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# Advocate-BREAST: advocates and patients' advice to enhance breast cancer care delivery, patient experience and patient centered research by 2025

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## Abstract

**Purpose** The aims of the Advocate-BREAST project are to study and improve the breast cancer (BC) patient experience through education and patient-centered research.

**Methods** In December 2021, an electronic REDCap survey was circulated to 6,918 BC survivors (stage 0–4) enrolled in the Mayo Clinic Breast Disease Registry. The questionnaire asked about satisfaction with BC care delivery, and education and support receive(d) regarding BC linked concerns. Patients also ranked Quality Improvement (QI) proposals.

**Results** The survey received 2,437 responses. 18% had Ductal Carcinoma in Situ, 81% had early breast cancer (EBC), i.e. stage 1–3, and 2% had metastatic breast cancer (MBC). Mean age was 64 (SD 11.8), and mean time since diagnosis was 93 months (SD 70.2). 69.3% of patients received all care at Mayo Clinic. The overall experience of care was good (> 90%). The main severe symptoms recalled in year 1 were alopecia, eyebrow/eyelash thinning, hot flashes, sexual dysfunction, and cognitive issues. The main concerns recalled were fear of BC recurrence/spread; loved ones coping; fear of dying, and emotional health. Patients were most dissatisfied with information regarding sexual dysfunction, eyebrow/eyelash thinning, peripheral neuropathy, and on side effects of immunotherapy/targeted therapies. Top ranking QI projects were: i) Lifetime access to concise educational resources; ii) Holistic support programs for MBC and iii) Wellness Programs for EBC and MBC.

**Conclusions** Patients with early and advanced BC desire psychological support, concise educational resources, and holistic care.

**Implications** Focused research and QI initiatives in these areas will improve the BC patient experience.

**Keywords** Breast cancer, Survivorship, Advocacy, Patient experience, Psycho-oncology

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**Text box 1. Contributions to the literature**


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- Patients with early and advanced BC desire early psychological support; our publication highlights the need for prompt detection and appropriate intervention given high rates of distress in our patient cohort. For rural-dwelling patients, the development of remotely delivered interventions should be prioritized.
  - In our study, patients with early and advanced BC strongly desired concise and lifetime-accessible educational resources. This illustrates the need for accessible and refined patient informational resources, to avoid "information overload".
  - Standard educational resources/support provided to address sexual dysfunction in our study were rated as suboptimal. Innovative solutions to address this are warranted (focus groups, etc.)
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## Introduction

In the United States (U.S.), ~287,850 new cases of invasive breast cancer (BC) were diagnosed in 2022, along with 51,400 new cases of non-invasive (in situ) BC [1]. In 2021, BC became the most common cancer globally (12% of all new annual cancer cases). Further, as of January 2022, >3.8 million women in the U.S have a history of BC. BC frequently affects older persons, those with co-existing medical co-morbidities, and minority populations, which has important implications for treatment decisions and personalization of care [2]. Treatments include surgery, radiation therapy, endocrine therapy, chemotherapy, targeted therapies and immunotherapy, based on clinicopathologic features and the patient's overall health and performance status [3]. Rapid advances in BC research have led to the addition of multiple new therapies, which has increased the complexity of treatment options and therapeutic decisions. Physicians and patients must weigh potential treatment benefits, related to progression-free survival (PFS) and overall survival (OS), against potential cons, such as treatment-related side effects and reduced quality of life [4]. Critically, BC patients benefit from a holistic approach to their care [5], including cancer distress screening and referral, if needed, for evidence-based psychosocial interventions [6].

The value of patient perspectives and advocacy in treatment decisions related to BC is increasingly recognized [7]. Patients often have different perspectives and priorities, than medical providers, regarding potential treatment benefits, side-effect profiles and the quality of care received [8]. Further, patients can provide important insights into living with a health condition and the impact of various interventions and treatments [9]. From a clinical standpoint, including patients in treatment planning and care decisions improves quality of life, adherence, and overall patient satisfaction [10]. From a research standpoint, it is important to obtain the patient's perspectives on what topics they perceive

to be most relevant to study, as well as including relevant patient reported outcomes in the design of clinical trials [11]. However, despite the efforts of their treating providers, not all BC patients receive patient-centered care [12]. Moreover, discordance between patients and providers on expectations for treatment goals and outcomes have been reported [13, 14]. Being proactive, as regards identifying knowledge gaps and barriers to BC care, is a critical component in reducing disparities nationally and globally [15].

This current study is the first stage in a collaboration between breast oncologists at Mayo Clinic in Rochester, Minnesota (MCR) and the Mayo Clinic BC Specialized Program of Research Excellence (SPORE) research advocates, entitled Advocate-BREAST: Advocates and Patients' Advice to Enhance Breast Cancer Care Delivery, Patient Experience and Patient Centered Research by 2025. Advocate-BREAST is an MCR initiative which hopefully will ultimately be under the auspices of a national oncology co-operative group. High level aims are to study and improve the overall patient experience through education, shared decision making, and patient-centered clinical trials. The overarching goal is to determine areas of unmet need in BC care delivery and research as identified by BC patients and advocates treated with either curative or palliative intent, with the goal of improving the patient experience and driving further research in lacking areas. The objective of this manuscript is to present results of a patient experience survey conducted in BC survivors enrolled in the Mayo Clinic Breast Disease Registry (MCBDR).

## Methods

### Advocate BREAST- formation of an advocate and patient led committee

Firstly, we aimed to determine the optimal process to study and improve the lived experience of BC patients. Our plan was based on the principles of patient-centered outcomes research (PCOR) to evaluate questions and outcomes relevant to BC patients, using the information gathered to focus future research efforts on areas that have been suboptimally addressed [16, 17]. The Advocate BREAST project uses a five-step framework as follows: Connecting, Comprehending, Analyzing, Implementing and Reflecting (Supplemental Fig. 1). The overall goals of the Advocate BREAST project are outlined in Supplemental Fig. 2.

### Oncologist and advocate led committee

We formed a Mayo Clinic project management team which included two Breast Medical Oncologists [COS and KJR], a Research Program Co-Ordinator [NL], a

statistician [RV] and two Mayo Clinic BC Specialized Programs of Research Excellence (SPORE) [MLS and CC] advocates. Our advocates are experienced long-term BC survivors, who have extensive connections within the national BC advocacy community. We also presented the Advocate BREAST concept to other SPORE BC advocates via an online platform and solicited their input regarding the design of the patient satisfaction and quality improvement (QI) surveys.

### Study design and recruitment

The Mayo Clinic Cancer Center (MCCC) is an NCI-designated comprehensive cancer center with three main campuses in Minnesota, Florida and Arizona. We performed a retrospective cohort study of patients enrolled in the MCBDR, a prospective longitudinal cohort study that enrolls patients with stage 0–4 BC, and who were seen at least once at MCR within one year of diagnosis, between 2001–2021. Informed consent was obtained from all participants prior to enrollment to the registry. Patients were excluded if they had received a prior breast cancer diagnosis, did not speak English, or did not live within the US.

### Data collection and processing

As part of the MCBDR, demographic information, histopathological tumor characteristics and treatment related factors were abstracted from the electronic medical record by trained nurse abstractors. For this study, we accessed age, sex, date of BC diagnosis and disease stage. Patients were classified into 3 groups: ductal carcinoma in situ (DCIS; stage 0), invasive non-metastatic BC (stage 1–3) and metastatic breast cancer (MBC; stage 4) at time of survey completion. ZIP code of residence was mapped to rural–urban commuting area (RUCA) codes, and rurality was defined as RUCA code 10 (primary commuting flow to a tract outside of an urban cluster or an urbanized area) [18]. The Mayo Clinic Institutional Review Board (IRB1815-04) reviewed and approved this study. Data were handled consistent with both US laws and the Declaration of Helsinki.

In addition to medical chart review, participants were asked to complete a survey addressing satisfaction with i) multiple aspects of cancer care delivery and ii) the education and/or support they receive(d) regarding practical, financial, emotional, societal and spiritual concerns linked to their diagnosis. Racial/ethnic, educational, rural/urban, and financial status data were used to inform the development of novel resources to address patient-reported gaps in care. Participants were also asked to rank potential QI projects in order of the likelihood the proposal could improve quality of life for patients and their families. Patients were also asked to

provide comments on how care for BC patients might be improved, and their thoughts as regards to what research topics should be prioritized. Responses were collected via anonymous local language questionnaires.

### Survey

Our 23-page survey, containing 147 items, was developed to broadly assess patient levels of concern and satisfaction with various aspects relating to their BC diagnosis. We used REDCap, a secure web application for developing and managing online surveys and databases, specifically tailored to support online and offline data capture for research studies. A questionnaire was sent electronically to all MCBDR participants that were consented, alive, and had an email address on file on 12/9/2021. Non-respondents were sent two reminder e-mails on 12/16 and 12/23/2021.

The questionnaire assessed the following: 1. Demographic Information; 2. BC Treatment; 3. Concerns Regarding Side Effects of BC Treatment; 4. BC Clinical Care Concerns ([i] level of symptoms experienced during the first year after BC diagnosis; and [ii] level of concern regarding health related, practical, financial, emotional, societal and spiritual issues related to BC during that time); 5. Clinical Care BC Patient Experience ([i] overall satisfaction with BC care, [ii] satisfaction with information and support received from the care team as regards symptom management during first year after BC diagnosis; [iii] satisfaction with information and support received from BC care team as regards practical, financial, emotional, societal and spiritual issues related to BC during the first year after diagnosis); 6. Ranking of proposed QI Projects; 7. Integrative Medicine; 8. Medical Second Opinions; 9. Clinical Trial Participation; 10. Thoughts/suggestions (patient comments on [i] how care for BC patients could be improved, and [ii] what research topics should be prioritized in BC). Results from Sects. 7–10 will be reported elsewhere.

Sections 3, 4 and 5 contained a different number of items to be scored, and each item was scored on a 10-point Likert scale. For section 3 and some items in section 4, respondents were asked to score their responses (0 = not at all concerned, 10 = highly concerned). Other items in section 4 related to symptom severity, and were scored accordingly (0 = None, 10 = [symptom] as bad as I can imagine); For section 5, respondents were asked to rate their overall satisfaction with their BC care (0 = very dissatisfied, 10 = extremely satisfied). Section 6 included a list of potential future QI projects, conceived by the study team a priori, and asked respondents to rate the likelihood that each listed project would improve patient care (0 = None, vs. 10 = As much as I can imagine).

### Declaration of ethical approval

This research was conducted in accordance with the Declaration of Helsinki, and the study protocol was reviewed by the Mayo Clinic Institutional Review Board (IRB 1815–04).

### Statistical analysis

Data were summarized using frequencies and percents for categorical variables; and means and standard deviations (SDs) for continuous variables. Self-reported levels of symptom severity, concerns, satisfaction, and interest in suggested QI projects were further visualized using means and 95% confidence intervals. We compared demographic and clinical characteristics across survey response status using chi-square tests of significance. Amongst those who returned surveys, associations of survey scores with demographic and clinical characteristics were first examined univariately using analysis of variance (ANOVA) methods. Subsequent multivariate models assessing the independent effects of each characteristic with survey scores were then fit using multiple linear regression analysis, modeling survey score as the dependent variable and simultaneously including all demographic and clinical characteristics as independent variables. Adjusted parameter estimates and corresponding standard errors from the regression models were estimated for level of the characteristics examined, while designating one level as the referent group. The following characteristics were examined: age at diagnosis (<50, 50–64, 65+); time (months) from diagnosis to survey completion (<6, 7–11, 12–23, 24–35, 36–59, 60–119, 120+); self-reported sexual orientation (heterosexual, LGBTQIA, unsure); race (non-white, white); ethnicity (Hispanic or Latino and non-Hispanic or Latino); marital status (married, living with someone in a marriage-like relationship, separated, divorced, widowed, never been married); religious affiliation (Catholic, Jewish, Ashkenazi Jewish, Protestant, Muslim, Other, None); English as a first language (yes and no); rural residency (rural vs. non-rural based on patient ZIP code and applying Rural–Urban Commuting Area (RUCA) codes using data from the 2020 decennial census); whether the patient has a Mayo Clinic primary care provider (PCP, no vs. yes); and BC stage (unknown, 0, 1–3 and 4). Drafts of the manuscript were sent electronically to our patient advocate collaborators for review.

### Results

A total of 6,918 patients (6,877 female) were eligible to participate in our study and 2,450 responses from MCBDR enrollees (response rate=35.4%) were received. Thirteen males were excluded, resulting in a final study size of 2,437. Comparisons of demographic and clinical

characteristics across survey response status are provided in Supplemental Table 1. Compared to non-responders, responders were more likely to be of white race and to have a shorter period between BC diagnosis and survey receipt ( $p < 0.001$ ). Responders were also slightly more likely to be widowed or never married than non-responders ( $p = 0.05$ ). We found no significant differences in current age, ethnicity or BC stage by response status ( $p > 0.05$  for each).

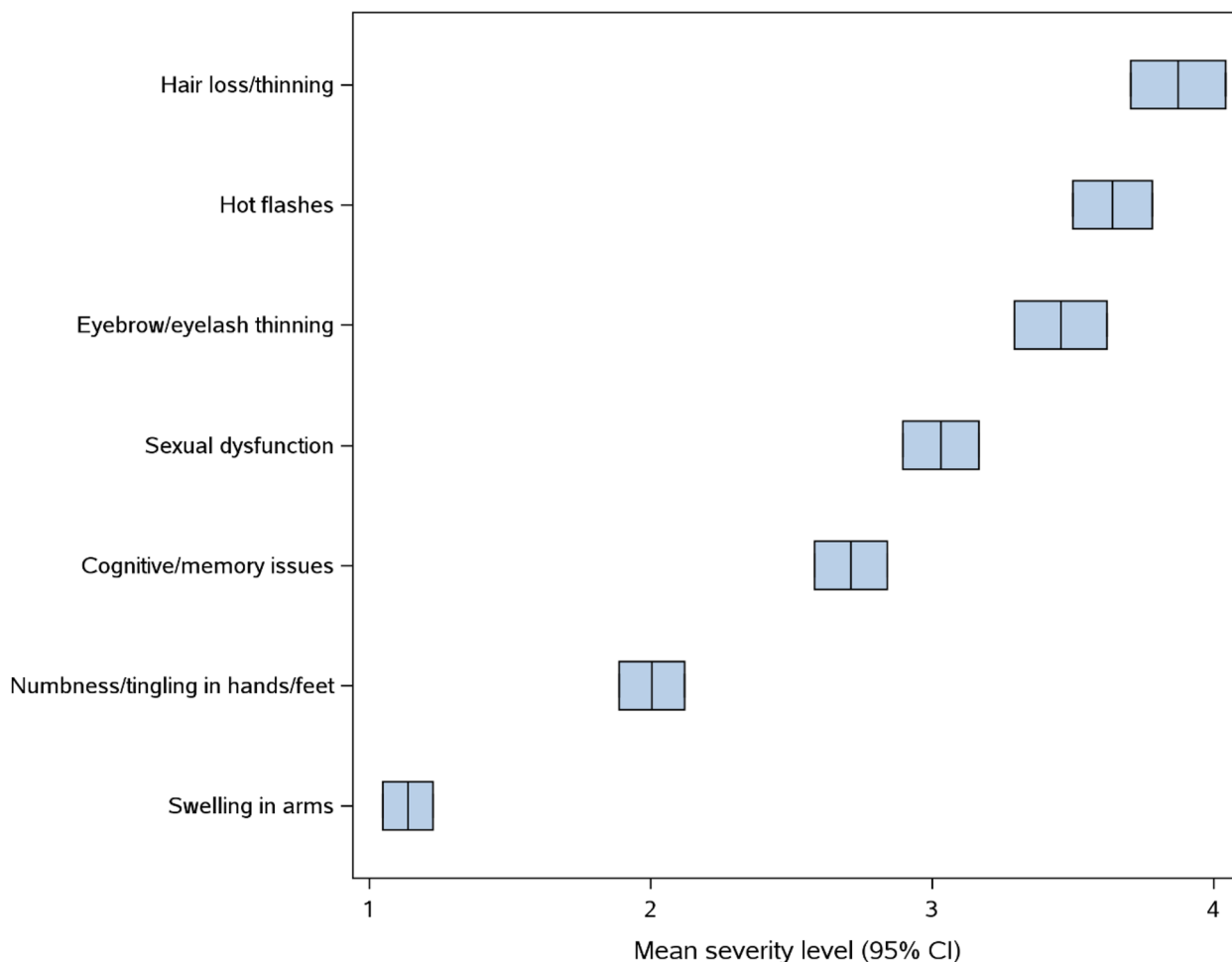
Demographic and clinical characteristics for the 2,437 female patients returning surveys are provided in Table 1. The main severe symptoms patients recalled in year 1 were hair loss/thinning, hot flashes, eyebrow/eyelash thinning, sexual dysfunction and cognitive/memory issues (Fig. 1, Supplemental Table 2). Survey respondents were least concerned with peripheral neuropathy and lymphedema.

The main concerns patients recalled in year 1 following diagnosis were i) fear of BC recurrence; ii) concerns as regards how loved ones would cope if they were to pass away from BC; iii) the diagnosis and prognosis; iv) fear of dying of BC; and v) their emotional health (Fig. 2, Supplemental Table 3). Our survey respondents were least concerned regarding i) cultural and/or religious issues related to BC diagnosis and treatment, ii) fertility; iii) impact of the BC diagnosis on dating/socializing; iv) the need for privacy regarding their diagnosis and v) the need to keep family and friends updated as regards BC diagnosis and treatment.

Overall, patients were pleased with the availability of information related to their BC diagnosis, noting ease of access and an appropriate level of same (Fig. 3, Supplemental Table 4). Patients were also satisfied with information received regarding self-advocacy, genetic testing/counseling and breast cancer recurrence or spread. Patients were least satisfied with information received regarding fertility, social impacts of their disease, and changes in intimacy with their partner.

In year 1 following diagnosis, patients were most satisfied with information and support related to management of the short-term side effects of i) surgery, ii) radiotherapy, and iii) chemotherapy for BC, iv) long term side-effects of BC surgery and v) the side effects of endocrine therapy (Fig. 4, Supplemental Table 5). Patients were least satisfied with information and support provided regarding the potential side-effects of i) immunotherapy, ii) targeted biologic therapies and iii) the long-term effects of chemotherapy, as well as for management of i) sexual dysfunction, ii) peripheral neuropathy and iii) eyebrow/eyelash thinning.

The highest ranking QI projects were: i) lifetime access to online patient educational resources: including summary “cheat sheets”; ii) educational, practical, emotional



**Fig. 1** Mean levels of symptom severity (10-point scale, 0 = none, 10 = as bad as I could imagine) as reported by survey respondents in the first year after breast cancer diagnosis and 95% confidence intervals

and holistic support programs for MBC patients, and iii) Wellness Programs for EBC and MBC patients (endorsed by 82.6%; 82.4% and 81.9% of respondents, respectively, Fig. 5, Supplemental Table 6). The lowest ranking QI projects were: i) reconnecting oncology providers with a past patient 5–10 years on; ii) a couples’ workshop to address relationship and intimacy issues in patients with EBC vs. MBC and iii) a study focusing on educational, practical, emotional and holistic support for caregivers/family members of patients with EBC.

We next looked at the associations of top concerns reported by survey respondents in year 1 after diagnosis with patient characteristics. All associations noted below were significant for both univariate and multivariate analyses. A higher concern for BC recurrence/spread was associated with i) younger age; ii) higher disease stage/metastatic disease; iii) marital status (Separated, Married, Divorced); iv) no primary care provider (PCP); and v) 120+ months since BC diagnosis

(Table 2 and Supplemental Table 7). Patients who were i) younger; ii) non-white; iii) divorced/married; iv) with higher BC stage/metastatic disease and v) without a PCP were more concerned as regards loved ones coping abilities if they were to pass away from BC (Table 2 and Supplemental Table 8). Higher concern regarding BC diagnosis and prognosis was noted in patients who were i) younger; ii) Ashkenazi Jewish or Muslim; iii) with a higher BC stage and iv) 120+ months out from BC diagnosis (Table 2 and Supplemental Table 9). A greater fear of dying from BC was noted in i) younger patients; ii) those 120+ months out from BC diagnosis and iii) those of Ashkenazi Jewish/Jewish/Other religious affiliations (Table 2 and Supplemental Table 10). Emotional health concerns were also more commonly seen in patients who were i) younger and ii) those of Jewish/Other religious affiliations; however, numbers were relatively small in these groups (Table 2 and Supplemental Table 11).

**Table 1** Patient Characteristics of 2,437 breast cancer survivors (stages 0–4) who completed and returned the survey

Demographic and clinical characteristics	Total (N = 2437)
<b>Current age, n (%)</b>	
Under 50	305 (12.5%)
50–64	895 (36.7%)
65 +	1237 (50.8%)
<b>Race, n (%)</b>	
Non-White	65 (2.7%)
White	2340 (97.3%)
Missing	32
<b>Ethnicity, n (%)</b>	
Hispanic or Latino	30 (1.3%)
Not Hispanic or Latino	2314 (98.7%)
Missing	93
<b>LGBTQIA, n (%)</b>	
Yes	30 (1.3%)
No	2358 (98.4%)
Unsure	9 (0.4%)
Missing	40
<b>Marital Status, n (%)</b>	
<b>Married</b>	1845 (76.3%)
Living with someone	87 (3.6%)
Separated	9 (0.4%)
Divorced	174 (7.2%)
Widowed	180 (7.4%)
Never been married	122 (5.0%)
Missing	20
<b>Religious Affiliation, n (%)</b>	
Catholic	680 (28.2%)
Jewish	17 (0.7%)
Ashkenazi Jewish	8 (0.3%)
Protestant	945 (39.2%)
Islam/Muslim	44 (1.8%)
Other	405 (16.8%)
None	314 (13.0%)
Missing	24
<b>English is first language, n (%)</b>	
Yes	2341 (97.6%)
No	57 (2.4%)
Missing	39
<b>Residency based on Census tract, n (%)</b>	
Non-Rural	2179 (89.7%)
Rural	250 (10.3%)
Missing	8
<b>Patient has primary care provider at Mayo Clinic, n (%)</b>	
No	1608 (66.0%)
Yes	829 (34.0%)
<b>Months since breast cancer diagnosis, n (%)</b>	
<6 months	72 (3.0%)

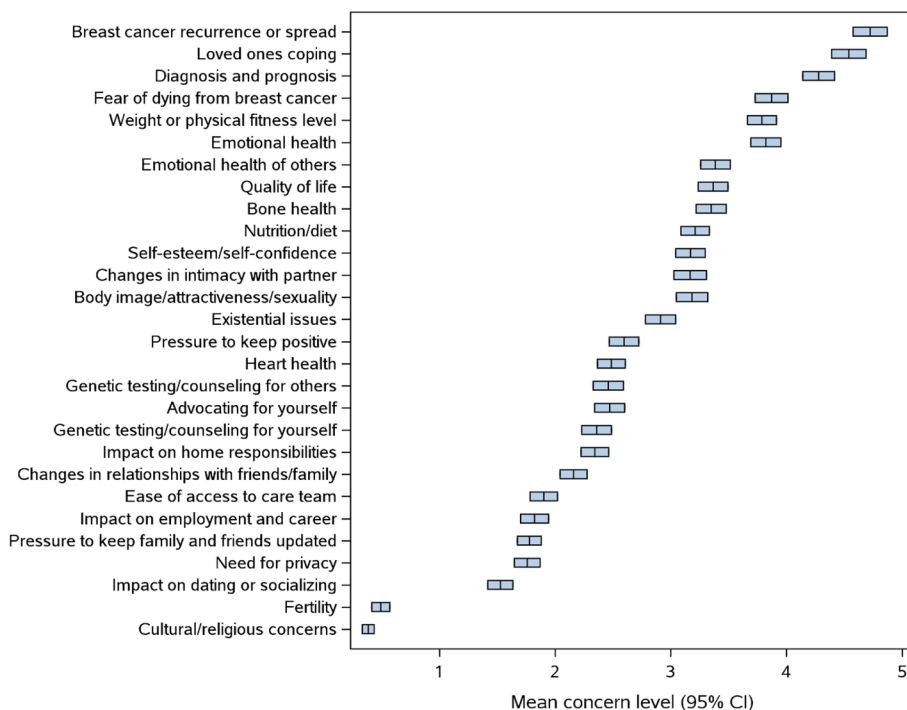
**Table 1** (continued)

Demographic and clinical characteristics	Total (N = 2437)
7–11 months	113 (4.6%)
12–23 months	189 (7.8%)
24–35 months	229 (9.4%)
36–59 months	427 (17.5%)
60–119 months	573 (23.5%)
120+ months	834 (34.2%)
<b>BC stage, n (%)</b>	
Stage 0	392 (17.5%)
Stage 1–3	1805 (80.7%)
Stage 4	41 (1.8%)
Missing	199
<b>Primary Breast Cancer Treatment Location(s), n (%)</b>	
Mayo Clinic Sites	1680 (69.4%)
Other (Non-Mayo Clinic)	142 (5.9%)
Both (Mayo Clinic and Non-Mayo Clinic)	598 (24.7%)
Missing	17

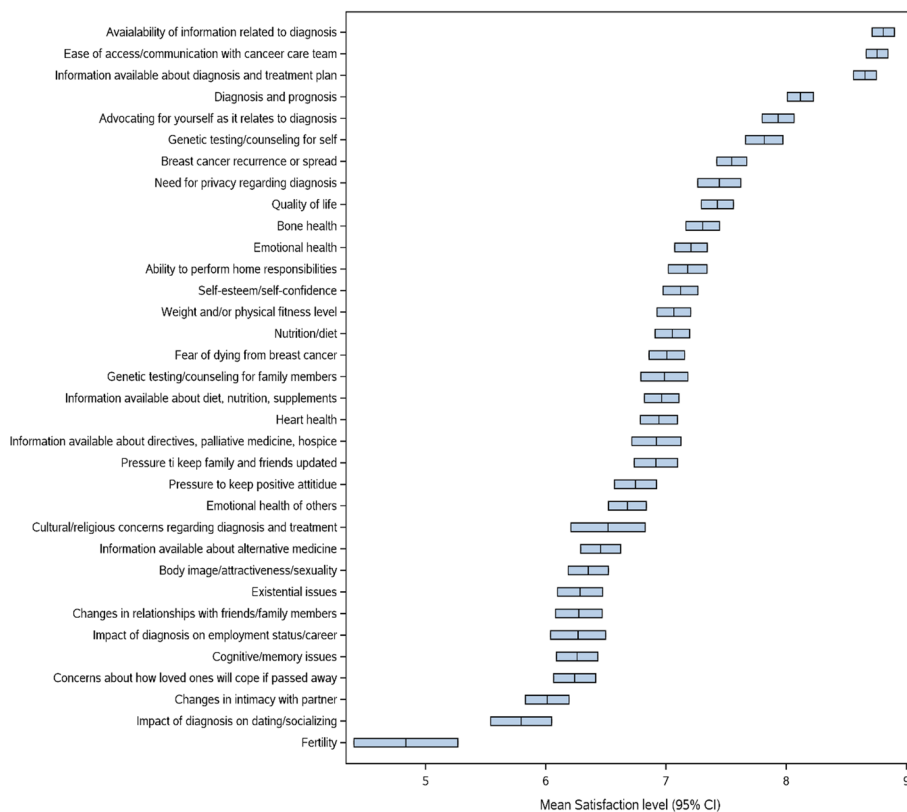
Regarding the top five symptoms which survey respondents reported as being most troublesome in year 1 after BC diagnosis (significant for both univariate and multivariate analyses), patients who reported hair loss were more likely to be i) younger; ii) with a higher BC stage, and iii) 120+ months out from their BC diagnosis (Table 3 and Supplemental Table 12). Those who experienced more distress with eyebrow/eyelash thinning were i) younger; ii) without a PCP; iii) with a higher BC stage and iv) 120+ months from BC diagnosis (Table 3 and Supplemental Table 13). Patients most troubled by hot flashes were i) <65 years; ii) married or living with someone; iii) with BC stage 1–4 and iv) at least 7 months out from BC diagnosis (Table 3 and Supplemental Table 14). Sexual dysfunction was most concerning for i) younger patients (<65 years); ii) married and partnered people; iii) patients with stage 1–4 BC and iv) >6 months out from their BC diagnosis (Table 3 and Supplemental Table 15). Patients most concerned as regards cognitive dysfunction were i) ≤50 years; ii) of other religion or with no religious affiliation; iii) without a PCP; iv) with higher BC stage and v) 120+ months out from diagnosis (Table 3 and Supplemental Table 16).

## Discussion

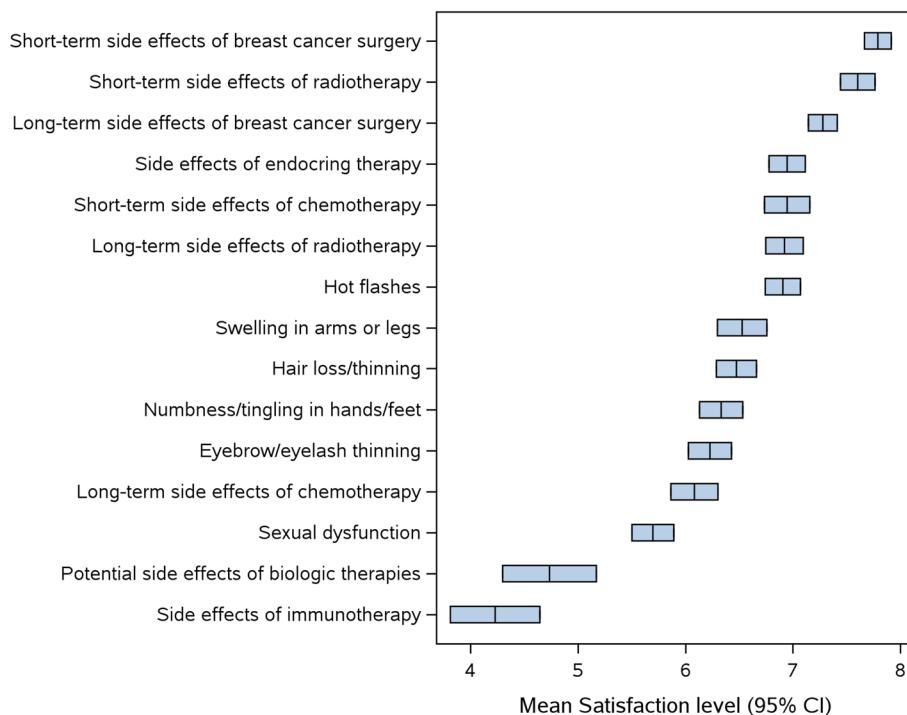
Herein we present the results of a patient experience survey conducted in BC survivors enrolled in the MCBDR, with a focus on primary symptoms and concerns experienced in year 1 after BC diagnosis, as well as the level of satisfaction with information and support provided regarding same. QI projects were also presented and



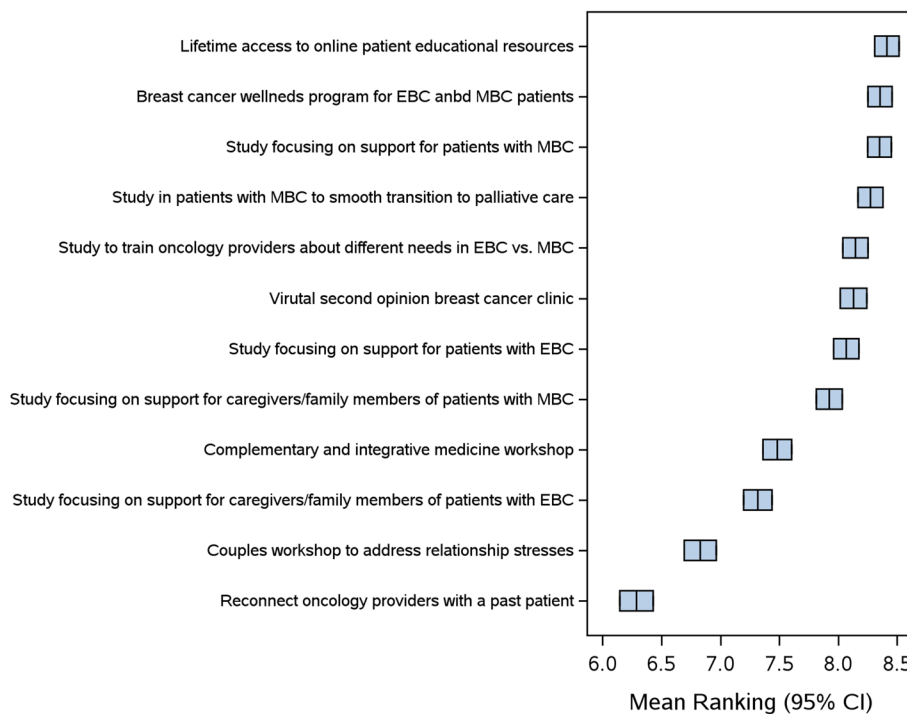
**Fig. 2** Mean levels of concern regarding health, practical and psychosocial issues (10-point scale, 0= not at all concerned, 10= highly concerned) as reported by survey respondents in the first year after breast cancer diagnosis and 95% confidence intervals



**Fig. 3** Mean levels of satisfaction with information and support received from cancer care team (10-point scale, 0= very dissatisfied, 10= very satisfied) as it relates to BC related concerns during the first year after diagnosis and 95% confidence intervals



**Fig. 4** Mean levels of satisfaction with information and support received from cancer care team (10-point scale, 0=very dissatisfied, 10=very satisfied) as it relates to BC related symptoms during the first year after diagnosis and 95% confidence intervals



**Fig. 5** Mean patient rankings of suggested quality improvement projects (10-point scale, 0=none, 10=as much as I can imagine) and 95% confidence intervals



**Table 2** Multivariate-adjusted associations of top concerns with demographic and clinical characteristics. 10-point scale, 0 = not at all concerned, 10 = highly concerned

Attribute	Concerns about breast cancer recurrence or spread		Concerns about coping		Concerns about diagnosis and prognosis		Concerns about fear of dying from breast cancer		Concerns about emotional health	
	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value
Age group		<.0001		<.0001		<.0001		<.0001		<.0001
Under 50	2.48 (0.25)		2.72 (0.25)		2.43 (0.24)		2.63 (0.24)		2.05 (0.23)	
50–64	1.51 (0.17)		1.72 (0.17)		1.43 (0.16)		1.59 (0.16)		1.49 (0.15)	
65 +	Ref		Ref		Ref		Ref		Ref	
Race		0.1199		0.0350		0.1922		0.4969		0.1767
Non-white	0.74 (0.48)		1.01 (0.48)		0.58 (0.44)		0.31 (0.46)		0.57 (0.42)	
White	Ref		Ref		Ref		Ref		Ref	
Ethnicity		0.2436		0.3119		0.5977		0.4397		0.8165
Hispanic or Latino	0.82 (0.71)		0.72 (0.71)		-0.35 (0.66)		-0.52 (0.68)		0.15 (0.63)	
Not Hispanic or Latino	Ref		Ref		Ref		Ref		Ref	
Identify as LGBTQIA		0.9843		0.3377		0.7081		0.5435		0.4161
Yes	0.20 (1.40)		-2.06 (1.40)		-0.97 (1.30)		-1.33 (1.33)		-1.39 (1.24)	
No	0.10 (1.24)		-1.58 (1.24)		-0.55 (1.15)		-1.30 (1.18)		-1.45 (1.10)	
Unsure	Ref		Ref		Ref		Ref		Ref	
Marital status		0.0105		0.0064		0.7005		0.0783		0.0807
Married	0.54 (0.34)		1.16 (0.34)		-0.15 (0.32)		0.82 (0.33)		0.10 (0.30)	
Living with someone	-0.33 (0.51)		0.43 (0.51)		-0.58 (0.48)		0.17 (0.49)		0.51 (0.45)	
Separated	-0.22 (1.27)		0.54 (1.27)		-0.10 (1.19)		0.19 (1.21)		1.12 (1.13)	
Divorced	0.56 (0.43)		1.43 (0.43)		-0.01 (0.40)		0.74 (0.41)		0.82 (0.38)	
Widowed	-0.32 (0.43)		0.98 (0.43)		-0.42 (0.41)		0.50 (0.41)		0.15 (0.39)	
Never been married	Ref		Ref		Ref		Ref		Ref	
Religious affiliation		0.1259		0.1108		0.0337		0.0266		0.0236
Catholic	0.03 (0.25)		0.75 (0.25)		0.20 (0.24)		0.29 (0.24)		-0.20 (0.23)	
Jewish	0.64 (0.98)		1.15 (0.99)		0.57 (0.92)		0.59 (0.94)		0.70 (0.87)	
Ashkenazi Jewish	0.00 (1.56)		-0.30 (1.57)		0.73 (1.46)		0.47 (1.49)		0.03 (1.39)	
Protestant	-0.36 (0.24)		0.20 (0.25)		-0.21 (0.23)		-0.25 (0.23)		-0.47 (0.22)	
Islam/Muslim	0.09 (0.59)		0.47 (0.59)		0.68 (0.55)		0.06 (0.56)		-0.13 (0.52)	
Other	0.25 (0.28)		0.94 (0.28)		0.44 (0.26)		0.39 (0.26)		0.22 (0.25)	
None	Ref		Ref		Ref		Ref		Ref	
English is first language		0.0856		0.4107		0.1581		0.2287		0.5034
Yes	0.90 (0.53)		0.42 (0.52)		0.68 (0.48)		0.60 (0.50)		0.31 (0.46)	
No	Ref		Ref		Ref		Ref		Ref	

**Table 2** (continued)

Attribute	Concerns about breast cancer recurrence or spread		Concerns about loved ones coping		Concerns about diagnosis and prognosis		Concerns about fear of dying from breast cancer		Concerns about emotional health	
	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value
Rural residency		0.9603		0.3274		0.7508		0.7575		0.7026
Non-Rural	0.01 (0.25)		-0.24 (0.25)		-0.07 (0.23)		-0.07 (0.24)		-0.08 (0.22)	
Rural	Ref		Ref		Ref		Ref		Ref	
Patient has PCP		0.0083		0.0152		0.0512		0.0002		0.1693
No	0.42 (0.16)		0.39 (0.16)		0.29 (0.15)		0.57 (0.15)		0.19 (0.14)	
Yes	Ref		Ref		Ref		Ref		Ref	
BC stage		<.0001		<.0001		<.0001		<.0001		0.0033
Unknown	-0.79 (0.78)		-1.38 (0.78)		-2.23 (0.73)		-1.07 (0.75)		0.79 (0.69)	
Stage 0	-1.61 (0.61)		-2.53 (0.61)		-3.04 (0.57)		-2.07 (0.59)		-0.24 (0.54)	
Stage 1–3	-0.59 (0.59)		-1.43 (0.59)		-1.76 (0.55)		-0.77 (0.56)		0.39 (0.52)	
Stage 4	Ref		Ref		Ref		Ref		Ref	
Months since BC diagnosis		0.0003		<.0001		<.0001		<.0001		0.0089
<6 months	-1.11 (0.69)		-1.17 (0.69)		-0.84 (0.65)		-1.29 (0.66)		-1.23 (0.62)	
7–11 months	-0.51 (0.56)		-0.84 (0.56)		-0.80 (0.52)		-1.15 (0.53)		-0.77 (0.49)	
12–23 months	-0.35 (0.30)		-0.56 (0.30)		-0.57 (0.28)		-0.72 (0.28)		-0.47 (0.26)	
24–35 months	-0.85 (0.28)		-1.09 (0.28)		-1.13 (0.26)		-0.86 (0.26)		-0.49 (0.24)	
36–59 months	-0.85 (0.22)		-1.01 (0.22)		-0.72 (0.21)		-1.06 (0.21)		-0.58 (0.20)	
60–119 months	-0.80 (0.20)		-0.96 (0.20)		-0.98 (0.19)		-1.03 (0.19)		-0.62 (0.18)	
120+ months	Ref		Ref		Ref		Ref		Ref	

PCP Primary care provider, BC Breast cancer, SE Standard error

Multiple linear regression analysis simultaneously including in model all variables listed in table. Parameters interpreted as estimated increase in concern score for category of interest compared to the referent category

**Table 3** Multivariate-adjusted associations of most severe symptoms with demographic and clinical characteristics. 10-point scale, 0 = none, 10 = as bad as I could imagine

Attribute	Hair loss/thinning		Eyebrow/eyelash thinning		Hot flashes		Sexual dysfunction		Cognitive dysfunction	
	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value
Age group		<.0001		<.0001		<.0001		<.0001		<.0001
Under 50	2.13 (0.29)		2.40 (0.28)		2.15 (0.24)		1.75 (0.23)		2.37 (0.22)	
50–64	0.82 (0.19)		0.93 (0.18)		2.14 (0.16)		1.43 (0.15)		1.32 (0.14)	
65+	Ref		Ref		Ref		Ref		Ref	
Race		0.8389		0.6914		0.8476		0.5282		0.2826
Non-white	0.11 (0.54)		-0.21 (0.52)		0.09 (0.45)		-0.27 (0.43)		0.44 (0.41)	
White	Ref		Ref		Ref		Ref		Ref	
Ethnicity		0.4404		0.3361		0.8550		0.5864		0.2867
Hispanic or Latino	0.62 (0.81)		0.77 (0.80)		-0.13 (0.68)		0.35 (0.64)		0.65 (0.61)	
Not Hispanic or Latino	Ref		Ref		Ref		Ref		Ref	
Identify as LBGTO/A		0.5221		0.7344		0.2795		0.0773		0.8419
Yes	-1.72 (1.59)		-0.92 (1.54)		-0.19 (1.32)		-2.63 (1.27)		-0.28 (1.20)	
No	-1.10 (1.41)		-0.39 (1.36)		-1.03 (1.17)		-2.54 (1.12)		0.05 (1.06)	
Unsure	Ref		Ref		Ref		Ref		Ref	
Marital status		0.6846		0.4233		0.0256		<.0001		0.0876
Married	0.31 (0.39)		0.45 (0.38)		0.91 (0.32)		1.92 (0.31)		0.65 (0.29)	
Living with someone	0.77 (0.58)		0.78 (0.56)		0.90 (0.48)		1.42 (0.46)		1.07 (0.44)	
Separated	1.55 (1.45)		1.06 (1.40)		0.66 (1.20)		0.66 (1.16)		-0.09 (1.09)	
Divorced	0.54 (0.49)		0.94 (0.47)		0.72 (0.41)		1.05 (0.39)		1.00 (0.37)	
Widowed	0.24 (0.49)		0.35 (0.48)		0.25 (0.41)		0.47 (0.40)		0.60 (0.37)	
Never been married	Ref		Ref		Ref		Ref		Ref	
Religious affiliation		0.2601		0.0687		0.6414		0.1914		0.0275
Catholic	0.15 (0.29)		0.03 (0.28)		0.16 (0.24)		-0.25 (0.23)		-0.09 (0.22)	
Jewish	0.69 (1.05)		0.42 (1.01)		1.01 (0.87)		0.34 (0.84)		-1.19 (0.79)	
Ashkenazi Jewish	0.32 (1.79)		0.18 (1.73)		-0.68 (1.48)		0.10 (1.42)		-0.69 (1.34)	
Protestant	-0.06 (0.28)		-0.33 (0.27)		-0.06 (0.23)		-0.50 (0.22)		-0.26 (0.21)	
Islam/Muslim	-0.11 (0.67)		-0.09 (0.64)		-0.14 (0.57)		-0.41 (0.54)		-0.46 (0.50)	
Other	0.60 (0.32)		0.49 (0.31)		0.21 (0.26)		-0.04 (0.25)		0.38 (0.24)	
None	Ref		Ref		Ref		Ref		Ref	
English is first language		0.5178		0.6945		0.8107		0.6430		0.2678
Yes	0.38 (0.59)		0.22 (0.57)		0.12 (0.49)		-0.22 (0.47)		0.49 (0.44)	
No	Ref		Ref		Ref		Ref		Ref	
Rural residency		0.4308		0.7031		0.8013		0.9780		0.3572

**Table 3** (continued)

Attribute	Hair loss/thinning		Eyebrow/eyelash thinning		Hot flashes		Sexual dysfunction		Cognitive dysfunction	
	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value	Adjusted parameter estimate (SE)	p-value
Non-Rural	-0.22 (0.28)		-0.10 (0.27)		-0.06 (0.23)		-0.01 (0.23)		-0.20 (0.21)	
Rural	Ref		Ref		Ref		Ref		Ref	
Patient has PCP		0.3282		0.0428		0.2194		0.0016		0.0053
No	0.18 (0.18)		0.35 (0.17)		0.18 (0.15)		0.46 (0.14)		0.38 (0.14)	
Yes	Ref		Ref		Ref		Ref		Ref	
BC stage		<.0001		<.0001		<.0001		<.0001		<.0001
Unknown	-2.89 (0.89)		-2.29 (0.86)		-0.24 (0.74)		-0.39 (0.71)		-0.84 (0.67)	
Stage 0	-4.07 (0.69)		-3.34 (0.67)		-1.11 (0.57)		-1.10 (0.55)		-2.02 (0.53)	
Stage 1–3	-1.01 (0.66)		-0.51 (0.64)		-0.05 (0.55)		-0.07 (0.53)		0.02 (0.51)	
Stage 4	Ref		Ref		Ref		Ref		Ref	
Months since BC diagnosis		<.0001		<.0001		<.0001		0.0352		<.0001
<6 months	-0.43 (0.79)		-1.14 (0.77)		-2.55 (0.66)		-1.40 (0.63)		-0.76 (0.60)	
7–11 months	0.72 (0.64)		0.02 (0.62)		-0.74 (0.53)		-0.75 (0.51)		-0.38 (0.48)	
12–23 months	-0.48 (0.34)		-0.64 (0.33)		-0.31 (0.28)		-0.74 (0.27)		-0.49 (0.25)	
24–35 months	-0.97 (0.31)		-0.90 (0.30)		-0.76 (0.26)		-0.13 (0.25)		-0.68 (0.23)	
36–59 months	-1.23 (0.25)		-1.28 (0.25)		-0.97 (0.21)		-0.47 (0.20)		-0.95 (0.19)	
60–119 months	-0.92 (0.23)		-0.98 (0.22)		-0.58 (0.19)		-0.25 (0.18)		-0.89 (0.17)	
120+ months	Ref		Ref		Ref		Ref		Ref	

PCP Primary care provider, BC Breast cancer, SE Standard error

Multiple linear regression analysis simultaneously including in model all variables listed in table. Parameters interpreted as estimated increase in severity score for category of interest compared to the referent category

ranked by respondents in order for the Advocate-BREAST team to prioritize future research. Based on our findings, major areas for BC care optimization include increased i) psychological support; ii) refinement and useability of patient education materials; and iii) better integration of holistic care approaches.

A strength of this study is the substantial number of BC patients who participated and our ability to supplement questionnaire data with demographic and clinical attributes by leveraging our institution's extensive electronic health record. Others include the high survey response rate (35%), and careful development of same, including input from BC advocates. Our survey also included 250 rural-dwelling women (10% of respondents), who are often underrepresented in cancer care delivery research. As we asked participants to rank-order the list of proposed QI projects, the development of pilot studies of most relevance to BC patients surveyed was prioritized. We can now perform subset analyses of survey respondents and conduct pilot studies to address key concerns, proceeding with larger scale efforts depending on the results. Regarding study limitations, most survey respondents were  $\geq 50$  years ( $n=2132$ ; 87.4%) and had stage 0–3 BC ( $n=2197$ ; 90.1%). Therefore, it is difficult to make firm conclusions outside these groups. For example, the impact of a BC diagnosis on fertility was not reported as a top concern in our survey respondents, however many younger patients are extremely concerned regarding same [19]. Younger BC patients [20], and those with MBC [21], have different concerns compared with older patients and/or those treated with curative intent [22]. Further, as most survey respondents were married, Caucasian, Christians living in the Midwest of the US, who received at least some care at a Mayo Clinic site, conclusions may not be generalizable to a wider BC population. Therefore, further research should include younger, more ethnically and racially diverse populations who received/are receiving BC care elsewhere. Further, ~58% of survey respondents were diagnosed 5–10 years ago, which may contribute to impaired recollection and recall bias when reporting symptom severity and BC related concerns. Finally, although our study questionnaire was intricately developed with input from a wide range of specialists including BC advocates, it hasn't been externally validated, which may limit reproducibility.

Regarding psychologic support, top concerns reported by BC patients in the first year after diagnosis included emotional distress and anxiety related to diagnosis, as well as concerns regarding their emotional health, and that of close relatives. Predictors of distress regarding the top 5 concerns related to key demographics (age, disease stage, time since diagnosis, etc.) were studied. Patients with no PCP who were younger, non-white,

with a higher disease stage, and who identified as Jewish/Other reported higher levels of concern. As previously noted, most patients in our study were  $\geq 50$  years. It has been noted that increasing age is associated with less symptom related distress, improved mood, and fewer fears of cancer recurrence (FCR) [23]. Nevertheless, FCR was a primary concern of our survey respondents, which infers that distress levels in younger BC patients is likely even higher in general. In a survey of younger BC survivors ( $\leq 45$  years), increasing age and longer time since diagnosis were linked with lower FCR levels [24] vs in our survey, where increased time since diagnosis was associated with increased distress levels. Timeline variances related to FCR can exist, however. Schapiro et al. identified 5 distinct trajectories that show moderate and severe FCR does not always improve over time and may require targeted mental health intervention [25]. Further, a study evaluating other factors that contribute to FCR ( $n=3,239$ ) showed that increased illness intrusiveness and anxiety were associated with increased FCR [26]. Interestingly, no association with BC stage was noted, but all mothers, irrespective of age, reported increased FCR. In another survey of BC survivors (2–10 years after diagnosis) unmet needs were reported three times more frequently in patients with clinical anxiety, highlighting the importance of optimizing mental health to enhance overall care satisfaction. Further, based on the results above, the PCP likely has a key role in providing practical and emotional support to many BC patients and survivors. As it can be difficult to access prompt psychologic care, especially for rural BC patients [27], a goal of the Advocate-BREAST project is to reduce these barriers for patients with significant cancer-associated anxiety and distress via implementation of a digital psycho-oncology model. An initial step will be to initiate pilot studies of an early digital healthcare intervention targeted at BC patients with high self-reported distress scores, with the intent of reducing distress via practical, psychological and pharmacological interventions, increasing coping skills and promoting self-care. If successful, we will submit large grant applications addressing national disparities in mental health care for rural BC patients. Regarding another priority, refinement and useability of education materials, BC patients were most satisfied with education provided regarding the short-term side effects of local regional and systemic therapy and less satisfied with materials regarding side effects of targeted therapies and immunotherapy. At a practice level, we can therefore focus on improving educational resources in areas found to be lacking. As specialized programs in cancer care settings can improve quality of clinician-patient discussions regarding a specific topic (e.g. sexual dysfunction) and improve patient satisfaction levels; this is also

an intervention worthy of consideration [28]. Regarding patient educational materials (OPEM), [29], many do not fit criteria for readability, understandability, and actionability [30–32]. BC patients also report substantial “information overload” which can impact recollection [33], but desire long-term access to concise, informative educational resources. To this end, our highest ranked QI project proposed providing lifetime access to OPEM with “cheat sheets” to assist navigation of same (endorsed by 82.6%). Therefore, an institutional pilot study focusing on the delivery of and access to concise OPEM, with instructions on how to quickly access same will be implemented and patient satisfaction levels assessed.

BC patients desire holistic care which focuses on improving wellness, nutrition and overall health [34]. Specifically, the second and third highest ranking QI projects, endorsed by 82.4% and 81.9% of respondents were: i) Educational, practical, emotional and holistic support programs for MBC patients, and ii) BC Wellness Programs for EBC and MBC patients. This infers that, despite the smaller number of patients with MBC participating in this survey, patients with DCIS and EBC recognize the importance of dedicated QI interventions to address the unique concerns of patients with MBC.

## Conclusions

These results have and will continue to inform and enable the Advocate-BREAST team to conceptualize and develop ideas for clinical trials, public online educational resources, and wellness/quality of life interventions, prioritizing those which have potential to quickly enact positive and tangible changes. The data has also uncovered gaps in cancer care delivery *as identified by a large number of BC survivors*. These will inform pilot studies, including projects to: i. assess the proportion of Mayo BC patients who are aware of and able to access Mayo-approved OPEM; ii. update lacking educational resources and create summary “cheat sheets” on topics relevant to BC care, assessing patient satisfaction with same; and iii. implement a remotely delivered psycho-oncology intervention, focusing on rural BC patients, subsequently evaluating satisfaction with same. If successful, we would plan larger studies to i) assess satisfaction with the revised educational resources and ii) target rural mental health disparities in BC nationally using a digital psycho-oncology intervention.

In summary, the results from our survey have provided useful information for us to move forward with research aiming to enhance BC care delivery, patient experience and patient centered research by 2025. We will address the issues identified, promoting an equitable and holistic model of BC care delivery with the goal of improving quality of life and visibility for all patients.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s13690-024-01351-z>.

Supplementary Material 1.

### Authors' contributions

Conception or design of the work: COS, RAV, KJR, MLS, CC Data collection- COS, RAV, NL Data analysis and interpretation- COS, RAV, NL, KJR, JO, MLS, CC, CLL Drafting the article- COS, RAV, NL, KJR, JO, CLL Critical revision of the article- All authors Final approval of the version to be published- All authors.

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### Availability of data and materials

The datasets for this study are available from the corresponding author upon request.

## Declarations

### Ethics approval and consent to participate

This research was conducted in accordance with the Declaration of Helsinki, and the study protocol was reviewed by the Mayo Clinic Institutional Review Board (IRB 1815–04).

### Consent to publication

The authors confirm that the work described has not been published before (except in the form of an abstract); that it is not under consideration for publication elsewhere; that its publication has been approved by all co-authors, and that its publication has been approved by the responsible authorities at the institution where the work is carried out. The authors warrant that their contribution is original and that they have full power to make this consent.

### Competing interests

C. O'Sullivan – Dr. O'Sullivan has research funding to Mayo Clinic from Lilly, Seagen Inc., Bavarian Nordic, Minnemarita Therapeutics, nference, Astra-Zeneca and Biovica. N. Larson—None R. Vierkant—None Mary Lou Smith – Consulting/advisory boards with Bayer, Eisai, Novartis, Pfizer, and Rising Tide. Grant funding to institution from Genentech, Foundation Medicine, Novartis, Seagen, Eli Lilly, Exact Sciences, Daiichi, ECOG-ACRIN Medical Research Foundation, Pfizer, Prelude DX, International Association for Study of Lung Cancer, Conquer Cancer Foundation, and Cholangiocarcinoma Foundation. Serves as Co-Chair of Cancer Research Advocate Committee and Member of Breast Core Committee, ECOG ACRIN Research Group. Was a member to the following: Breast Cancer Treatment Guidelines Committee, National Comprehensive Cancer Network (NCCN) External Advisory Board, University of Wisconsin Comprehensive Cancer Center Board of Directors, National Accreditation Program for Breast Centers Board of Directors, Gateway for Cancer Research NCI BOLD Task Force Mayo Clinic Breast SPORE Steering Committee, ASCO TAPUR Study Stakeholder Advisory Board, COMET study Advisory Board, PRO-TECT study Advisory Committee, NCI-NCORP Breast Cancer Guidelines Advisory Group, American Society of Clinical Oncology (ASCO) EVOLV Study NCI Tolerability Consortium Women's Advisory Board, TMIST study Cynthia Chauhan—None Fergus Couch—None Janet E. Olson – Research support: Grail, Inc. Research grant: Exact Sciences, Exact-001. Charles Loprinzi—PledPharma, Disarm Therapeutics, Asahi Kasei/Veloxis, Metys Pharmaceuticals, OnQuality, Mitsubishi Tanabe, NKMax, HengRui, Osmol Therapeutics, Inc., Grunenthal, Bexion, Metys pharmaceuticals, Hengrui Pharmaceuticals, Neuropathix, Dersli Therapeutics, Galendia, Genentech, Nevro, and Toray. Kathryn J. Ruddy – None. N. Larson—None.

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Foundation. Serves as Co-Chair of Cancer Research Advocate Committee and Member of Breast Core Committee, ECOG ACRIN Research Group. Was a member to the following:  
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 External Advisory Board, University of Wisconsin Comprehensive Cancer Center.  
 Board of Directors, National Accreditation Program for Breast Centers.  
 Board of Directors, Gateway for Cancer Research.  
 NCI BOLD Task Force.  
 Mayo Clinic Breast SPORE.  
 Steering Committee, ASCO TAPUR Study.  
 Stakeholder Advisory Board, COMET study.  
 Advisory Board, PRO-TECT study.  
 Advisory Committee, NCI-NCORP.  
 Breast Cancer Guidelines Advisory Group, American Society of Clinical Oncology (ASCO).  
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