study is needed to optimize and refine supportive care delivery.

> "When I heard I had cancer, I did not know what to do. I was...trying to handle the food problems, the nightmares, and daily life with cancer. So, I looked up the Cancer Support Community online. That's when they connected me with my buddy, Marcia [at CSC]. She helps me by listening and gives good advice because she knows where I'm coming from. She really has made a big difference in my life."
>
> **– Laura, stomach cancer patient**

The Stomach Cancer Registry, which includes questions uniquely relevant to people living with stomach cancer, was launched in February 2016. In this 2020 Registry Report, we present results on 45 stomach cancer participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with stomach cancer are represented in the results of the Caregiver Registry.

8.2 STOMACH CANCER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 8A. STOMACH CANCER REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 57 yrs	26 to 88 yrs
Female	27	60%
White	35	78%
Non-Hispanic Ethnicity	38	84%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 1.9 yrs	<1 to 10 yrs
Stage at Diagnosis		
0–I	7	18%
II–III	14	36%
IV	12	31%
Other/Don't know	6	15%
Ever Metastatic	10	26%
Experienced Recurrence	4	10%

*Total number of participants = 45. Sample sizes for Select Clinical Characteristics range from 37 to 39.

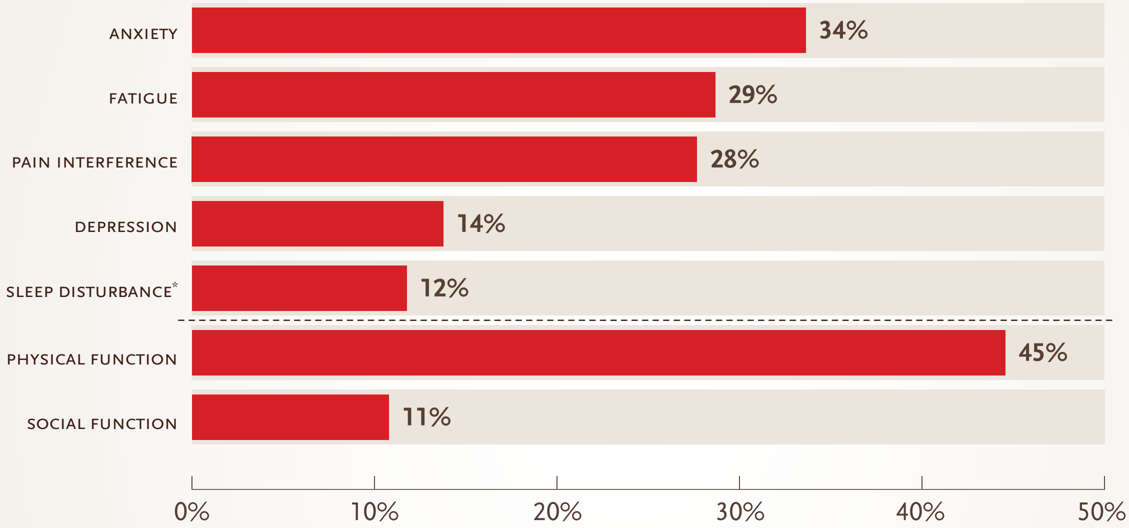
8.3 STOMACH CANCER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

As noted in the Key Findings, physical functioning was a prominent issue among stomach cancer participants. Nearly one-half (45%) reported physical function symptoms that were substantially worse than the national average.

One-third (34%) reported anxiety levels that were substantially worse (Figure 8B).

FIGURE 8B. PERCENT OF STOMACH CANCER PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 26 to 29.

8.4 STOMACH CANCER REGISTRY: CANCER-RELATED DISTRESS

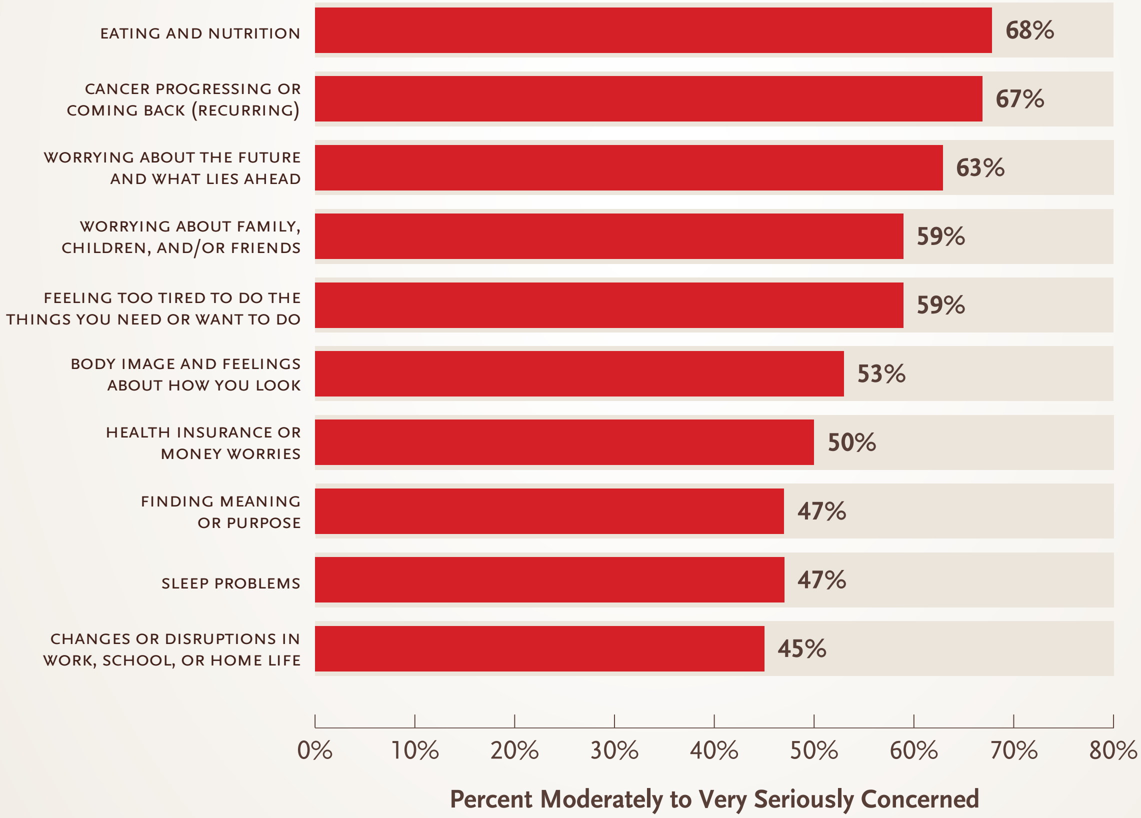
As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Stomach cancer participants had a number of notable concerns, the top ones of which included physical and future-oriented matters.

As noted in the Key Findings, two-thirds of respondents (68%) reported moderate to very serious concerns about eating and nutrition.

Stomach cancer participants were also quite concerned about the future: two-thirds reported moderate to very serious concerns about their cancer progressing or coming back and nearly as many (63%) were moderately to very seriously concerned about worrying about the future and what lies ahead.

Worrying about family, children, and/or friends was also a salient concern among stomach cancer patients, at 59% (Figure 8C).

FIGURE 8C. TOP 10 CONCERNS AMONG STOMACH PARTICIPANTS



Sample sizes range from 28 to 31, except for the recently added exploratory item, "Cancer progressing...," where the sample size is 9.

9. NEW INITIATIVE: LIVER CANCER REGISTRY

Approximately 90,000 people in the U.S. are currently living with liver or intrahepatic bile duct cancer.[8] Hepatocellular carcinoma (HCC) is the most common form, accounting for at least 85 percent of all primary liver cancers.[20] The cancer care options for liver cancer patients are complex and varied in nature and include surgical intervention, unique forms of radiation, and systemic therapy such as chemotherapy or immunotherapy. Health care team communication, symptom management/palliative care, and social support are among the facets of the liver cancer patient's lived experience that are important to understand.

In September 2019, CSC launched its Liver Cancer Registry for patients affected by primary liver cancer. This Registry focuses on people who have a primary liver cancer diagnosis – that is, the cancer originated in the liver rather than spread to the liver. The Liver Cancer Registry explores access to cancer care and the nature of that care, treatment options (including liver transplant), and cancer perceptions among liver cancer patients. Results from the Liver Cancer Registry will be provided in future reports.

AML REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**61%** were at risk for clinically significant levels of anxiety **50%** were at risk for clinically significant levels of depression	**64%** were moderately to very seriously concerned about exercising and being physically active **61%** were moderately to very seriously concerned about eating and nutrition	**47%** rated their overall health as poor or fair
SIDE EFFECT AND SYMPTOM MANAGEMENT	**45%** felt inadequately prepared to manage side effects of treatment	**47%** did not recall receiving information about long-term side effects of treatment	**1 out of 2** held back from telling their health care team about side effects and symptoms
TREATMENT DECISION-MAKING	While **67%** were involved in treatment decision-making, only **36%** felt prepared to discuss treatment options with their doctor	**3 out of 10** were not satisfied with how much they participated in making the treatment decision	**48%** indicated that they make decisions about medical care together with their loved ones
FINANCIAL IMPACT	**2 out of 3** reported that no one from their health care team talked to them about the cost of their care	**4 out of 10** spent over $500 in monthly out-of-pocket costs to cover cancer care	**1 out of 2** were moderately to very seriously concerned about health insurance or money worries
PRACTICAL CONCERNS	**51%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**42%** were moderately to very seriously concerned about thinking clearly (“chemo brain” or “brain fog”)	**16%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 21 to 38.

10. ACUTE MYELOID LEUKEMIA REGISTRY HIGHLIGHTS

10.1 ACUTE MYELOID LEUKEMIA REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 65,000 people in the U.S. are currently living with acute myeloid leukemia (AML)[8] — one of the four main types of leukemia or cancer of the bone marrow. Recent developments in science have revealed that AML, in and of itself, is actually a number of different sub-types based on genetic profiles or molecular testing. These findings alone have led to promising and complex care scenarios for patients and families. In addition, AML is an "acute" cancer which, by definition, means that the patient's health status is rapidly changing and must be monitored closely for a period of weeks, months, and even years. Given the complexity and high degree of uncertainty surrounding the AML patient experience, it is critically important that the cancer care community understand as much as possible about the journey through the eyes of both the patient and the caregiver in order to best understand service delivery, patient care, and policy implications that may impact access to care, frameworks of care, and home, family, and work life.

> "Receiving a diagnosis of such an aggressive disease really leaves you in a difficult psychological space. You are trying to balance treatment decisions, family and friend responses, and your own emotional turmoil. By having the chance to complete the registry, you can really prioritize your thoughts and plans and feel good that the information that is gathered will help others going through the same thing."
>
> **– Kelly, AML survivor and CEO,**
> **Cancer Support Community, Greater Philadelphia**

The AML Registry, which includes questions uniquely relevant to people living with AML, was launched in October 2018. In this 2020 Registry Report, we present results on 51 AML participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with AML are represented in the results of the Caregiver Registry.

10.2 ACUTE MYELOID LEUKEMIA REGISTRY: WHO IS IN THE REGISTRY

FIGURE 10A. AML REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 52 yrs	20 to 77 yrs
Female	32	63%
White	44	86%
Non-Hispanic Ethnicity	44	86%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 5.7 yrs	<1 to 40 yrs
Experienced Recurrence	11	26%

*Total number of participants = 51. Sample size for Select Clinical Characteristics = 43.

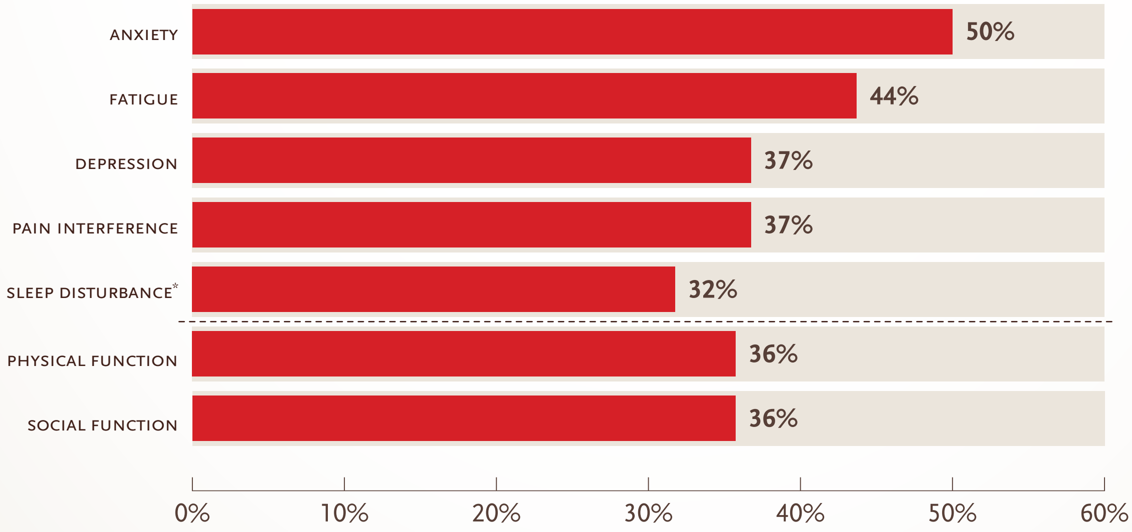
10.3 ACUTE MYELOID LEUKEMIA REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data on AML participants, anxiety was a particularly salient issue: one-half of participants reported symptoms of anxiety that were substantially worse than the national average – consistent with the clinical anxiety risk noted previously in the Key Findings.

Fatigue is also a notable issue among AML respondents: more than 4 out of 10 (44%) reported levels of fatigue that were substantially worse than the national average (Figure 10B).

FIGURE 10B. PERCENT OF AML PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 27 to 28.

10.4 ACUTE MYELOID LEUKEMIA REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15).

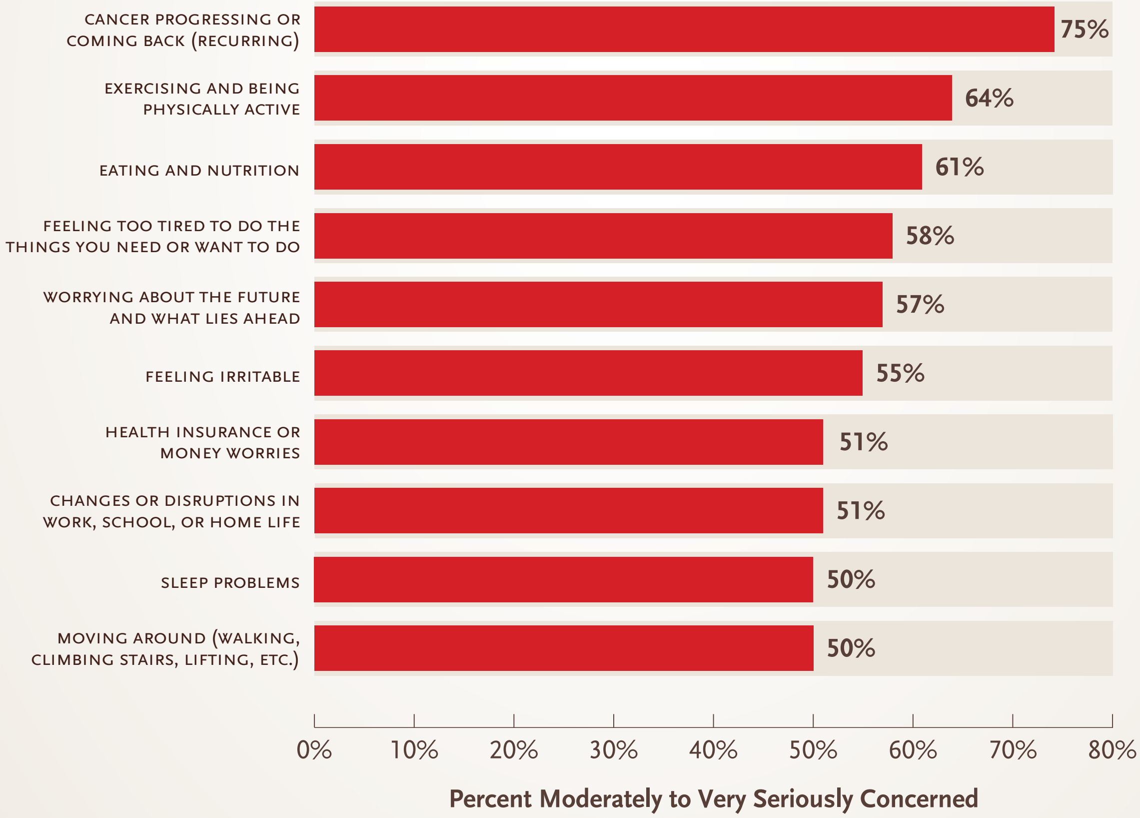
AML respondents reported a number of substantial concerns, the most prominent ones of which were future-focused or physical in nature.

The future weighed quite heavily among our AML participants: three-quarters were moderately to very seriously concerned about their cancer progressing/coming back and nearly 6 out of 10 (57%) were worried about the future and what lies ahead.

With respect to physical concerns, the majority of respondents (64%, 61%, and 58%, respectively) reported being moderately to very seriously concerned about exercising/being physically active, eating/nutrition, and feeling too tired to do the things they need/want to do – the last of these is consistent with our quality of life findings on fatigue.

Irritability was also a notable concern for many AML participants, at 55% (Figure 10C).

FIGURE 10C. TOP 10 CONCERNS AMONG AML PARTICIPANTS



Sample sizes range from 36 to 38, except for the recently added exploratory item, "Cancer progressing…," where the sample size is 12.

CHRONIC LYMPHOCYTIC LEUKEMIA REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**36%** were at risk for clinically significant levels of anxiety **31%** were at risk for clinically significant levels of depression	**52%** were moderately to very seriously concerned about eating and nutrition **42%** were moderately to very seriously concerned about exercising and being physically active	**20%** rated their overall health as poor or fair
PSYCHOSOCIAL IMPACT	**34%** of survivors said that CLL somewhat to very much affects their ability to work	**42%** reported that CLL somewhat to very much affects their day-to-day finances	**30%** said that CLL somewhat to very much affects their relationships with friends and family
TREATMENT DECISION-MAKING	**72%** were involved in treatment decision-making **62%** felt prepared to discuss treatment options with their doctor	**56%** indicated that they make decisions about medical care together with their loved ones	**23%** described themselves as not at all comfortable or somewhat uncomfortable with "watch and wait" (active surveillance)
FINANCIAL IMPACT	**7 out of 10** reported that no one from their health care team talked to them about the cost of their care	**1 out of 3** spent over $250 in monthly out-of-pocket costs to cover cancer care	**1 out of 3** were moderately to very seriously concerned about health insurance or money worries
PRACTICAL CONCERNS	**32%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**24%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**7%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 116 to 165.

11. CHRONIC LYMPHOCYTIC LEUKEMIA REGISTRY HIGHLIGHTS

11.1 CHRONIC LYMPHOCYTIC LEUKEMIA REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 186,000 people in the U.S. are living with chronic lymphocytic leukemia (CLL), making it one of the most common forms of adult leukemia.[8] Within CLL, there are at least two subtypes which can impact the patient experience and outcomes. Additionally, the diagnostic and treatment landscape has evolved in a way that makes it vitally important to ensure that the CLL patient journey is well understood and that it is shared across the cancer care community. One example of this is a previous finding from the CLL Registry: at a time when conversations about new treatments and shared decision-making are paramount, many patients report not having these types of conversations with their health care teams.[21] Additional information about quality of life, patients' feelings about the timing of treatment, "watch and wait," financial toxicity, and stigma associated with appearance have also been uncovered and reported as a part of the Cancer Experience Registry work. Findings like these and the others noted in this report allow patients, providers, and loved ones to proactively engage in the journey to facilitate optimal care and ensure the best possible outcomes for patients and their loved ones.

> "To a patient or caregiver, I would say 'Your voice can be heard and you can still remain private! Participating in the Cancer Experience Registry provides valuable insights to a wide range of researchers and providers. These insights transform into better cancer journeys and outcomes for you and those who share your path. Please consider participating today!'"
>
> **– Jeff, CLL patient and CSC Advisory Board Member**

The CLL Registry, which includes questions uniquely relevant to those living with the disease, was launched in April 2015. In this 2020 Registry Report, we present results on 191 CLL participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with CLL are represented in the results of the Caregiver Registry.

11.2 CHRONIC LYMPHOCYTIC LEUKEMIA REGISTRY: WHO IS IN THE REGISTRY

FIGURE 11A. CLL REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 61 yrs	18 to 89 yrs
Female	95	50%
White	181	95%
Non-Hispanic Ethnicity	183	96%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 6.6 yrs	<1 to 25 yrs
Stage at Diagnosis		
0 (or A)	68	42%
1 or 2 (or B)	40	25%
3 or 4 (or C)	26	16%
Other/Don't know	28	17%
Experienced Recurrence	32	19%

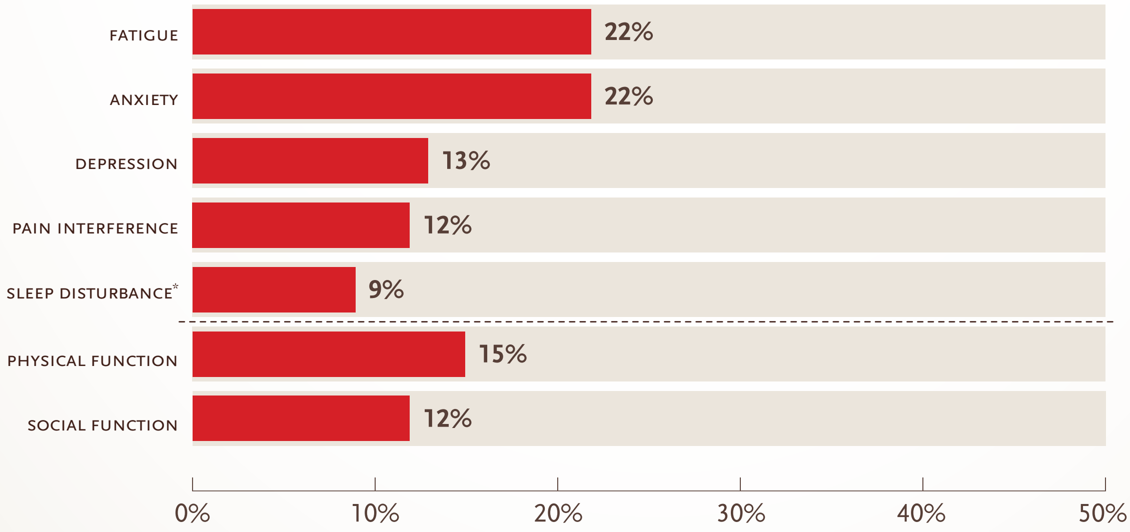
*Total number of participants = 191. Sample sizes for Select Clinical Characteristics range from 162 to 172.

11.3 CHRONIC LYMPHOCYTIC LEUKEMIA REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

The PROMIS-29 data suggest that anxiety and fatigue were the most notable quality of life issues among CLL participants: about one-fifth (22%, each) reported anxiety and fatigue symptoms that were substantially worse than the national average for each (Figure 11B).

FIGURE 11B. PERCENT OF CLL PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 149 to 154.

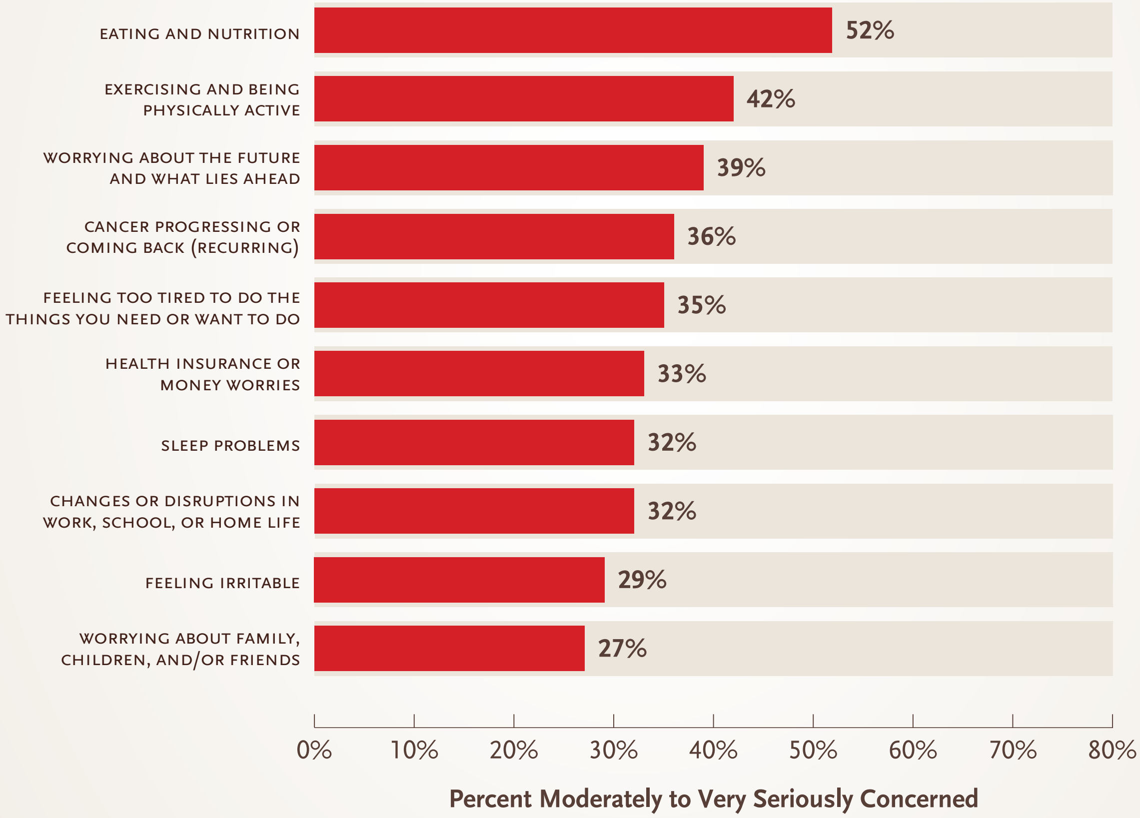
11.4 CHRONIC LYMPHOCYTIC LEUKEMIA REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Among CLL participants, the highest rated concerns included physical and future-focused matters.

As noted in the Key Findings, about one-half (52%) of respondents reported being moderately to very seriously concerned about eating and nutrition and about 4 out of 10 (42%) were moderately to very seriously concerned about exercising and being physically active.

Nearly as many (39% and 36%, respectively) were concerned about the future/what lies ahead and their cancer progressing/coming back (Figure 11C).

FIGURE 11C. TOP 10 CONCERNS AMONG CLL PARTICIPANTS



Sample sizes range from 155 to 158, except for the recently added exploratory item, “Cancer progressing…,” where the sample size is 14.

CHRONIC MYELOID LEUKEMIA REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**50%** were at risk for clinically significant levels of anxiety **41%** were at risk for clinically significant levels of depression	**69%** were moderately to very seriously concerned about eating and nutrition **61%** were moderately to very seriously concerned about feeling too tired to do the things they need/want to do	**46%** rated their overall health as poor or fair
ADHERENCE TO ORAL MEDICATION	**18%** reported that they miss a dose of CML medicine at least once a month	**31%** believed it is okay to miss a dose of CML medicine every now and then	**29%** indicated that they never tell their health care team if they miss or skip a dose or doses of medication
SIDE EFFECT AND SYMPTOM MANAGEMENT	**70%** said that fatigue interfered with their daily life over the past 30 days	**44%** reported that loss of concentration/memory interfered with their daily life	**26%** believed their family members have little to no understanding of their side effects and symptoms
FINANCIAL IMPACT	**1 out of 2** reported an unexpected financial burden because of the cost of oral medications	Nearly **4 out of 10** depleted savings or used money from retirement to cover treatment costs	**3 out of 10** spent over $250 in monthly out-of-pocket costs to cover cancer care
PRACTICAL CONCERNS	**48%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**53%** were moderately to very seriously concerned about thinking clearly ("chemo brain" or "brain fog")	**52%** were moderately to very seriously concerned about sleep problems

Sample sizes range from 24 to 289.

12. CHRONIC MYELOID LEUKEMIA REGISTRY HIGHLIGHTS

12.1 CHRONIC MYELOID LEUKEMIA REGISTRY: INTRODUCTION AND KEY FINDINGS

Chronic myeloid leukemia (CML) is a particularly noteworthy patient experience scenario. Due to advancements in science, it has been projected that, in 2020, approximately 70,000 people in the U.S. will be living with CML. Moreover, that number is expected to more than double to 144,000 by 2030.[22] This anticipated increase in prevalence is largely attributed to improved treatment options for CML, which began in 2001 and led to what is now one of the most controllable long-term cancers – contingent, in large part, on patient adherence to their medication schedule. The treatment breakthrough for CML significantly shifted the way in which this type of cancer is experienced in terms of quality of life, financial planning, family engagement, and beyond. Past findings from the CML Registry have revealed a number of patient experience concerns, including suboptimal medication adherence related to the combination of financial toxicity and risk for clinically significant depression.[23] Understanding these concerns has led to interventions to assist with both potential obstacles to care, but the work in this area is ongoing as the patient and caregiver experience continues to evolve.

> "Treatment for CML is a journey over years' time and includes several medicine choices, side effect management, investigating links to other aspects of one's health such as cardiovascular/heart health, and at present includes the possibility of stopping treatment someday. Finding the psychosocial support and tools to navigate this journey successfully is essential and a part of taking care of not just the CML but the whole person and those on the journey with them."
>
> **– Michael, MD, Leader, Myeloproliferative Neoplasms Program, Member, Memorial Sloan Kettering Cancer Center, Professor, Weill Cornell Medicine**

The CML Registry, which includes questions uniquely relevant to people living with CML, was launched in October 2013. In this 2020 Registry Report, we present results on 410 CML participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with CML are represented in the results of the Caregiver Registry.

12.2 CHRONIC MYELOID LEUKEMIA REGISTRY: WHO IS IN THE REGISTRY

FIGURE 12A. CML REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 55 yrs	18 to 84 yrs
Female	272	66%
White	365	89%
Non-Hispanic Ethnicity	368	90%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 6.8 yrs	<1 to 25 yrs
Stage at Diagnosis		
Chronic	259	90%
Advanced	5	2%
Other/Don't know	23	8%
Experienced Recurrence	5	19%

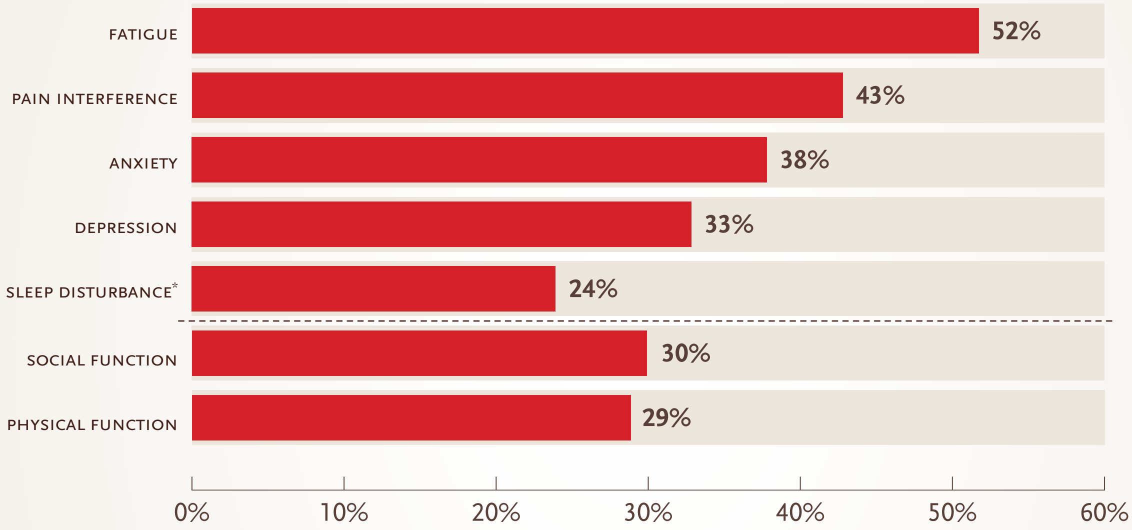
*Total number of participants = 410. Sample sizes for Select Clinical Characteristics range from 26 to 287.

12.3 CHRONIC MYELOID LEUKEMIA REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data, among CML participants, the most prominent issue was fatigue: about one-half (52%) reported levels of fatigue that were substantially worse than the national average. This speaks to the theme of fatigue among CML participants noted in the Key Findings. Pain interference was also a notable issue: more than 4 out of 10 (43%) reported levels of pain interference that were substantially worse than the national average (Figure 12B).

FIGURE 12B. PERCENT OF CML PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 20 to 21.

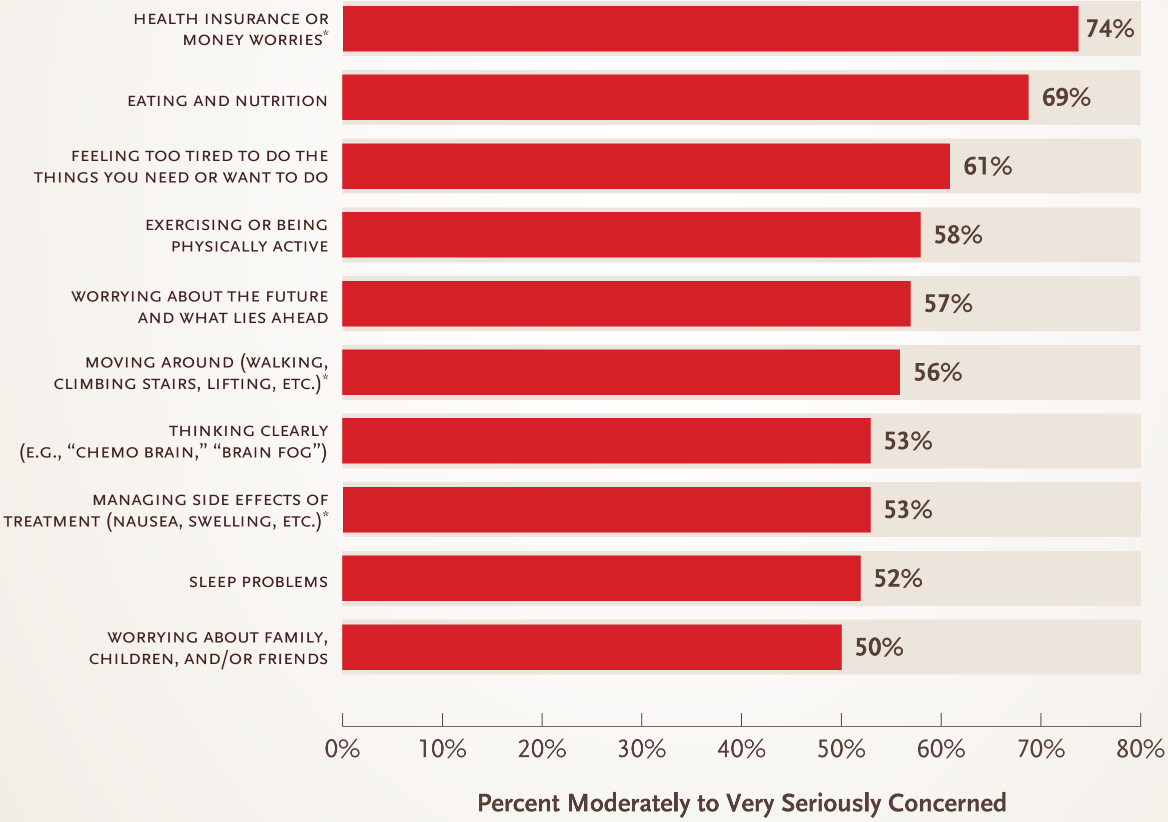
12.4 CHRONIC MYELOID LEUKEMIA REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15). Among CML participants, the most prominent concerns included financial and physical issues.

Three-quarters (74%) of CML participants were moderately to very seriously concerned about health insurance or money worries. This is consistent with the "unexpected financial burden" experienced by many CML respondents noted in the Key Findings.

With regard to physical well-being, 7 out of 10 (69%) reported being moderately to very seriously concerned about eating/nutrition and 6 out of 10 (61%) reported being moderately to very seriously concerned about feeling too tired to do the things they want or need to do; the latter result further speaks to the theme of fatigue noted among CML participants (Figure 12C).

FIGURE 12C. TOP 10 CONCERNS AMONG CML PARTICIPANTS



Sample sizes range from 284 to 289 with the following exceptions: the *'d items have sample sizes of 18 to 19 due to changes in the survey from an earlier version.

MULTIPLE MYELOMA REGISTRY: 2020 KEY FINDINGS

QUALITY OF LIFE AND DISTRESS	**38%** were at risk for clinically significant levels of anxiety **33%** were at risk for clinically significant levels of depression	**61%** were moderately to very seriously concerned about eating and nutrition **58%** were moderately to very seriously concerned about moving around (walking, climbing stairs, lifting, etc.)	**50%** rated their overall health as poor or fair
SOCIAL AND WORK IMPACT	**43%** were reluctant to ask for help	**42%** reported having limited contact with family or friends	**38%** reported having forgone job opportunities or career advancement
SIDE EFFECT AND SYMPTOM MANAGEMENT	**65%** said that fatigue interferes with their daily life	**35%** reported substantially worse fatigue than the national average	Nearly **3 out of 10** held back from telling their health care team about side effects and symptoms
FINANCIAL IMPACT	Nearly **1 out of 2** were moderately to very seriously concerned about health insurance or money worries	**4 out of 10** depleted savings or used money from retirement to cover treatment costs	**1 out of 4** spent over $500 in monthly out-of-pocket costs to cover cancer care
PRACTICAL CONCERNS	**42%** were moderately to very seriously concerned about changes or disruptions in work, school, or home life	**46%** were moderately to very seriously concerned about thinking clearly (“chemo brain” or “brain fog”)	**12%** were moderately to very seriously concerned about transportation to treatment and appointments

Sample sizes range from 60 to 296.

13. MULTIPLE MYELOMA REGISTRY HIGHLIGHTS

13.1 MULTIPLE MYELOMA REGISTRY: INTRODUCTION AND KEY FINDINGS

Approximately 141,000 individuals in the U.S. are currently living with multiple myeloma.[8] Multiple myeloma is another of the cancer types which has largely become more of a manageable and chronic illness. Due to the longevity of the Multiple Myeloma Registry, CSC has published a number of findings on the unique nature of this type of cancer. These publications illuminate the patient experiences with, for example, symptoms, quality of life, sleep disturbance, and financial toxicity. A key learning is that the cyclical nature of multiple myeloma may contribute to patients feeling a lack of control over the course of their disease and this perceived lack of control is associated with higher levels of anxiety, depression, and fatigue.[24] As the disease management outlook continues to evolve, it is important to understand how the psychosocial experiences and needs of patients and families are also evolving.

> "I have to build my immune system. I went to a nutritionist [Registered Dietitian] and she gave me great information on how to keep up with good nutrition. It really helps me."
>
> **– Cathy, diagnosed with multiple myeloma**

The Multiple Myeloma Registry, which includes questions uniquely relevant to people living with multiple myeloma, was launched in June 2013. In this 2020 Registry Report, we present results on 442 multiple myeloma participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information. Caregivers of patients with multiple myeloma are represented in the results of the Caregiver Registry.

13.2 MULTIPLE MYELOMA REGISTRY: WHO IS IN THE REGISTRY

FIGURE 13A. MULTIPLE MYELOMA REGISTRY DEMOGRAPHICS AND SELECT CLINICAL CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 62 yrs	28 to 97 yrs
Female	260	59%
White	365	83%
Non-Hispanic Ethnicity	395	89%
SELECT CLINICAL CHARACTERISTICS:		
Time Since Diagnosis	Average: 4.4 yrs	<1 to 54 yrs
Stage at Diagnosis		
0–I	55	18%
II–III	145	47%
IV	11	4%
Other/Don't know	98	32%
Experienced Recurrence	23	31%

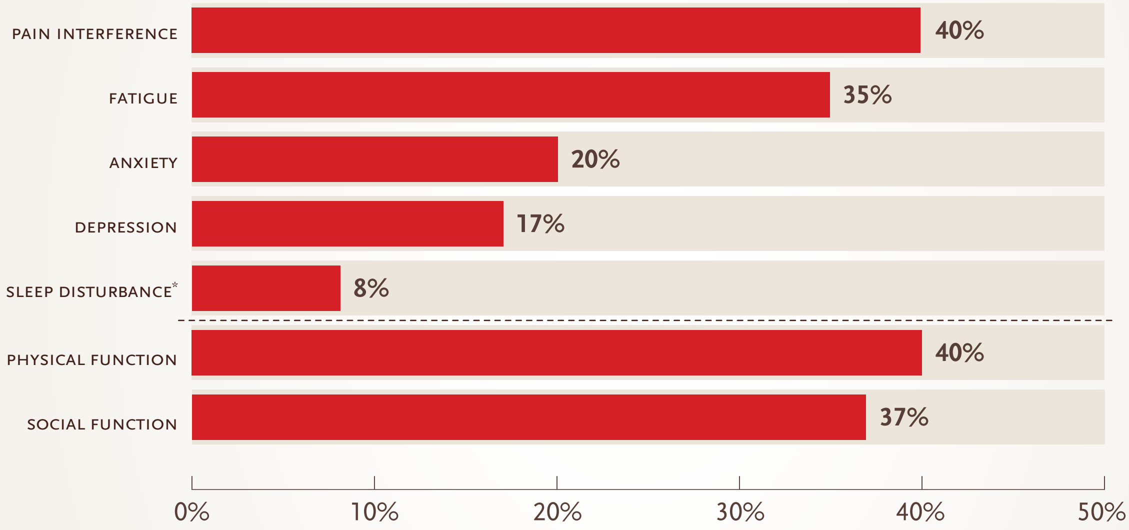
*Total number of participants = 442. Sample sizes for Select Clinical Characteristics range from 74 to 309.

13.3 MULTIPLE MYELOMA REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how patients describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Within the PROMIS-29 data, pain interference, physical functioning, and social functioning were the most prominent issues among multiple myeloma participants. Four out of 10 participants (40%, each) reported pain interference and physical function symptoms that were substantially worse than the national average for each. Nearly as many (37%) reported social function symptoms that were substantially worse. These results, collectively, are consistent with the mobility and fatigue concerns noted in the Key Findings (Figure 13B).

FIGURE 13B. PERCENT OF MULTIPLE MYELOMA PARTICIPANTS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

Sample sizes range from 276 to 292, except for Pain Interference (58) and Social Function (59) due to changes in the survey from an earlier version.

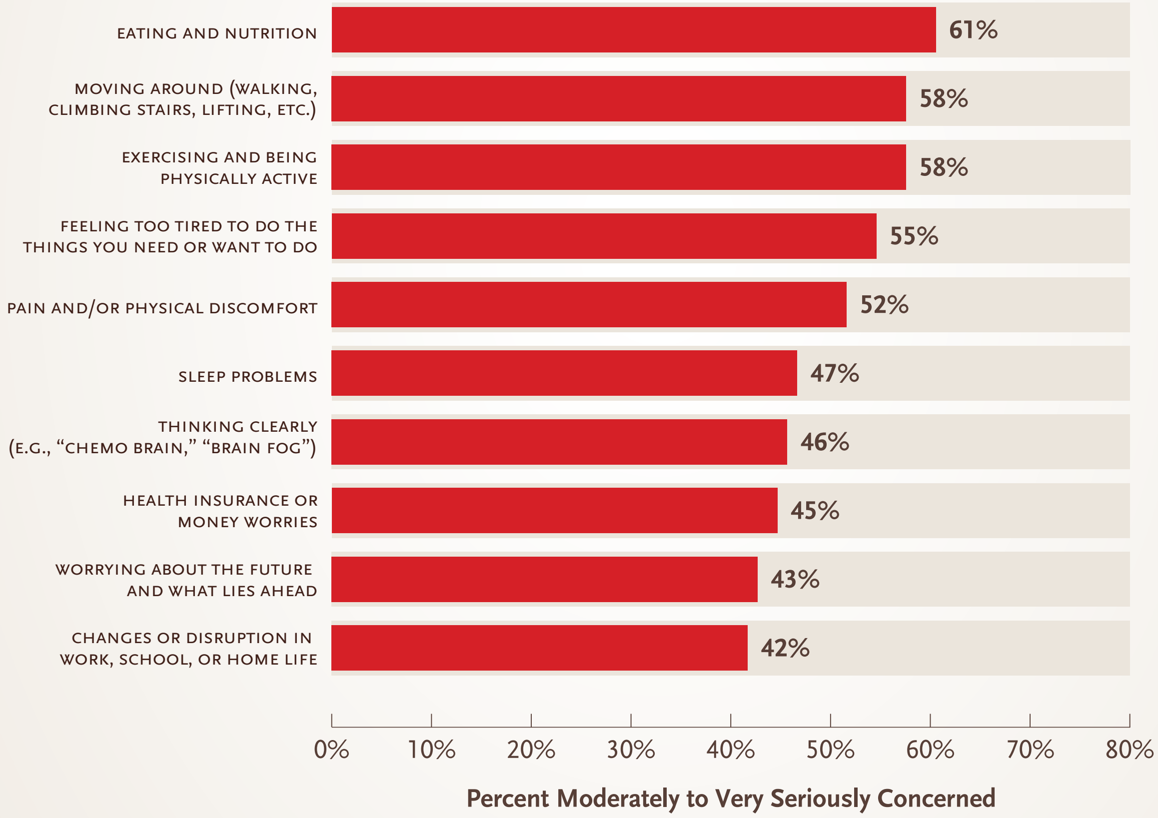
13.4 MULTIPLE MYELOMA REGISTRY: CANCER-RELATED DISTRESS

As described in Section 1.4, the Cancer Experience Registry measures cancer-related distress using CSS-25 and 4 additional exploratory items (see page 15).

Among multiple myeloma participants, not surprisingly, the most salient concerns were primarily physical in nature. As reported earlier, 6 out of 10 respondents (61%) reported moderate to very serious concern about eating and nutrition. Nearly as many (58%, 58%, and 55%, respectively) were moderately to very seriously concerned about moving around, exercising and being physically active, and feeling too tired to do the things they want or need to do. These last findings further support the themes of fatigue and impaired mobility noted previously among our multiple myeloma patients.

Thinking clearly ("chemo brain") was also a notable concern in this participant group, at 46% (Figure 13C).

FIGURE 13C. TOP 10 CONCERNS AMONG MULTIPLE MYELOMA PARTICIPANTS



Sample sizes range from 290 to 296.

CAREGIVER REGISTRY: 2020 KEY FINDINGS

CAREGIVER ROLES	**89%** were quite a bit/very much involved in providing emotional support **80%** were quite a bit/very much involved in going to medical appointments with the patient	**20%** spent more than 100 hours per week caregiving	**16%** reported having received formal caregiving training **41%** of those trained wanted additional training
TREATMENT DECISION-MAKING	**39%** reported making decisions together with the patient	**2 out of 3** were quite a bit/very much involved in patients' treatment decisions	**29%** reported that patients make decisions after considering their opinion
PREPAREDNESS	More than **1 out of 2** felt at least pretty well prepared to respond to and handle patient emergencies **(60%)** and care for physical needs **(58%)**	**58%** did not feel prepared to care for patient's emotional needs	**68%** did not feel prepared to handle caregiving stress
QUALITY OF LIFE AND DISTRESS	**49%** reported substantially worse anxiety than the national average	**34%** reported substantially worse fatigue than the national average	**39%** said their health was somewhat or much worse than before they began their caregiver role
CAREGIVER NEEDS	**3 out of 4** wanted help with understanding the patient's medical condition and treatment	More than **1 out of 2** wanted help managing health benefits and financial services	Nearly **1 out of 2** reported at least sometimes experiencing a sense of loss of control over their own life

Sample sizes range from 81 to 655.

14. CAREGIVER REGISTRY HIGHLIGHTS

14.1 CAREGIVER REGISTRY: INTRODUCTION AND KEY FINDINGS

Caregivers include partners, spouses, adult children, siblings, and non-family members providing informal care to cancer patients. The vast majority of caregivers are involved in supporting patient-clinician interactions, researching treatment options and medical information, ensuring treatment compliance, and serving as a general "point person" in care. There is growing recognition of the benefits that caregivers provide in patient outcomes, particularly as cancer treatment is increasingly provided through outpatient services. Yet, cancer caregivers are often thrust into their role with little advanced warning or preparation. Moreover, caregiving can have a significant impact on the physical and psychological well-being of caregivers.[25]

To understand the psychosocial and practical needs of caregivers, the Caregiver Registry was launched in December 2014. In this section, we present results on 688 caregiver participants who resided in the U.S. or U.S. protectorates at the time of enrollment and who provided at least basic demographic information.

> "People talk about a caregiver, but you don't really know what a caregiver is until you're really in that role…I learned that a caregiver wears many hats: listener, observer, protector, planner, anticipator, the backup brain to the patient, the organizer, the strong one, the levelheaded one. The caregiver is the go-to person all the time…I quickly realized that I could not do it all and that I needed help."
>
> **– Sheri, Bereaved/Former caregiver for a close friend**

14.2 CAREGIVER REGISTRY: WHO IS IN THE REGISTRY

FIGURE 14A. CAREGIVER REGISTRY DEMOGRAPHICS AND SELECT CAREGIVING CHARACTERISTICS

	NUMBER OF PARTICIPANTS*	PERCENT OR RANGE
DEMOGRAPHICS:		
Age	Average: 52 yrs	18 to 91 yrs
Female	548	80%
White	577	84%
Non-Hispanic Ethnicity	587	85%
SELECT CAREGIVING CHARACTERISTICS:		
Person Caring For		
Spouse/Partner	283	53%
Parent/Parent-in-law	132	25%
Other	122	23%
Years Providing Care	Average: 3.6 yrs	<1 to 35 years

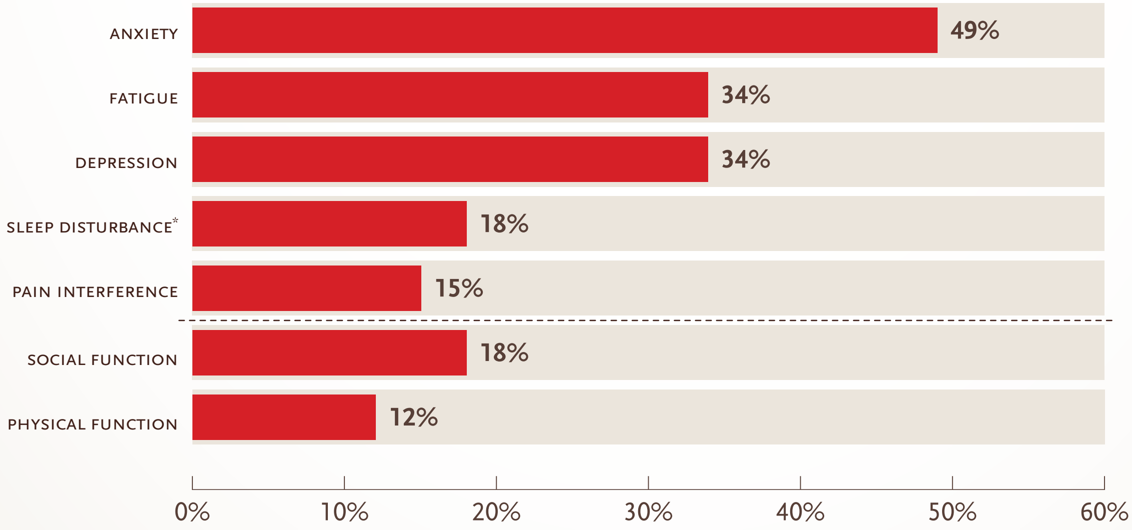
*Total number of participants = 688. Sample sizes for Select Caregiving Characteristics ranged from 527 to 537.

14.3 CAREGIVER REGISTRY: QUALITY OF LIFE

As described in Section 1.3, the Cancer Experience Registry incorporates the PROMIS-29, which examines how caregivers describe their quality of life compared to the U.S. population average in 7 different domains (see page 14).

Anxiety is a particularly salient issue among our Caregiver Registry participants. One-half (49%) of respondents reported anxiety levels substantially worse than the national average. One-third (34%, each) reported fatigue and depression levels that were substantially worse. The fatigue, in particular, is consistent with the substantial support caregivers provide, as described in the Key Findings (Figure 14B).

FIGURE 14B. PERCENT OF CAREGIVERS REPORTING WORSE QUALITY OF LIFE*



*Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than that of the United States general population. For Sleep Disturbance, comparisons are to a mix of the U.S. population and people with chronic illness.

The sample sizes range from 542 to 562, except the exception of physical function (261) and pain interference (256), which were recently added to the Caregiver Registry survey.

14.4 CAREGIVER REGISTRY: CANCER-RELATED DISTRESS

The Caregiver Registry examines cancer-related distress using a unique 33-item version of CSS (Cancer Support Source-Caregiver or CSS-CG) developed specifically for use with cancer caregivers (see page 15).[26]

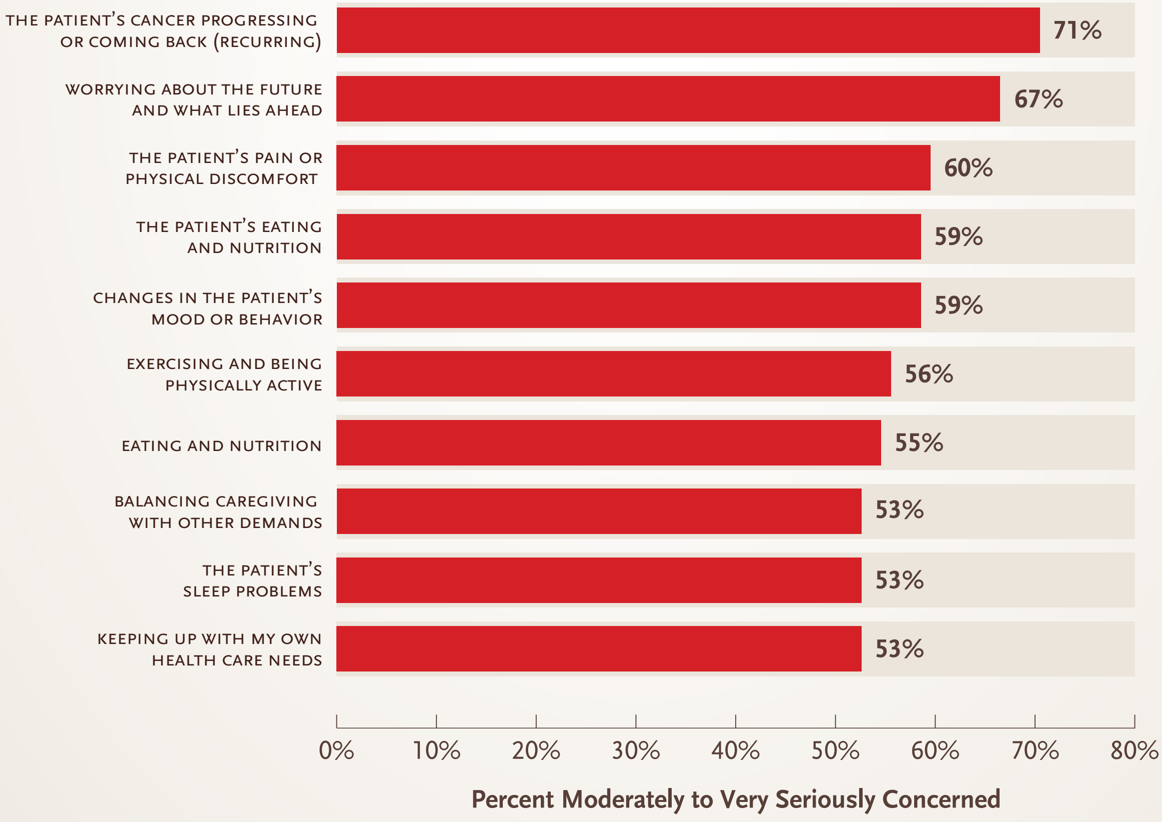
Our findings demonstrate that the future weighs quite heavily on caregivers: a sizable majority (71%) reported moderate to very serious concerns about the patient's cancer progressing or coming back, and nearly as many (67%) reported moderate to very serious concerns about worrying about the future and what lies ahead.

Caregivers also had substantial worries about the patient's physical and emotional health: specifically, caregivers expressed moderate to very serious concerns over the patient's pain or physical discomfort, the patient's eating and nutrition, and changes in the patient's mood or behavior, at 60%, 59%, and 59%, respectively.

Caregivers' own well-being concerned them as well: more than one-half reported moderate to very serious concerns about exercising/being physically active (56%) and eating/nutrition (55%).

One other notable area of concern among caregivers – which is often overlooked – was balancing caregiving with other demands (53%; Figure 14C).

FIGURE 14C. TOP 10 CONCERNS AMONG CAREGIVER PARTICIPANTS



Sample sizes range from 285 to 297.

CLOSING STATEMENT

The results presented in this report are intended to provide a broad overview of the physical, emotional, social, practical, and functional issues facing patients and caregivers in the cancer journey. The findings presented are not intended to be comprehensive; we continue to explore facets of the cancer experience in the ever-evolving cancer care landscape.

Highlights from our research portfolio can be found at www.CancerSupportCommunity.org/our-research

We are also actively committed to expanding our respondent pool to include the experiences and perspectives of underrepresented communities to better represent the U.S. cancer patient and caregiver populations by gender, age, sexual identity, race, ethnicity, income, geography, and cancer type to address their unique challenges to care. CSC looks forward to even greater collaboration with patients, caregivers, and our dedicated community of health care clinicians and researchers, donors, and sponsors.

We invite you to join us as we continue the important work of elevating the evolving needs and concerns of people impacted by cancer and sharing the major findings highlighted in this report. And, we encourage you to promote the Cancer Experience Registry to patients and caregivers.

Learn more at cancerexperienceregistry.org or contact us at research@cancersupportcommunity.org

CSC RESOURCES

The resources below are just a few of the many free offerings at CSC that are available for patients, survivors, and caregivers:

Cancer Support Helpline (888.793.9355) – a helpline staffed by licensed mental health professionals and resource specialists which provides information, referrals, financial counseling, and emotional support to both patients and caregivers

Caregiver Resources (www.CancerSupportCommunity.org/caregivers) – a website dedicated to providing support, tips, and resources specifically for caregivers

Frankly Speaking About Cancer® (www.CancerSupportCommunity.org/franklyspeakingaboutcancer) – a cancer education series that provides valuable information on a range of topics important to people affected by cancer through a variety of formats, including print, digital, and in-person programming

MyLifeLine® (www.mylifeline.org) – an online platform where patients and caregivers can safely and privately join discussion boards and connect with others in their own personal community

Open to Options® (www.CancerSupportCommunity.org/opentooptions) – a decision-support counseling program that helps prepare patients at any stage of cancer for treatment decision-making with their health care team

Grassroots Policy Movement (www.CancerSupportCommunity.org/join-our-movement) – a network where patients and caregivers can get up-to-date information on key issues in the cancer care landscape and where participants have an opportunity to interact with policy makers on issues important to those impacted by cancer

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ACKNOWLEDGEMENTS

We thank all of the advisors to our Cancer Experience Registry for their expert guidance and contributions to the work of the Research and Training Institute. We are inspired by their commitment to improving quality of life of cancer patients, survivors, and caregivers. Please see the full list of RTI Advisory Council members at www.CancerSupportCommunity.org/research-and-training-institute-advisory-council.

We thank the following Registry sponsors for their critical contributions of information and support that make the Cancer Experience Registry a reality: **AbbVie, Inc.**, **Amgen**, **Astellas Pharma US, Inc.**, **AstraZeneca**, **Bayer Healthcare**, **Boehringer-Ingelheim**, **Bristol Myers Squibb**, **Celgene Corporation**, **Eisai, Inc.**, **EMD Serono, Inc.**, **Genentech, Inc.**, **Janssen Oncology**, **Jazz Pharmaceuticals**, **Lilly Oncology**, **Novartis**, **Pfizer Oncology**, **Pharmacyclics, Inc.**, **Sanofi-Genzyme**, and **Takeda Oncology**.

We thank **Bristol Myers Squibb** and **Merck & Co.** for serving as Inaugural Sponsors of Post-Doctoral Fellowships at the Research and Training Institute.

We also thank the staff at CSC without whom the Registry would not be possible.

Most importantly, we express our deep gratitude to the thousands of individuals who have shared their experiences in the Registry, many of whom continue to receive cancer therapy, manage adverse effects, and care for loved ones.

If you or someone you know is interested in joining the Cancer Experience Registry, please visit cancerexperienceregistry.org

If you are interested in becoming an advisor for or helping to support the Cancer Experience Registry, or one of its Specialty Registries, contact research@cancersupportcommunity.org

ABOUT THE CANCER SUPPORT COMMUNITY

COMMUNITY IS STRONGER THAN CANCER™

The Cancer Support Community (CSC) is a global non-profit network of 175 locations – including 39 CSC and Gilda's Club affiliates, ten hospital and clinic partners, 1 federally qualified health center, and satellite locations – that together deliver more than $50 million in free support services to patients and families each year. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people annually. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes nearly 30,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way. For more information, visit www.CancerSupportCommunity.org.

THE RESEARCH AND TRAINING INSTITUTE AT CSC (RTI)

The RTI conducts cutting-edge psychosocial, behavioral, and survivorship research to inform policy initiatives and education and training programs. The RTI staff draws on the expertise of a broad range of strategic partnerships with other organizations, academics, and individuals representing the cancer community to achieve its goals. Key research areas include: cancer patient and caregiver needs and well-being; the impact of distress screening and psychosocial support; access to care; clinician-patient communications; shared treatment decision-making; treatment adherence and adverse effects management; and patient, survivor, and caregiver knowledge and attitudes on notable issues, such as cost of cancer care and clinical trials. For more information, please contact us at 267.295.3000 or research@cancersupportcommunity.org.

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