

Metastatic Breast Cancer Specialty Registry Report 2017

What is the Metastatic Breast Cancer Specialty Registry?






In 2017, 252,000 women are expected to be diagnosed with invasive breast cancer, in which cancerous cells move into outer breast tissue (American Cancer Society, 2017). Metastasis—when cancerous cells spread to vital organs, lymph nodes, and other parts of the body—greatly increases the severity of the disease. Approximately 6-10% of new breast cancer diagnoses are metastatic (stage IV; Metastatic Breast Cancer Network, 2016).

The Metastatic Breast Cancer Specialty Registry, which began accepting participants in March 2013, documents the experiences of a cross-section of people living with metastatic breast cancer. The Metastatic Breast Cancer Advisory Council—made up of breast cancer specialists and other oncologists, behavioral scientists, patient advocates, and industry representatives—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at www.cancersupportcommunity.org/RegistryIndexReport2017).



KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS INTO THE METASTATIC BREAST CANCER EXPERIENCE. KEY FINDINGS INCLUDE:

 <p>QUALITY OF LIFE</p>	<p>33%</p> <p>OF SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT</p>	<p>43%</p> <p>REPORT WORSE FATIGUE THAN THE NATIONAL AVERAGE</p>	<p>62%</p> <p>ARE AT RISK FOR CLINICAL DEPRESSION</p>
 <p>SYMPTOMS AND SIDE EFFECTS</p>	<p>56%</p> <p>REPORTED EXPERIENCING NEUROPATHY, THE NUMBNESS AND PAIN CAUSED BY NERVE DAMAGE FROM CHEMOTHERAPY</p>	<p>35%</p> <p>INDICATED NEUROPATHY WAS DISRUPTIVE TO THEIR DAILY LIFE</p>	<p>60%</p> <p>REVEALED THEIR DIAGNOSIS HAD A NEGATIVE IMPACT ON THEIR SEXUAL LIFE</p>
 <p>DOCTOR-PATIENT COMMUNICATION</p>	<p>WHILE 69% WERE INVOLVED IN TREATMENT DECISION-MAKING, ONLY 31% FELT FULLY PREPARED TO MAKE A DECISION</p>	<p>24%</p> <p>DID NOT DISCUSS COSTS WITH THEIR HEALTH CARE TEAM</p>	<p>74%</p> <p>SAID NO ONE FROM THEIR CARE TEAM EVER ASKED ABOUT PROBLEMS WITH SEXUAL FUNCTION</p>
 <p>PSYCHOSOCIAL IMPACT</p>	<p>71%</p> <p>ARE RELUCTANT TO ASK FOR HELP</p>	<p>65%</p> <p>ARE WORRIED ABOUT THE FUTURE AND WHAT LIES AHEAD</p>	<p>60%</p> <p>HAVE LIMITED THEIR CONTACT WITH FRIENDS</p>
 <p>FINANCIAL IMPACT</p>	<p>69%</p> <p>ARE UPSET ABOUT MONEY AND COST OF CARE</p>	<p>28%</p> <p>SPEND OVER \$500 IN MONTHLY OUT-OF-POCKET COSTS RELATED TO THEIR CANCER CARE</p>	<p>44%</p> <p>REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS AROUND MANAGING THE COSTS OF CANCER CARE</p>

Who is in the Registry?

This 2017 report presents analysis from 1,252 metastatic breast cancer (MBC) patients who reside in the United States and completed survey questions from the opening of the Registry in March 2013 to December 31, 2016 (in the tables below, the number of responses is 1,252 unless otherwise noted).

FIGURE 1 METASTATIC BREAST CANCER REGISTRY SURVEY DEMOGRAPHICS		
	<i>NUMBER OF PARTICIPANTS (n)</i>	<i>PERCENT</i>
AGE	(n = 964)	
Mean age	54.4 years, SD = 10.2	Range: 24 to 91
18-44	168	17%
45-64	644	67%
>=65	152	16%
GENDER	(n = 981)	
Male	8	1%
Female	973	99%
RACE	(n = 977)	
White	886	91%
NON-HISPANIC ETHNICITY	(n = 888)	
	812	91%
EDUCATION	(n = 966)	
High school or less	89	10%
Associate degree or some college	290	30%
Bachelor degree	280	29%
Graduate degree or higher	298	31%
REGION	(n = 878)	
Urban	174	20%
Suburban	510	58%
Rural	178	20%
EMPLOYMENT STATUS	(n = 914)	
Full-time	296	32%
Part-time	99	11%
Retired	194	21%
Not employed due to disability	254	28%
Not employed (reason not specified)	71	8%
ANNUAL INCOME	(n = 835)	
<\$40K	182	22%
\$40-59.9K	128	15%
\$60-79.9K	89	10%
\$80-99.9K	78	9%
\$100K+	173	21%
Prefer not to share	181	22%

FIGURE 2 CANCER STAGE, TIME SINCE DIAGNOSIS AND CANCER STATUS OF SURVEY PARTICIPANTS

	NUMBER OF PARTICIPANTS (n)	PERCENT
STAGE AT DIAGNOSIS	(n = 160)	
Stage 0	6	4%
Stage I	20	12%
Stage II	43	27%
Stage III	34	21%
Stage IV	52	33%
I don't know	5	3%
TIME SINCE DIAGNOSIS	(n = 683)	
<1 year	33	5%
1–1.9 years	73	11%
2–4.9 years	207	30%
>=5 years	370	54%
RECURRENCE	(n = 672)	
	361	54%
GENETIC TESTING		
Was tested for BRCA1 (n = 671)	367	55%
Tested BRCA1 positive (n = 367)	18	5%
Was tested for BRCA2 (n = 669)	318	48%
Tested BRCA2 positive (n = 318)	25	8%
Not tested but would consider it (n = 297)	136	46%
HORMONE-RECEPTOR STATUS		
Hormone-receptor positive (ER/PR) (n = 647)	507	78%
Hormone-receptor negative (ER/PR) (n = 647)	90	14%
HER2 positive (n = 657)	185	28%
HER2 negative (n = 657)	373	57%
ER/PR/HER2 negative (triple negative) (n = 622)	58	9%

What are we learning?

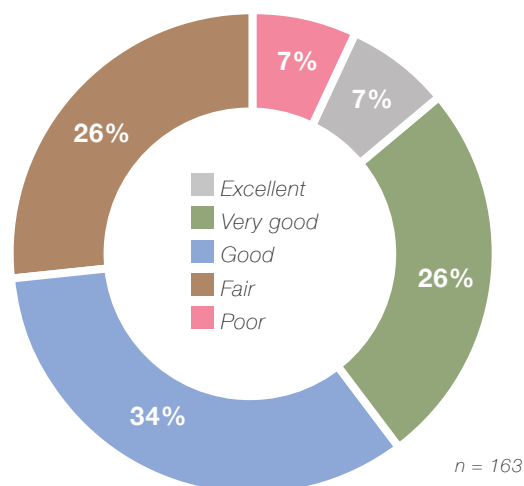
PERCEPTIONS ABOUT HEALTH

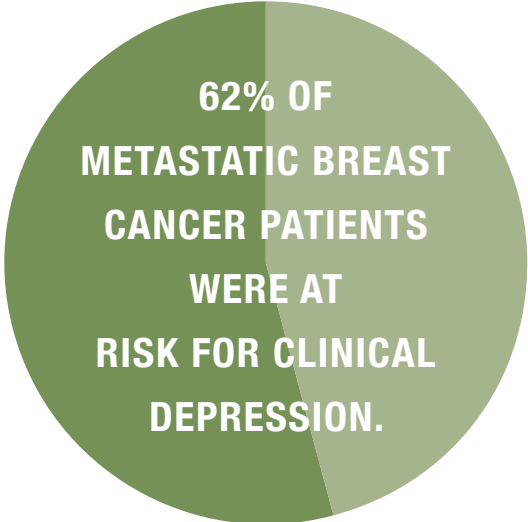
In the survey, 33% of participants described their overall health as excellent or very good, but over one-quarter (26%) reported fair health, and 7% reported they were in poor health (Figure 3).

CANCER-RELATED DISTRESS

A metastatic breast cancer diagnosis—given the life-threatening nature of the disease—can cause patients considerable distress. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to CancerSupportSource®, a validated distress screening instrument.¹

FIGURE 3 SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH



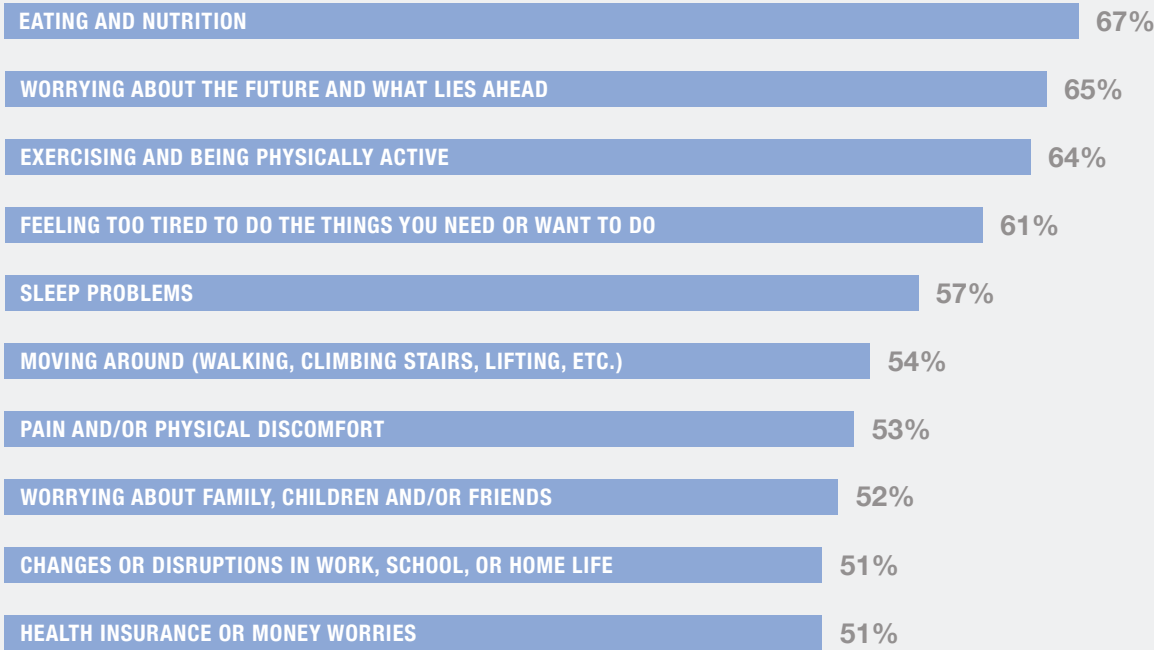


CancerSupportSource features a depression subscale, which demonstrated that 62% of respondents were at risk for clinical depression.

QUALITY OF LIFE

While survival and stopping disease progression are of utmost concern, how a patient describes quality of life is fundamental to understanding the cancer experience. The Metastatic Breast Cancer Specialty Registry incorporates the PROMIS-29, which compares how patients describe their quality of life to other U.S. population groups across seven different areas of life.² As Figure 5 illustrates, many metastatic breast cancer patients reported substantially worse quality of life than the national average for fatigue (43% of respondents), physical functioning (38%), anxiety (37%), and depression (24%). In addition, 21% of respondents reported worse sleep disturbance, 21% reported worse social functioning, and 16% reported worse pain interference.

FIGURE 4 TOP 10 CONCERNS ACROSS METASTATIC BREAST CANCER PATIENTS



*Percent of Patients Moderately to Very Seriously Concerned
n = 647*

SOCIAL IMPACT

Metastatic breast cancer affects many aspects of life. Figure 6 illustrates that many respondents have made numerous life-changing decisions to their professional, social, and family lives because of their diagnosis that can lead to greater social isolation.

TREATMENT DECISION-MAKING AND PLANNING

With the advent of new tailored therapies, treatment decision-making has become increasingly complex. Although patients are very involved in treatment decision-making, they are far less likely to report feeling knowledgeable about treatment options or prepared to discuss treatment options with their doctor (Figure 7).

SEXUAL INTIMACY

For many patients, concerns around sexual intimacy are common. Patients may experience diminished desire, increased pain and discomfort, and reduced sensation. Many survivors feel reluctant to discuss intimacy issues with their care team or loved ones. Sixty percent of MBC participants revealed that their diagnosis had a negative impact on their sexual life. Figure 8 illustrates how many respondents

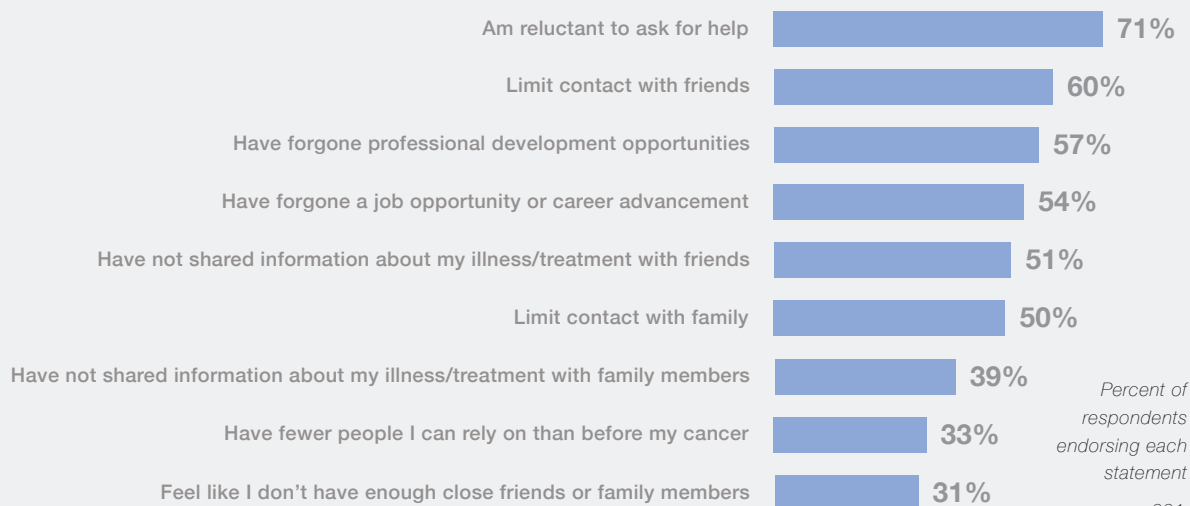
FIGURE 5 PERCENT OF MBC SURVIVORS REPORTING WORSE QUALITY OF LIFE



Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.

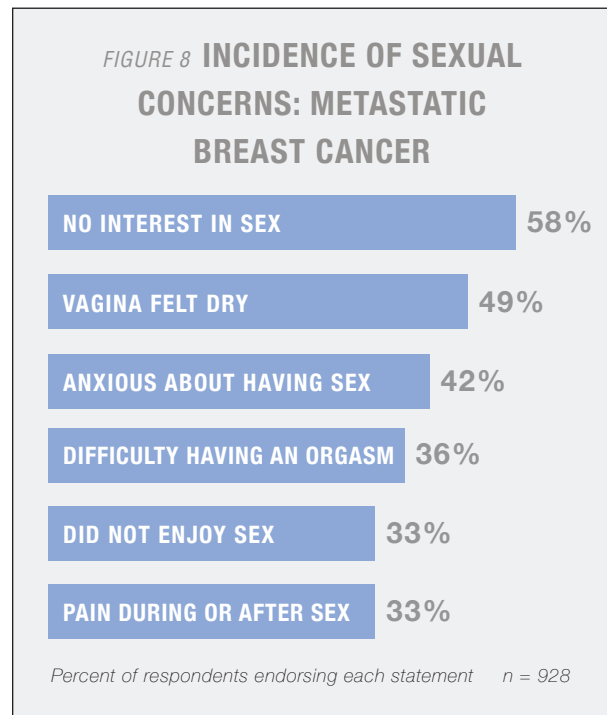
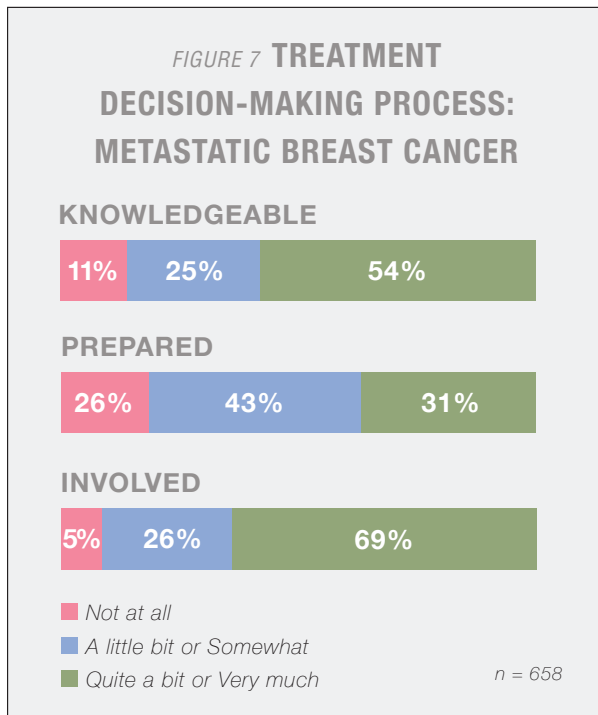
n = 160

FIGURE 6 SOCIAL IMPACT OF METASTATIC BREAST CANCER



Percent of respondents endorsing each statement

n = 661



experienced intimacy problems for a period of several weeks or more during the past six months leading up to the completion of the survey.

Many women are reluctant to discuss intimacy issues with their oncologist, a psychologist, and even their partner. Seventy-four percent indicated that no one from their health care team had ever asked about problems with sexual function, though 52% felt they would be able to discuss them. Over three-quarters (76%) reported they had never sought treatment for sexual intimacy issues. Indeed, 24% of MBC

patients reported they would never go to a medical provider, with 26% indicating they would go only if it was covered by insurance. Thirty-nine percent of respondents said they would never go to a mental health counselor for sexual problems, while 48% responded that they would never attend a support group for cancer patients with sexual problems.

COST OF CARE

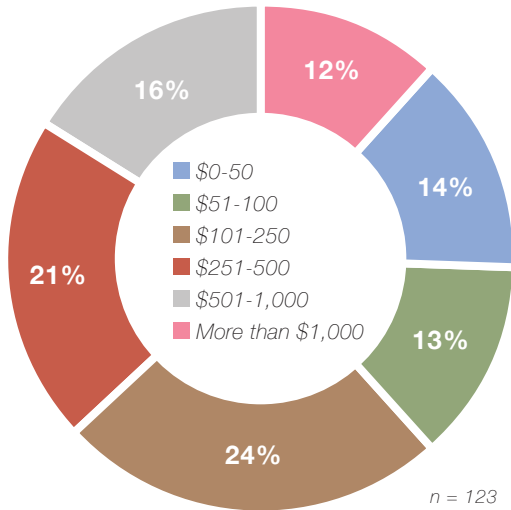
MBC patients face high costs for care and ancillary activities such as co-pays and traveling to treatment centers and doctor visits. Forty-four percent of metastatic breast cancer respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale.³ Twenty-four percent of respondents did not discuss costs with someone on their health care team, such as a counselor, nurse, or doctor.

Insurance coverage can mask the monetary impact that patients experience on a regular basis. Many respondents were able to quantify monthly out-of-pocket costs related to their cancer (Figure 9). Of note, 12% of respondents spent over \$1,000 per month.

NEUROPATHY

Over half (56%) of metastatic breast cancer registrants reported they experienced neuropathy, the numbness and pain caused by nerve damage from chemotherapy, while 41% had not. In addition, 35% indicated neuropathy was disruptive to their daily life.

FIGURE 9 METASTATIC BREAST CANCER MONTHLY OUT-OF-POCKET COSTS



The financial cost of care can be a source of distress for many breast cancer survivors. Figure 10 describes the patient experience of coping with the cost of care.

Many respondents have anxieties related to cost and how they will pay for their treatment: 69% are at least sometimes upset about money and nearly half (49%) reported they feel “overwhelmed” about

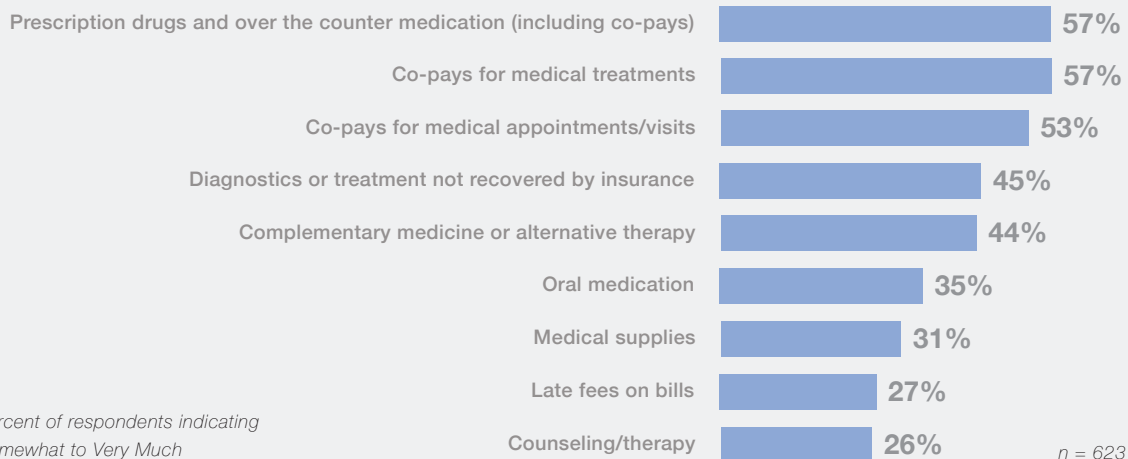
FIGURE 10 EXPERIENCE OF COPING WITH THE COST OF CARE: METASTATIC BREAST CANCER



cost sometimes, often, or always. One-third (33%) believed there was not enough time to fight their disease *and* manage costs.

Many people with MBC face a number of unanticipated costs. Figure 11 lists some of these unexpected costs and how many respondents felt these costs were an undue burden.

FIGURE 11 BURDEN OF UNEXPECTED COSTS ASSOCIATED WITH METASTATIC BREAST CANCER





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- General Registry Report
- Lung Cancer Specialty Registry Report
- Melanoma Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report



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2. Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S.,...Hays, R. D. on behalf of the PROMIS Cooperative Group. (2010). Initial item banks and first wave testing of the Patient-Reported Outcomes Measurement Information System (PROMIS) network: 2005-2008. *Journal of Clinical Epidemiology*, 63(11), 1179-94.
3. Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine*, 41(3), 209-218.

ACKNOWLEDGMENTS

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