

Elevating the Patient Voice

Overview of the Cancer Experience Registry Index Report 2013-2014

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Overview of the Registry

The Cancer Experience Registry is an online community of people touched by cancer.

- The primary focus of the Registry is to collect, analyze and share information about the experience and needs of patients and their families throughout the cancer journey.
- Any person who is living with cancer can join the Cancer Experience Registry at www.cancerexperienceregistry.org.
- Whether they have just been diagnosed, are currently in treatment or their treatment had ended, we encourage people to take the time to enroll and answer questions.
- All personal information remains confidential and is used
 - To support greater understanding of the needs of people living with cancer
 - To develop innovative programs and services that improve the quality of life of people impacted by cancer.

Participant Characteristics

	General	Chronic Myeloid Leukemia	Metastatic Breast Cancer	Multiple Myeloma
Median Age	56 years	59 years	56 years	64 years
Gender				
Female	83%	67%	99%	54%
Male	17%	33%	1%	46%
Race and Ethnicity				
Caucasian	88%	90%	93%	87%
Black or African American	4%	3%	2%	10%
Hispanic	4%	3%	3%	2%
Education				
College Degree or Higher	58%	51%	61%	56%

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

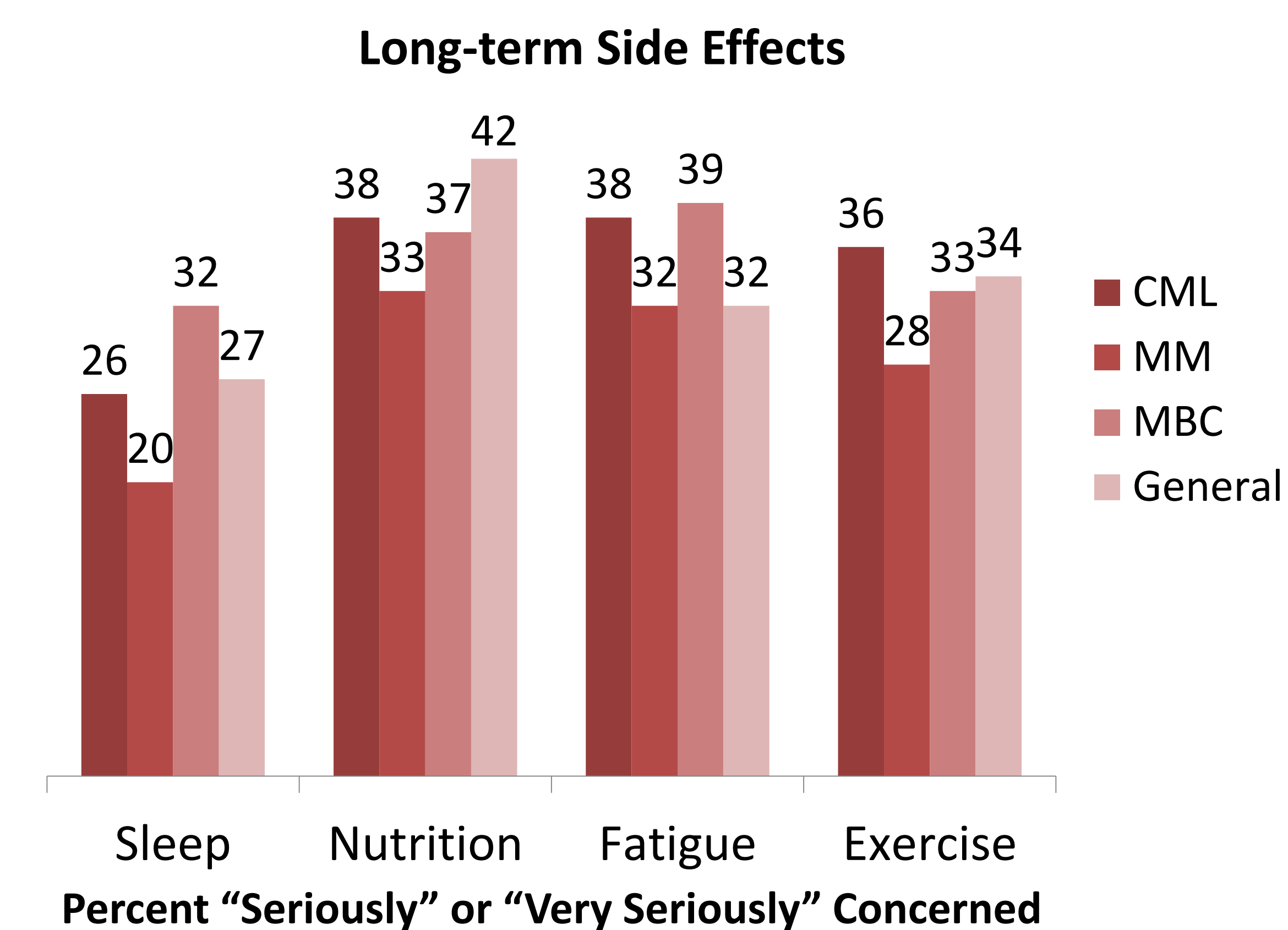
There are now over 7,300 cancer patients have enrolled in the Cancer Experience Registry, representing more than 40 different cancer diagnoses. In 2014, the Cancer Support Community launched sub-registries for people living with Metastatic Breast Cancer (MBC), Multiple Myeloma (MM) and Chronic Myeloid Leukemia (CML). Each has an Advisory council that includes experts in the clinical and psychosocial aspects of the cancer type, experts on policy, patient advocacy groups, industry representatives, as well as patients who are experts in living with their own specific condition.

Top 5 Concerns People Want More Help Managing

1. Long-term side effects
2. Emotions related to cancer
3. Short-term side effects
4. Financial impact of cancer
5. Lifestyle changes

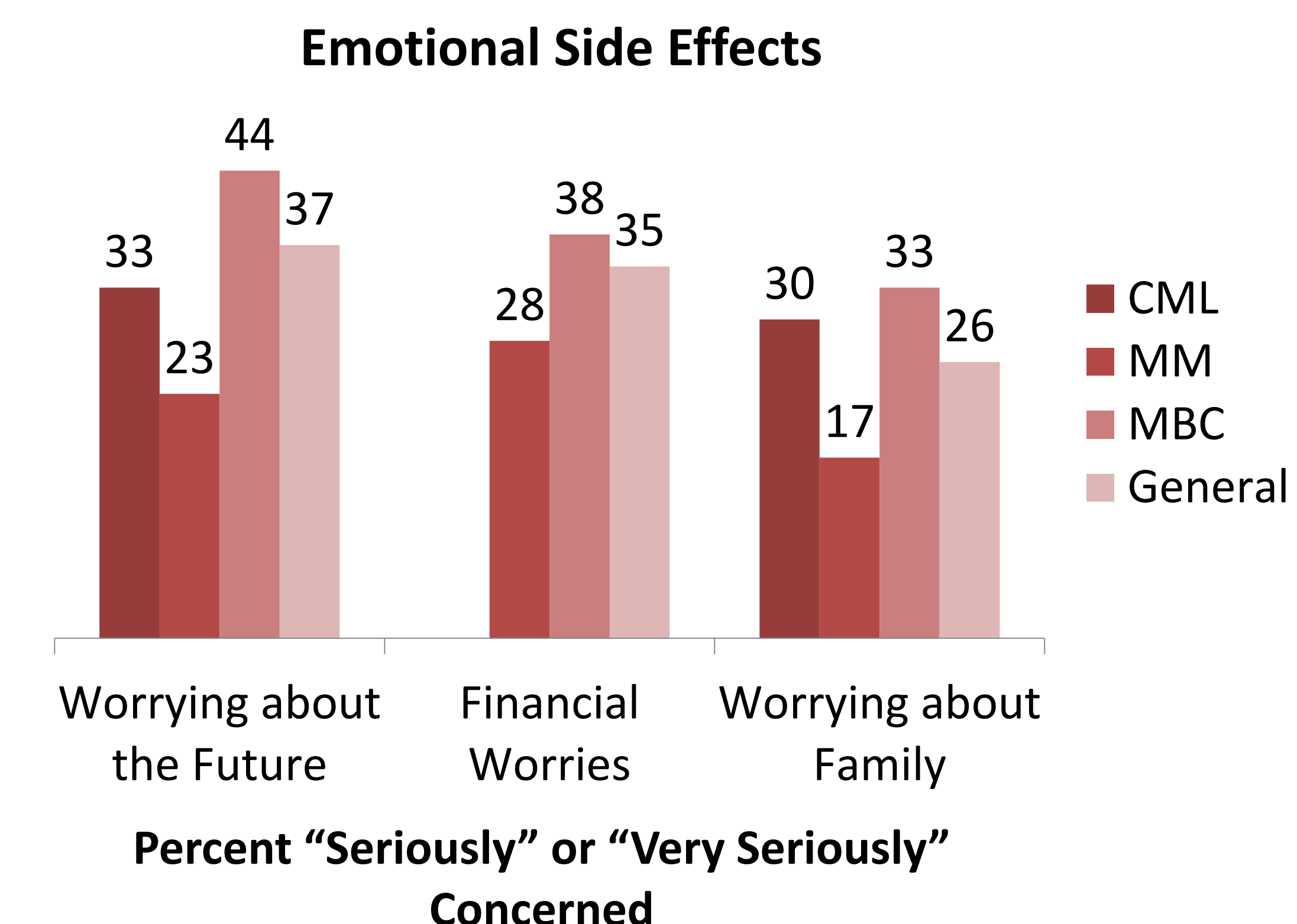
Long-term Side Effects

- New agents, targeted therapies, better use of existing drugs, more precise approaches to radiation and surgery, and novel therapies such as immunotherapy are contributing to longer survival while placing increased emphasis on the patient experience and quality of life.
- At least 50% of cancer survivors experience treatment-related side effects including physical, psychosocial, cognitive and sexual problems, lasting many months or even years.



Emotional Side Effects

- Data from the Registry reinforces the critical importance of making emotional and psychosocial support an integral component of treatment.
- Patients report high levels of anxiety related to worrying about the future, finances, and the family.
- 54% wished they had more help with emotions related to their cancer, 43% wished they had more help with financial advice and/or assistance, and 41% wished they had more help with changing their lifestyle behaviors.



Cost of Cancer Care

- The Registry demonstrates how deep and broad financial issues are for people facing cancer.
- 9% of participants said they have made their treatment decision based on the cost of the drug, opting for less expensive and potentially less effective therapy.

Because of the medical cost of cancer, I have...

Foregone vacations, celebrations and social events	48%
Cut my grocery expenses	37%
Depleted my savings	36%
Used pharmaceutical assistance programs	31%
Borrowed against or used money from a retirement plan (401K, IRA)	24%

Percent that responded "yes"