Breast Cancer
Specialty Registry Report 2017

What is the Breast Cancer Specialty Registry?

With more than 250,000 new cases expected for 2017 (American Cancer Society, 2016), breast cancer is one of the most common cancers among women in the United States.

In March 2013, the Cancer Support Community migrated all of the breast cancer registrants from its legacy platform (the Breast Cancer Survivor Registry: MAP Project) to the new platform of the Cancer Experience Registry. At that time, the Breast Cancer Specialty Registry continued to enroll breast cancer survivors and document the experiences of a cross-section of people living with non-metastatic breast cancer. The 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**).

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

GILDA'S CLUB WORLDWIDE

the wellness community

KEY FINDINGS

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

QUALITY OF LIFE

46% ARE AT RISK FOR CLINICAL DEPRESSION

30% REPORT WORSE ANXIETY AND 25% REPORT WORSE FATIGUE THAN THE NATIONAL AVERAGE

50% OF BREAST CANCER SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT

CANCER-RELATED DISTRESS

50% ARE WORRIED ABOUT THE FUTURE AND WHAT LIES AHEAD

58% ARE CONCERNED ABOUT EXERCISING AND REMAINING PHYSICALLY ACTIVE

65% ARE CONCERNED ABOUT EATING AND NUTRITION

SYMPTOMS AND SIDE EFFECTS

38% REPORTED THEY EXPERIENCE NEUROPATHY, THE NUMBNESS AND PAIN CAUSED BY NERVE DAMAGE FROM CHEMOTHERAPY

51% INDICATED NEUROPATHY WAS SOMEWHAT TO VERY DISRUPTIVE TO THEIR DAILY LIFE

42% SAID THEIR DIAGNOSIS HAD A NEGATIVE IMPACT ON THEIR SEXUAL LIFE

DOCTOR-PATIENT COMMUNICATION

WHILE 75% WERE INVOLVED IN TREATMENT DECISION-MAKING, ONLY 40% FELT FULLY PREPARED TO MAKE A DECISION

18% HAD DISCUSSED COSTS WITH THEIR HEALTH CARE TEAM

76% SAID NO ONE FROM THEIR HEALTH CARE TEAM EVER ASKED ABOUT PROBLEMS WITH SEXUAL FUNCTION, YET 60% WOULD BE OPEN TO DISCUSSING SEXUAL CONCERNS

SURVIVORSHIP CARE PLAN

39% WERE REFERRED BACK TO THEIR PRIMARY CARE PHYSICIAN FOR FOLLOW-UP CARE

82% REPORTED NOT RECEIVING A SURVIVORSHIP CARE PLAN

ONLY 50% REPORTED THAT SOMEONE PROVIDED INFORMATION ABOUT LONG-TERM SIDE EFFECTS OF TREATMENT

SOCIAL IMPACT

50% ARE RELUCTANT TO ASK FOR HELP

38% HAVE LIMITED THEIR CONTACT WITH FAMILY

44% HAVE LIMITED THEIR CONTACT WITH FRIENDS

FINANCIAL IMPACT

82% DID NOT DISCUSS CANCER-RELATED COSTS WITH ANYONE FROM THEIR HEALTH CARE TEAM

49% ARE OVERWHELMED BY THE DEMANDS OF PAYING FOR MEDICAL CARE

35% REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS AROUND MANAGING THE COSTS OF CANCER CARE

Who is in the Registry?

This 2017 report presents an analysis of 4,877 non-metastatic breast cancer patients who reside in the United States and completed survey questions from the opening of the Registry in May 2010 until December 31, 2016 (in the tables below, the number of responses is 4,877 unless otherwise noted).

FIGURE 1 **NON-METASTATIC BREAST CANCER SPECIALTY REGISTRY SURVEY DEMOGRAPHICS**

	NUMBER OF PARTICIPANTS (n)	PERCENT
AGE	(n = 4,187)	
Mean age	54.4 years, SD = 10.3	Range: 29 to 92
18-44	728	17%
45-64	2,830	68%
>=65	629	15%
GENDER	(n = 4,156)	
Male	16	<1%
Female	4,139	99%
RACE	(n = 3,936)	
White	3,422	87%
Black or African American	356	9%
NON-HISPANIC ETHNICITY	(n = 1,009) 934	93%
EDUCATION	(n = 3,712)	
High school or less	394	11%
Associate degree or some college	875	23%
Bachelor degree	1,290	35%
Graduate degree or higher	1,137	31%
REGION	(n = 993)	
Urban	200	20%
Suburban	578	58%
Rural	190	19%
EMPLOYMENT STATUS	(n = 3,524)	
Full-time	1,709	49%
Part-time	485	14%
Retired	742	21%
Not employed due to disability	89	2%
Not employed (reason not specified)	499	14%
ANNUAL INCOME	(n = 3,247)	
<$40K	482	15%
$40-59.9K	367	11%
$60-79.9K	358	11%
$80-99.9K	332	10%
$100K+	823	25%
Prefer not to share	857	27%

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

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
STAGE AT DIAGNOSIS	(n = 810)	
Stage 0	60	7%
Stage I	272	34%
Stage II	292	36%
Stage III	112	14%
Stage IV	40	5%
I don't know	34	4%
TIME SINCE DIAGNOSIS	(n = 820)	
<1 year	138	17%
1–1.9 years	182	22%
2–4.9 years	241	29%
>=5 years	259	32%
RECURRENCE	(n = 824)	
	83	10%
GENETIC TESTING		
Was tested for BRCA1 (n = 406)	225	55%
Tested BRCA1 positive (n = 225)	14	6%
Was tested for BRCA2 (n = 406)	202	50%
Tested BRCA2 positive (n = 202)	20	10%
Not tested but would consider it (n = 175)	59	34%
HORMONE RECEPTOR STATUS		
Hormone-receptor positive (ER/PR) (n = 399)	265	66%
Hormone-receptor negative (ER/PR) (n = 399)	65	16%
HER2 positive (n = 401)	105	26%
HER2 negative (n = 401)	172	43%
ER/PR/HER2 negative (triple negative) (n = 397)	44	11%

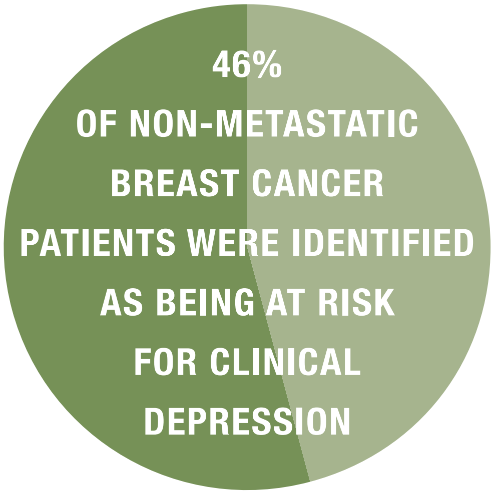
What are we learning?

PERCEPTIONS OF HEALTH

Only 15% of respondents reported their overall health as fair or poor, with the remainder indicating good, very good, or excellent health (Figure 3).

CANCER-RELATED DISTRESS

People with non-metastatic breast cancer can experience distress related to the short- and long-term physical and emotional consequences of their illness and treatment. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about, measured using CancerSupportSource®, a validated distress screening instrument.[1]



46%

OF NON-METASTATIC BREAST CANCER PATIENTS WERE IDENTIFIED AS BEING AT RISK FOR CLINICAL DEPRESSION

QUALITY OF LIFE

Patients describe cancer's impact on their quality of life in different ways, and quantifying quality of life impairments among breast cancer patients can go a long way toward addressing their needs. The 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 non-metastatic breast cancer patients reported substantially worse quality of life than the national average for anxiety (30% of respondents), fatigue (25%), physical functioning (21%), depression (18%), and sleep disturbance (17%). In addition, 14% of respondents reported worse pain interference and 14% reported worse social functioning.

FIGURE 3 **SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH**

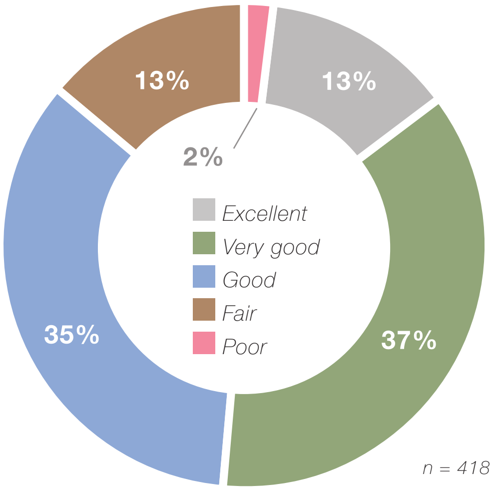
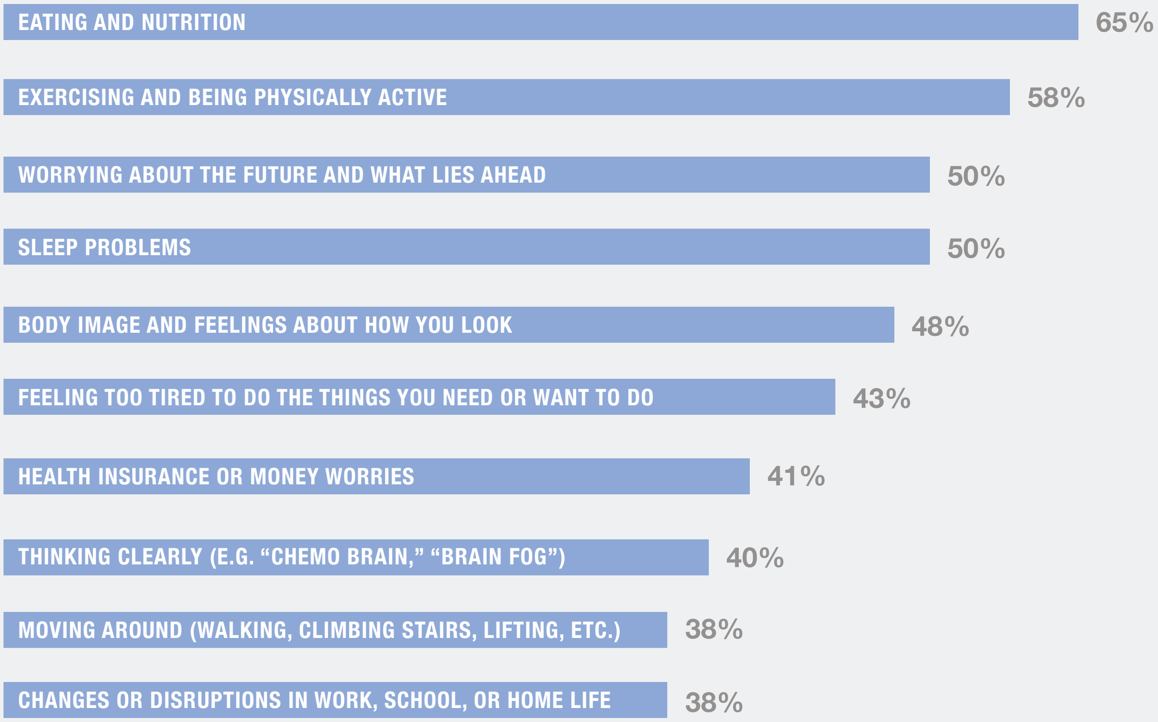


FIGURE 4 **TOP 10 CONCERNS OF NON-METASTATIC BREAST CANCER PARTICIPANTS**



Percent represents patient answering Moderately to Very Seriously concerned

n = 771

SOCIAL IMPACT

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

Shared decision-making is a critical aspect of treatment, especially when patients have to make choices between multiple modes of therapy from multiple health care providers at multiple facilities. 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. Cancer therapies may diminish desire, increase pain and discomfort, and reduce sensation. Many survivors can feel reluctant to discuss intimacy issues with their care team or loved ones.

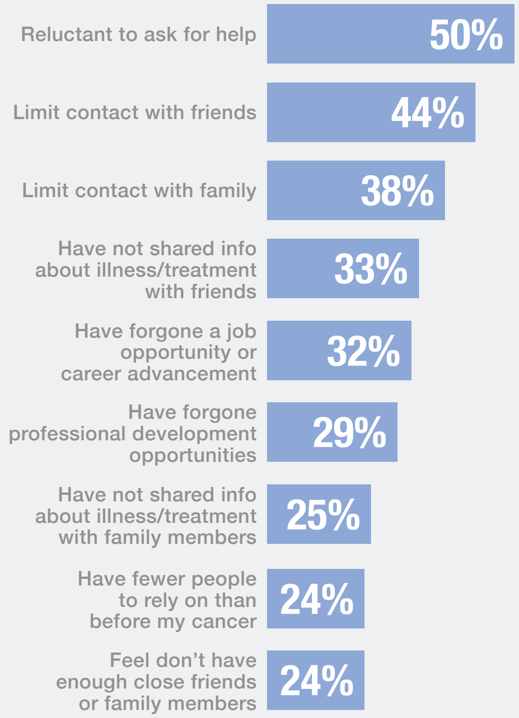
Among non-metastatic breast cancer respondents, 40% reported that they were sexually active and 42% reported that their diagnosis had a negative impact on their sex life. Only 18% indicated that treatment-related changes to their sex life contributed to relationship issues with their partners. Further, over a quarter of respondents (28%) reported that sexual activity was a source of distress. Figure 8 illustrates how often respondents experienced intimacy problems for a period of

FIGURE 5 **PERCENT OF NON-METASTATIC BREAST CANCER 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 = 385

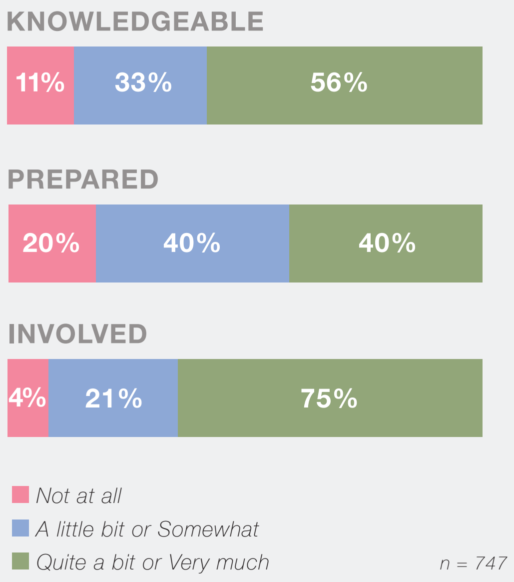
FIGURE 6 **SOCIAL IMPACT OF NON-METASTATIC BREAST CANCER**



n = 372

Percent represents patient answering Somewhat to Very much

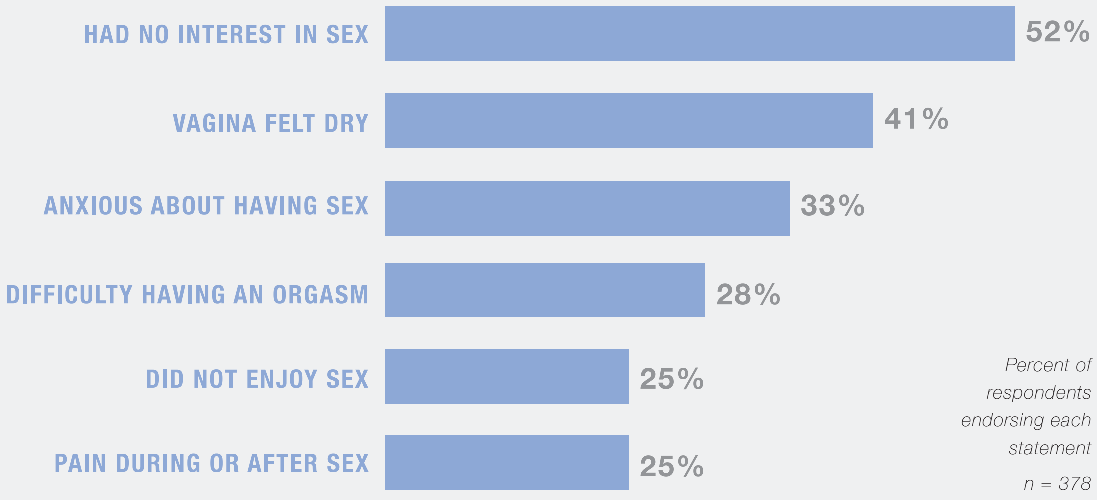
FIGURE 7 **TREATMENT DECISION-MAKING PROCESS: NON-METASTATIC BREAST CANCER**



several weeks or more during the six months prior to completing the survey.

Three-quarters (76%) of respondents were never asked by a member of their health care team whether they had experienced problems with sexual function, yet a majority (60%) indicated that they would be open to discussing these concerns with their provider. Over half (55%) reported they would visit a medical provider to address sexual problems, but 26% indicated they would go only if insurance covered it, and 22% said they would never go under any circumstances. Additionally, 25% would go to a mental health expert only if the visit was covered by insurance and, 28% would never go. An even higher percentage (31%) reported they would never see a mental health expert for counseling if their spouse or partner were to accompany them. Support groups were even less popular among breast cancer respondents: 50% said they would never attend a support group to discuss their sexual problems. In fact, only 10% of respondents had ever actively sought treatment for sexual dysfunction due to their

FIGURE 8 **INCIDENCE OF SEXUAL CONCERNS: NON-METASTATIC BREAST CANCER**



cancer treatment.

COST OF CARE

Non-metastatic breast cancer patients face cancer-related expenses that can exacerbate the emotional toll of the disease. Thirty-five percent of non-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] Eighty-two percent had not discussed cancer-related costs with anyone from their team.

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).

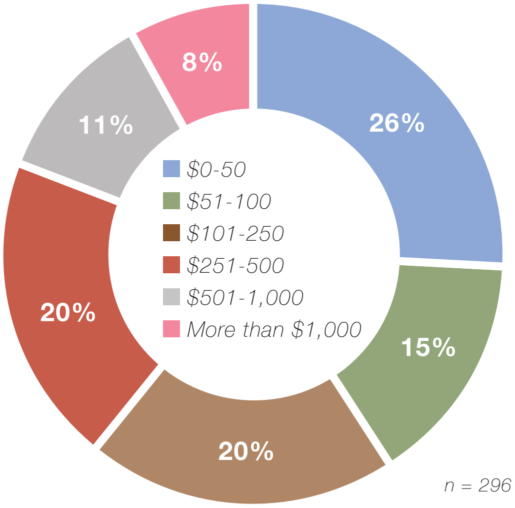
The financial cost of care can also be a source of distress for many breast cancer survivors. Figure 10 describes the patient experience of coping with the cost of care.

SURVIVORSHIP PLANNING

After overcoming the difficulties and stresses of treatments, survivors face the ongoing challenge of caring for their health. The coordination of survivorship care across a range of health professionals is a well-documented problem in the current health care system. Further, a rapidly growing cancer survivor population, in combination with shortages in oncologists and primary care physicians, adds ongoing pressure to the health care system. Survivors need help managing physical and emotional needs. Some health care providers are developing structured care plans to help patients maintain their health and improve their quality of life after treatment. However, just 18% of non-metastatic breast cancer respondents to the survey reported that they received a survivorship care plan from a member of their care team. Additionally, only 50% reported that someone provided information about long-term side effects of treatment, and just 39% were referred back to their primary care physician.

> Thirty-eight percent of survey respondents reported experiencing peripheral neuropathy, the numbness and pain caused by nerve damage from chemotherapy. Of those with neuropathy, slightly over half (51%) indicated the neuropathy was "somewhat" to "very much" disruptive to their daily life.

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



n = 296

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

69%	49%	46%	33%
Upset about money and the cost of care	Overwhelmed by the demands of paying for my medical care	Worried that I won't be able to leave any assets to my family once I'm gone	There is not enough time in the day to fight my cancer and figure out how to pay for treatment

Percent of respondents indicating Sometimes to Always

n = 376

Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Caregiver Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Lung Cancer Specialty Registry Report
- Melanoma Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report

1. Miller M. F., Mullins, C.D., Onukwugha, E., Golant, M., & Buzaglo, J.S. Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. *Quality of Life Research*, *23*, 2855-2863.

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.

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