



Breast cancer knowledge and understanding treatment rationales among diverse breast cancer survivors

Rachel A. Freedman^{1,2} · Naomi Y. Ko³ · Ruth I. Lederman⁴ · Haley Gagnon¹ · Tsion Fikre³ · Daniel A. Gundersen⁴ · Anna C. Revette⁴ · Ashley Odai-Afotey⁵ · Olga Kantor^{2,6} · Dawn L. Hershman⁷ · Katherine D. Crew⁷ · Nancy L. Keating^{5,8}

Received: 19 July 2022 / Accepted: 18 September 2022 / Published online: 11 October 2022
© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

Abstract

Purpose The degree to which breast cancer survivors know about their tumors and understand treatment rationales is not well understood. We sought to identify information gaps within a diverse sample and explore whether knowledge about breast cancer and treatment may impact care.

Methods We conducted a one-time, interviewer-administered survey of women who were diagnosed with breast cancer during 2013–2017 and received care at one of three centers in Boston, MA, and New York, NY. We examined knowledge of breast cancer and treatment rationales, information preferences, and treatment receipt.

Results During 2018–2020, we interviewed 313 women (American Association for Public Opinion Research Cooperation Rates 58.4–76.5% across centers) who were 56.9% White, 23.6% Black, 14.1% Hispanic, and 5.4% other. Among the 296 included in analyses, we observed high variability in knowledge of breast cancer and treatment rationales, with a substantial number demonstrating limited knowledge despite feeling highly informed; > 25% actively avoided information. Black and Hispanic (vs. White) women consistently knew less about their cancers. Lack of understanding of treatment rationales for chemotherapy, radiation, and hormonal therapy was common but not consistently different by race and ethnicity. Understanding treatment rationale (but not cancer knowledge) was associated with treatment initiation, but small sample sizes limited in-depth examination.

Conclusions Our study highlights the need for enhanced informational support for breast cancer survivors, who are challenged with complex information during the decision-making process and beyond. More research is needed to understand how to further educate and empower diverse populations of patients with breast cancer.

Keywords Breast cancer survivors · Knowledge · Treatment rationales · Survey · Decision making · Disparities

✉ Rachel A. Freedman
rafreedman@partners.org

¹ Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA, USA

² Breast Oncology Program, Dana-Farber Brigham Cancer Center, Boston, MA, USA

³ Section of Hematology and Medical Oncology, Department of Medicine, Boston University School of Medicine, Boston, MA, USA

⁴ Survey and Qualitative Methods Core, Dana-Farber Cancer Institute, Boston, MA, USA

⁵ Department of Medicine, Brigham and Women's Hospital, Boston, MA, USA

⁶ Division of Breast Surgery, Department of Surgery, Brigham and Women's Hospital, Boston, MA, USA

⁷ Department of Medicine and Epidemiology, Columbia University Irving Medical Center, Herbert Irving Comprehensive Cancer Center, New York, NY, USA

⁸ Department of Health Care Policy, Harvard Medical School, Boston, MA, USA

Introduction

Racial disparities in breast cancer treatment exist in many forms, including delays, non-initiation, and incomplete treatment, such as early discontinuation or suboptimal adherence. The reasons for under-treatment include a complex interplay of physician, institutional, access, and patient factors [1–7]. Although not well studied, knowledge about one's breast cancer and the degree to which one understands the rationales for recommended treatment may also affect care and adherence [8, 9]. Evidence suggests that general cancer knowledge is poor [10–15], and individuals with breast cancer often want more information from their clinicians than they received [16].

Many people with breast cancer—particularly Black and Hispanic individuals—do not know basic information about their cancer stage and other tumor characteristics [17]. Although the specific impact of this knowledge has not been studied in breast cancer populations, limited cancer knowledge may impact screening [18–20], cancer-related outcomes [9, 17, 21–25], and satisfaction with care [10, 26, 27]. In addition to knowledge about cancer, understanding why specific treatments are being recommended (*e.g.*, to lower the risk of a local or a systemic recurrence) may also play an important role in decision-making and treatment receipt. Qualitative work among breast cancer patients suggests that many lack knowledge about their diagnoses and treatments, and those with a better understanding more often adhere to treatment [24]. Other evidence suggests that breast cancer patients have highly variable knowledge about treatment pathways and outcomes (*e.g.*, that lumpectomy and mastectomy offer equivalent long-term survival) [11], although the impact of this knowledge on treatment was not examined.

These small studies support a hypothesis that improved knowledge about one's cancer and the reasons for treatment recommendations may improve receipt of and adherence to treatments, and ultimately, improve outcomes. Although many factors contribute to disparities in breast cancer care, improving breast cancer knowledge and understanding of disease are mutable factors amenable to interventions [23]. Further, greater cancer knowledge and knowledge about one's own disease may also impact a woman's trust, communication, confidence, and experiences with her treatment team.

In this study, we explored whether the degree of understanding of one's breast cancer and treatment rationales is associated with treatment receipt. Specifically, we surveyed a large, diverse population of women with previous breast cancer to examine knowledge about one's cancer and the reasons for treatment and assess whether differences in knowledge exist by race and ethnicity and whether

such knowledge is associated with treatment initiation and completion. We also explored information-seeking behaviors and preferences, with the goal to identify opportunities and strategies to engage patients in their health and decision-making about breast cancer treatments.

Methods and patients

Study overview and population

We invited adult women diagnosed with a first invasive, stage I–III breast cancer during 2013–2017 to participate in a one-time interviewer-administered survey. We aimed to include a diverse population of White, Black, and Hispanic participants. Participants had to understand and speak English or Spanish and had to receive some or all of their cancer care (at least 3 visits) at a participating center (Dana-Farber Cancer Institute [DFCI] or Boston Medical Center [BMC] in Boston, MA or Columbia University Irving Medical Center [CUIMC] in New York, NY). The Institutional Review Board of each participating center approved the study (protocol number 17–612) and the study conforms to the standards set forth in the Declaration of Helsinki.

Survey instrument

The survey (Data Supplement, File 1) was designed to be completed in 25–40 min. It included eight sections: (1) general health[28]; (2) breast cancer knowledge [17], perception of recurrence risk[29], genetic testing utilization[30], decision-making styles[31, 32]; (3) treatments recommended/received, reasons for initiating/not initiating treatments[33–36], adherence[36, 37], knowledge about treatment rationales[35]; (4) social support[38], religiosity[39, 40]; (5) information-seeking preferences[41–43], trust [42], health care experiences[35]; (6) discrimination [44, 45], health literacy[46], numeracy[47]; (7) demographics (age, race, ethnicity, language, country of origin, highest educational level, marital status, finances [48, 49], primary health insurance, employment status, impact on work/finances)[48, 49]; and (8) mood[50] and social activity [51]. Whenever possible, we used or adapted previously validated survey items. Surveys underwent cognitive testing with 10 patients to ensure comprehension and clear mapping of answers to response options. The results presented herein focus on data collected in Sects. (2), (5), and (6).

Survey administration

Figure 1 displays the study schema. For patients treated at Boston centers (Fig. 1A), we utilized electronic medical record reports to identify patients meeting eligibility criteria

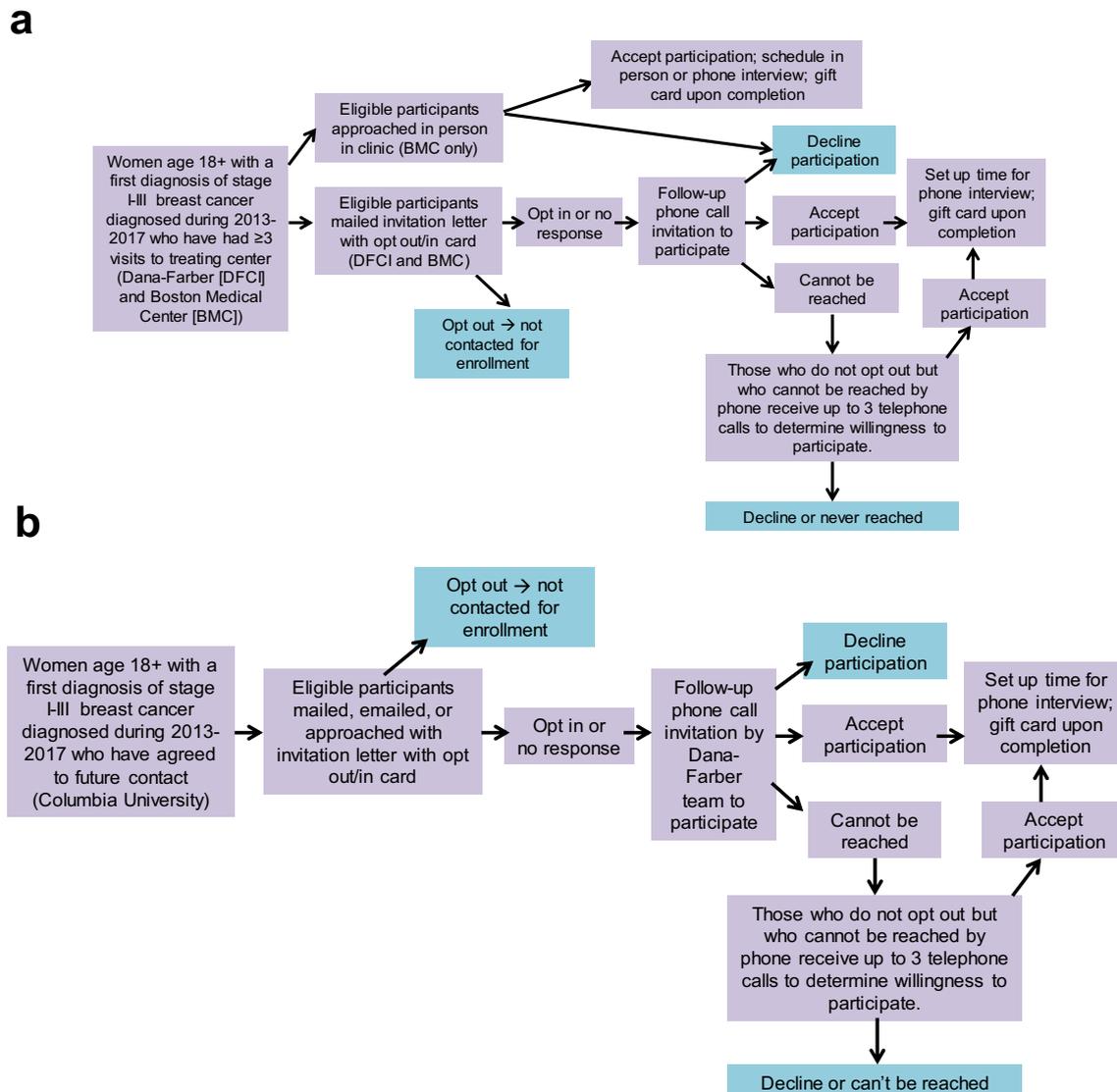


Fig. 1 Schema for patient approach at Boston centers (Dana-Farber Cancer Institute and Boston Medical Center) (Fig. 1A) and Columbia University Irving Medical Center (Fig. 1B)

who were Black, Hispanic, or White, oversampling for Black and Hispanic patients. Study invitations and postage-paid opt-out cards were mailed to eligible patients in English and Spanish. At CUIMC (Fig. 1B), study staff identified and contacted eligible women who previously agreed to contact for research.

Interviews were conducted (via telephone or in-person) by trained staff. Patients provided verbal, informed consent at the start of the interview, including permission to review medical records. The survey was conducted in English or Spanish using computer-assisted interview software. Data from the survey were entered directly into the survey software. All participants were provided a \$20 gift card upon interview completion. We abstracted participants' medical

records to confirm tumor characteristics and treatment, when available.

Interviews were conducted between June 1, 2018, and June 30, 2020; 96% of participants were diagnosed with breast cancer > 2 years before their interview; all were within 5 years. Accrual slowed during the COVID-19 pandemic, where in-person contact/consenting was not permitted; we halted study accrual once 326 women enrolled (187 from DFCI, 100 from BMC, 39 from CUIMC; 5 were interviewed in Spanish), fewer than the planned enrollment of 500. Because analyses focused on breast cancer knowledge (*i.e.*, agreement of medical record and patient report for tumor characteristics), 13 women were excluded

(2 Black, 1 Native American, 1 White, 9 missing race) for incomplete medical record information.

Given the different contact procedures at each site, we calculated response, cooperation, refusal, and contact rates for each center separately using American Association for Public Opinion Research (AAPOR) definitions[52] (Supplemental Fig. 1A-1C). Response rates varied by site: DFCI= 30.3% (cooperation rate 58.4%, refusal rate 21.6%, contact rate 51.9%); BMC= 38.5% (cooperation rate 63.3%, refusal rate 22.3%, contact rate 60.8%). CUIMC response rates were not easily measurable given the uncertain denominator of patients receiving/reading broadcast emails (CUIMC cooperation rate = 76.5%, refusal rate = 2.3%; Fig. 2C).

Dependent variables

Dependent variables of interest were derived from the questions in Supplemental Table 1.[17, 35] The survey (English version) is provided in the Data Supplement [17, 35]. Patients were asked about knowledge of their breast cancer tumor characteristics, including stage, grade, hormone receptor (HR) status, and human epidermal growth factor receptor 2 (HER2) status; hereafter called “breast cancer knowledge.” Participants were considered knowledgeable about each characteristic if their response matched the medical record documentation. Two participants with unconfirmed stage in medical records were categorized as ‘correct’ for stage, regardless of their response. We examined each item and the sum of the number of correct answers (range 0–4).

Patients were asked about understanding of treatment rationale(s) for each recommended therapy in the neo/adjuvant setting by adapting prior surveys [35]. Each question on treatment rationale and preferences was examined and

reported individually. Participants were only asked treatment rationale questions about recommended treatments, defined by participant report of whether treatments were recommended. Patients also reported whether any recommended treatments were initiated and completed.

We additionally inquired about information-seeking preferences, whether understanding treatment rationales was important in decision-making, and the degree to which participants felt information was provided to them by their clinicians.

Independent variables

Patients self-reported their race and ethnicity, categorized as Non-Hispanic (NH) White, NH Black (or African American), Hispanic, or Other/Unknown (race and ethnicity data were missing for 17 patients who were excluded from analyses). We additionally documented age, general health, country of birth, education, treatments recommended/received, preferred decision-making role, and insurance, categorized as in Table 1. Health literacy and numeracy were each categorized based on responses to three questions, and we summarized the proportion of participants by race and ethnicity reporting the most health literacy[46] and numeracy for each item [47].

Statistical analysis

We examined participant characteristics and individual breast cancer knowledge and the responses to questions on treatment rationales for recommended therapies by race and ethnicity. We examined associations of breast cancer knowledge and understanding treatment rationales with initiating recommended treatment(s) using contingency tables and Chi-square tests among those recommended for each treatment modality. Because missing/non-responses were

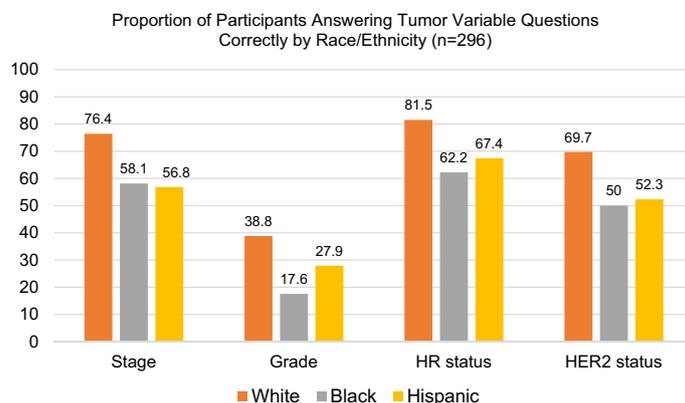


Fig. 2 Proportion of participants answering tumor variable questions correctly by race and ethnicity

Findings were significant for each comparison (stage, $p = 0.003$; grade, $p = 0.004$; hormone receptor [HR] status, $p = 0.003$; human epidermal growth factor receptor 2 [HER2] status, $p = 0.005$)

Table 1 Participant characteristics for the 313 women with complete medical record information

Characteristic, N (%)	Overall (n = 313)	White (n = 178)	Black (n = 74)	Hispanic (n = 44)	Other (n = 17)	p-value ^a
<i>Age, years</i>	58 (18.7)	21 (11.9)	19 (26.0)	14 (31.8)	4 (25.0)	0.001
≤ 50	154 (49.7)	85 (48.0)	39 (53.4)	23 (52.3)	7 (43.8)	
51–60	98 (31.6)	71 (40.1)	15 (20.6)	7 (15.9)	5 (31.3)	
≥ 61						
<i>Tumor subtype at diagnosis</i>	257 (81.7)	146 (82.0)	56 (75.7)	37 (84.1)	15 (88.2)	0.82 for ER
ER-positive	35 (11.2)	15 (8.4)	11 (14.9)	8 (18.2)	1 (5.9)	0.42 for HER2
HER2-positive						
<i>Stage at diagnosis^b</i>	182 (58.2)	111 (62.4)	35 (47.3)	23 (52.3)	13 (76.5)	< 0.0001 ^c
I	100 (32.0)	56 (31.5)	27 (36.5)	15 (34.1)	2 (11.8)	
II	26 (8.3)	7 (3.9)	11 (14.9)	6 (13.6)	2 (11.8)	
III	3 (1.0)	3 (1.7)	0 (0)	0 (0)	0 (0)	
DCIS	2 (0.6)	1 (0.6)	1 (1.4)	0 (0)	0 (0)	
Not confirmed						
<i>Would you say your general health is...</i>	47 (15.1)	30 (16.9)	7 (9.6)	7 (15.9)	3 (17.7)	< 0.0001
Excellent	118 (37.8)	85 (47.8)	15 (20.6)	12 (27.3)	6 (35.3)	
Very good	92 (29.5)	47 (26.4)	28 (38.4)	11 (25.0)	6 (35.3)	
Good	47 (15.1)	12 (6.7)	23 (31.5)	12 (27.3)	0 (0)	
Fair	8 (2.6)	4 (2.3)	0 (0)	2 (4.6)	2 (11.8)	
Poor						
<i>Country of birth</i>	244 (79.0)	172 (97.2)	51 (68.9)	15 (34.9)	6 (40.0)	< 0.0001
U.S	65 (21.0)	5 (2.8)	23 (31.1)	28 (65.1)	9 (60.0)	
Other ^d						
<i>Highest educational attainment (3 missing information)</i>	19 (6.1)	3 (1.7)	10 (13.5)	6 (14.3)	0 (0)	< 0.0001 ^c
Did not graduate high school	113 (36.5)	59 (33.2)	37 (50.0)	16 (38.1)	1 (6.3)	
High school graduate and/or some college	74 (23.9)	41 (23.0)	18 (24.3)	6 (14.3)	9 (56.3)	
College graduate	104 (33.6)	75 (42.1)	9 (12.2)	14 (33.3)	6 (37.5)	
Additional coursework and/or advanced degree						
<i>Treatments recommended (by patient report)</i>	157 (50.2)	76 (42.7)	50 (67.6)	26 (59.1)	5 (29.4)	0.007 (chemo)
Chemotherapy (+ 1 not sure)	242 (77.3)	127 (71.4)	67 (90.5)	34 (77.3)	14 (82.4)	0.060 (RT)
Radiation (RT) (+ 2 not sure)	242 (77.3)	139 (78.1)	53 (71.6)	36 (81.8)	14 (82.4)	0.540 (HT)
Hormonal therapy (HT)	32 (3.9)	14 (7.9)	12 (16.2)	5 (11.4)	1 (5.9)	0.050 (T)
Trastuzumab (T) (12 not sure about trastuzumab)						
<i>Treatments received (among those recommended for treatment from above)</i>	151 (95.6)	74 (96.1)	48 (96.0)	24 (92.3)	5 (100)	0.86 (chemo)
Chemotherapy	234 (95.9)	124 (96.1)	63 (94.0)	33 (97.1)	14 (100)	0.008 (RT)
Radiation (RT)	241 (77.0)	138 (77.5)	54 (73.0)	36 (81.8)	13 (76.5)	0.918 (HT)
Hormonal therapy (HT)	31 (70.5)	14 (82.4)	11 (61.1)	5 (62.5)	1 (100)	0.567 (T)
Trastuzumab (T)						
<i>Treatment(s) declined (n = 23) [declined any component of recommended therapy]</i>	23 (7.4)	11 (6.2)	7 (9.5)	3 (6.8)	2 (11.8)	0.718
<i>Preferred role when making decisions about treatments for your breast cancer? (1 missing)</i>	1 (0.3)	0 (0)	1 (1.4)	0 (0)	0 (0)	< 0.0001 ^c
65 (20.8)	41 (23.2)	14 (18.9)	8 (18.2)	2 (11.8)		
Make decisions with little or no input from doctors	222 (71.2)	125 (70.6)	54 (73.0)	32 (72.7)	11 (64.7)	
Make decisions after considering your doctor's opinion	20 (6.4)	9 (5.1)	5 (6.8)	3 (6.8)	3 (17.7)	
You and your doctor make decisions together	4 (1.3)	2 (1.1)	0 (0)	1 (2.3)	1 (5.9)	
Your doctors make decisions after considering your opinion						
Your doctors make decisions with little or no input from you						
<i>Primary Health Insurance</i>	48 (15.3)	14 (7.9)	21 (28.4)	12 (27.3)	1 (5.9)	< 0.0001
Medicaid	58 (18.5)	39 (21.9)	15 (20.3)	1 (2.3)	3 (17.7)	
Medicare	1999 (63.6)	124 (69.7)	36 (48.7)	28 (63.6)	11 (64.7)	
Commercial/HMO	8 (2.6)	1 (0.6)	2 (2.7)	3 (6.8)	2 (11.8)	
None/other						

Table 1 (continued)

Characteristic, N (%)	Overall (n = 313)	White (n = 178)	Black (n = 74)	Hispanic (n = 44)	Other (n = 17)	p-value ^a
<i>Health Literacy</i> [46] (5–6 missing per question)	272 (88.6)	167 (94.4)	58 (78.4)	21 (77.5)	16 (100)	0.0003
Extremely confident / quite a bit confident filling out forms by yourself	257 (83.7)	161 (91.0)	57 (77.0)	26 (65.0)	13 (81.3)	0.0004
Never/rarely have problems learning about your condition because of difficulty understanding written information	245 (79.6)	147 (82.6)	61 (82.4)	24 (60.0)	13 (81.3)	0.0044
Never/rarely have someone help you read hospital materials						
<i>Numeracy</i> [47]	138 (45.0)	94 (53.1)	21 (28.4)	13 (32.5)	10 (62.5)	<0.0001 ^c
‘Extremely good’ or ‘very good’ at working with fractions	222 (72.3)	141 (79.2)	44 (60.3)	21 (52.3)	16 (100)	<0.0001 ^c
‘Extremely good’ or ‘very good’ at calculating 25% off of a shirt	223 (72.9)	138 (78.0)	47 (64.4)	25 (62.5)	13 (81.3)	<0.0001 ^c
Always/often find numerical information useful						

^aby Chi-square testing unless specified

^bTwo participants reported having stage I breast cancer but on medical record review had DCIS

^cby Fisher’s Exact testing

^dother: 35 countries other than continental U.S. were represented., most common countries of birth were (Dominican Republic [n=6], Haiti [n=6], Puerto Rico [n=9], Trinidad [n=4], and Jamaica [n=3]; rest of countries had 2 or less people born there)

DCIS ductal carcinoma in situ, ER estrogen receptor, HER2 human epidermal growth factor receptor 2

infrequent for each knowledge question (<8% for each item), we excluded patients who did not provide a response for that particular question only. Finally, we examined associations of knowledge with each of the three health literacy[46] and numeracy questions[47] using contingency tables and chi-square tests. Sample sizes for each analysis are described below. Since treatment recommendation and receipt were self-reported, we examined agreement between self-report and medical records among participants with medical record treatment information; agreement was 95–97% across treatments. Two-sided P values <0.05 were considered statistically significant.

Results

Among 313 survey respondents with complete medical record data on tumor characteristics (Table 1), 56.9% were White, 23.6% were Black, and 14.1% were Hispanic; 21.0% were born outside the U.S. Overall, 23 did not initiate at least one component of their therapy; this did not differ by race or ethnicity. Because the focus of our study was to evaluate breast cancer knowledge and understanding treatment rationales by race and ethnicity and to examine impact on treatment receipt, we excluded 17 women with unknown/missing race and ethnicity from analyses on knowledge and understanding treatment rationales. The final sample size for analysis was 296 female participants.

Breast cancer knowledge and understanding treatment rationales

Overall, 69.0%, 75.3%, and 62.2% answered questions correctly about their stage, HR status, and HER2 status, respectively; 31.7% knew tumor grade (Fig. 2). For each tumor characteristic, a higher proportion of White (vs. Black and Hispanic) women answered questions correctly. For HR status, 81.5%, 62.2%, and 67.4% of White, Black, and Hispanic women, respectively, answered correctly; $p < 0.01$. Differences in knowledge about stage were also apparent, with 76.4% of White women knowing their cancer stage compared with 58.1% and 56.8% of Black and Hispanic women ($p < 0.01$). Most women knew some degree of information about their tumors, although 2.8%, 8.6%, and 11.6% of White, Black, and Hispanic women, respectively, reported none of the four tumor characteristics correctly ($p < 0.001$; Supplemental Fig. 2). Of note, women with the highest health literacy more frequently knew their cancer stage, HR and HER2 status. Similar trends were noted for numeracy, although these were not statistically significant (not shown).

Participants varied in their understanding of rationales for recommended treatments (Fig. 3). For example, among 228 (of 242) recommended for radiation (Fig. 3A) who responded to these questions, most (88.2%) understood that radiation lowers risk for breast cancer recurrence in one’s breast or scar, although nearly 50% incorrectly responded ‘true’ to radiation’s goal being to lower the risk for distant cancer recurrence. Black women answered this correctly

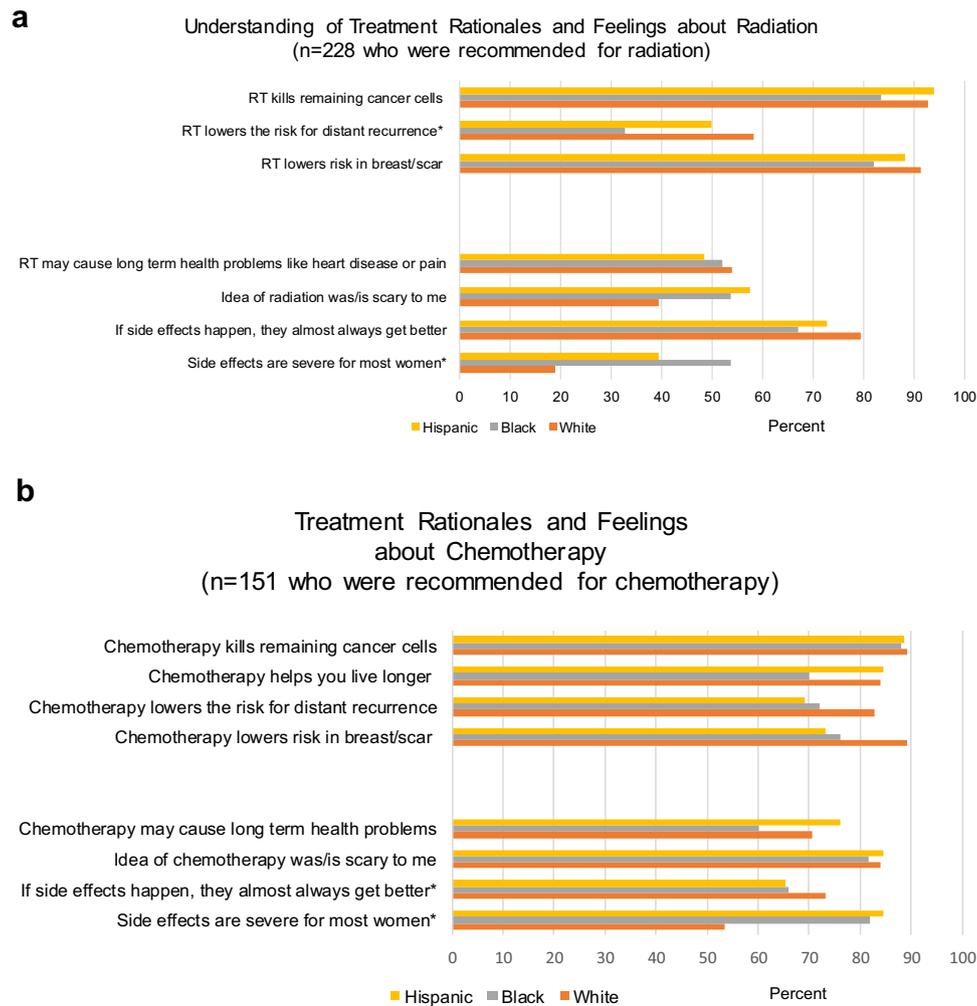


Fig. 3 Understanding treatment rationales and feelings/beliefs about each recommended treatment for radiation (3A), chemotherapy (3B), and hormonal therapy (3C)

3A: Comparisons by race and ethnicity (* when significant in chart above): $p = 0.003$ for RT lowers risk of distant recurrence, $p < 0.0001$ for side effects are severe for most women; remaining responses not significant. Abbreviations: RT, radiation therapy. **3B:** Comparisons by race and ethnicity (* when significant in

chart above): $P = 0.001$ for side effects are severe for most women; $p = 0.009$ for if side effects happen, they almost always get better; remaining responses not significant. **3C:** Comparisons by race and ethnicity (* when significant in chart above): $p = 0.0009$ for HT lowers risk in breast/scar; $p = 0.018$ for HT lowers the risk of distant recurrence, $p = 0.032$ for HT kills cancer cells; remaining responses not significant. Abbreviations: HT, hormonal therapy

less frequently than others (32.8% vs. 50.0 and 58.3% in Hispanic and White women, respectively).

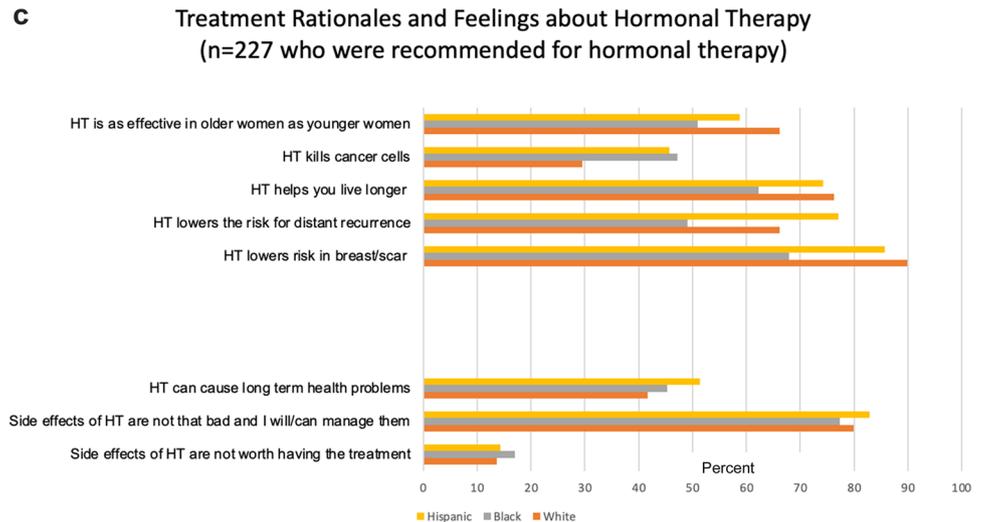
Among 151 respondents who were recommended for chemotherapy (Fig. 3B), nearly 90% across race and ethnicity groups replied that chemotherapy killed remaining cancer cells, although participants demonstrated less knowledge about chemotherapy's impact on survival (70.0%–84.6% responded that chemotherapy improved survival, but only 69.2%–82.7% responded that it lowered the risk of distant recurrence; $p > 0.05$ for race and ethnicity comparisons).

Among 227 (of 242) recommended for hormonal therapy (HT) (Fig. 3C), 63.9% and 84.9% correctly responded that the treatment lowered distant recurrence and localized recurrences, respectively. The proportion of Black women

answering these questions correctly was lower than other groups (49.1% and 67.9% correctly acknowledging that HT lowered risk for distant and local recurrences). Overall, 72.7% of participants correctly answered that HT 'helps you live longer,' and 36.1% responded correctly that HT "kills cancer cells." Many (50.0–66.2%) also thought that the effects of HT were different for younger and older women.

We explored potential associations between a lack of initiation of recommended therapy among 23 women reporting this and participants' degree of breast cancer knowledge. Although numerically higher proportions of women declining therapy had less breast cancer knowledge, sample sizes were small, and these differences were not statistically significant. For example, 9.5% of those declining therapy (vs.

Fig. 3 (continued)



5.1% of those initiating treatment) answered none of the four tumor knowledge questions correct. In addition, 9.5% of those declining therapy answered all four tumor questions correctly (vs. 18.3% of those initiating treatment; overall $p=0.69$; Supplemental Table 2).

Feelings about treatment

Feelings and worries about recommended treatments were variable (Figs. 3A–3C, bottom). Concerns that side effects were severe with radiation, chemotherapy, and HT were expressed more frequently by Black participants, although most participants (~75%), regardless of race or ethnicity, believed that side effects of radiation and chemotherapy would improve. Of note, 14.5% of overall participants (13.7% of White, 17.0% of Black, and 14.3% of Hispanic women, $p=0.44$) felt that the side effects of HT were not worth having the treatment.

Information-seeking preferences

Overall, >90% of participants reported that understanding the treatment rationale for recommended therapy was important in making decisions about each treatment component. Most also reported that their clinical team explained the goals of recommended treatments, including 94.6%, 95.0%, and 91.3% of those recommended for radiation, chemotherapy, and HT, respectively, without differences by race or ethnicity. Over 84% ‘strongly agreed’ that their doctors encouraged them to ask questions, and 86.1% ‘strongly agreed’ that their doctors explained things in a way they could understand, with similar findings across race and ethnicity subgroups. For those recommended for HT, nearly

80% ‘strongly agreed’ that their doctors gave them enough information to make decisions about treatment ($p=0.61$ for comparisons by race and ethnicity); most ‘strongly agreed’ that the doctor fully explained the benefits (79.9%) and risks (65.5%) of therapy.

When asked about their preferences for obtaining information about their cancer, overall, of the 296 women, 76.0% reported they had looked for cancer-related information from sources other than their doctor or nurse, and 26.8% ($n=77$) reported they had purposely avoided information at times (22.5% of White, 32.4% of Black, 31.0% of Hispanic participants, $p=0.196$). They cited reasons for avoiding information including (not mutually exclusive): too difficult to deal with emotionally (84.4%), trusting my health care providers (39.0%), because I couldn’t do anything about my illness (14.3%), or it was too difficult to understand (13%). Responses were similar across subgroups by race and ethnicity.

Among those seeking information elsewhere, the most common (not mutually exclusive) sources were the internet (90.8%), other cancer survivors (71.0%), pamphlets/books (66.0%), cancer information/support organizations (56.7%), friends or family (50.8–53.4%), other healthcare providers (35.7%), a library or hospital resource center (27.7%), television/radio (23.5%), or support groups (22.3%). Participants endorsed a number of emotions regarding information about their cancers (Supplemental Fig. 3), with most feeling informed, empowered, and satisfied, but some also feeling anger or fear. These findings were similar across subgroups but fewer Black (59.5%) and Hispanic (68.2%) women felt motivated by information (75.3% White women $p=0.04$) and informed (82.4% of Black, 77.3% of Hispanic, 95.3% of White women, $p<0.01$).

Discussion

Among a diverse population of nearly 300 women with breast cancer, a substantial number of participants did not know about their own tumors and/or how treatments would benefit them, with statistically significant differences in knowledge of breast cancer and treatment rationale by race and ethnicity. These findings were observed despite the vast majority of participants reporting they were sufficiently informed for treatment decision-making and that understanding treatment rationale was important to them. Breast cancer knowledge was highly variable overall, with 8.1% of Black and 11.6% of Hispanic women not answering any tumor characteristic questions correctly. Our findings of limited knowledge about tumor grade were not surprising and consistent with prior work [17], but many women did not know other key elements of their cancer's features, all of which drive treatment recommendations. We also observed that many patients did not understand goals of therapy or the distinctions between local and systemic risk reduction, and particularly the rationale for HT. However, because few patients reported that they declined treatment, we were limited in our ability to further examine how tumor knowledge and understanding treatment rationales might impact care.

Clinical implications

To our knowledge, this is the first study to include an in-depth examination of how well patients understand the rationale for their individually recommended local and systemic therapies. Understanding how this information may impact care has not been well studied, although there is some suggestion that treatment receipt would be improved if patients better understood the goals of therapy [9, 25, 34]. This assumes that side effects are managed effectively and that other barriers are avoided, given the frequency of physical and access challenges reported during longer-term treatments like HT [25, 35]. Of note, approximately 14% of women in our study reported that side effects of HT limited their interest in having the treatment.

Our findings highlight important information gaps for patients and the need to develop ways to individualize educational approaches to supporting each patient through initial treatment decision-making and their longer-term treatment journey. This may be of particular importance for HT, where treatment durations are long, and women may tire of taking a medication that has unclear benefits to them. To address this, a longitudinal commitment to informational, decisional, and emotional support for breast cancer survivors may be required through regular communication and an individually tailored, patient-facing, educational curriculum. Most women in our study reported that receiving breast

cancer information resulted in feelings of empowerment and satisfaction, suggesting an unmet but welcome opportunity for this type of patient education and support.

The currently enrolling 'GET SET' study (NCT04379570) will assess how informational support impacts adherence to HT beyond passive reminders to take medication [53]. Patients in this study are randomized to texting reminders to take medication (with concomitant education on HT at treatment initiation), motivational interviewing, both interventions, or usual care. If positive, this may represent a new care delivery model to improve connections with patients and novel methods for information delivery beyond simple reminder strategies.

Study limitations

Our study's strengths included collecting rich data from a diverse population of several hundred women in three academic centers in two U.S. cities and studying cancer survivors beyond primary therapy to understand longer-term treatment adherence. We acknowledge several study limitations. During the COVID-19 pandemic, our study teams had increasing difficulty reaching patients for telephone surveys. Thus, our response rates were lower than anticipated, although, our cooperation rates were high among patients reached. In addition, we surveyed women who were engaged in care at three academic centers, where treatment completion rates may have been higher than for other patients. Further, even with outreach designed to recruit Spanish-speaking patients, only 5 patients opted for Spanish-language interviews. Finally, we used patient self-report to understand treatment recommendations and completion, although we observed a high degree of agreement between patient and medical record data.

In conclusion, our study highlights the need for enhanced informational support for breast cancer survivors, who are challenged with complex treatment rationales and tumor information during the decision-making process and beyond. More research is needed to understand how to further educate and empower diverse populations of patients with breast cancer.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10549-022-06752-8>.

Acknowledgements We thank all survey participants. We thank Valerie Goldstein and Kate Bifolck for assistance with manuscript preparation and submission.

Author contributions RAF, NYK, RIL, DAG, ACR, DLH, KDC, and NLK contributed to conceptualization; RAF, NYK, RIL, HG, TF, DAG, ACR, AO-D, DLH, KDC, and NLK contributed to data curation; RAF, NYK, RIL, ACR, OK, and NLK contributed to formal analysis; RAF contributed to funding acquisition; RAF, NYK, and RIL contributed to investigation; RAF, NYK, RIL, HG, TF, DAG, ACR,

DLH, KDC, and NLK contributed to methodology; RAF, NYK, RIL, HG, and ACR contributed to project administration; RAF, NYK, and RIL contributed to resources; RAF and RIL contributed to software; RAF and NLK contributed to supervision and validation; RAF, RIL, AO-D, and NLK contributed to writing—original draft; and all authors contributed to writing—review and editing.

Funding American Cancer Society (MRS-14-240-01-CPPB to RAF), Susan G. Komen (CCR-18552788 to RAF), NCI (P30 CA013696 to KDC).

Data availability The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Competing Interest No relevant conflict to disclose.

Ethical approval The Institutional Review Board of each participating center approved the study (protocol number 17–612) and the study conforms to the standards set forth in the Declaration of Helsinki.

Consent to participation Informed consent was obtained from all individual participants in the study.

Consent to publication Not applicable.

References

- Coughlin SS (2019) Social determinants of breast cancer risk, stage, and survival. *Breast Cancer Res Treat* 177(3):537–548. <https://doi.org/10.1007/s10549-019-05340-7>
- Sadigh G, Gray RJ, Sparano JA et al (2022) Assessment of racial disparity in survival outcomes for early hormone receptor-positive breast cancer after adjusting for insurance status and neighborhood deprivation: a post hoc analysis of a randomized clinical trial. *JAMA Oncol*. <https://doi.org/10.1001/jamaoncol.2021.7656>
- Hassett MJ, Tramontano AC, Uno H, Ritzwoller DP, Punglia RS (2022) Geospatial disparities in the treatment of curable breast cancer across the US. *JAMA Oncol* 8(3):445–449. <https://doi.org/10.1001/jamaoncol.2021.7337>
- Cho B, Han Y, Lian M et al (2021) Evaluation of racial/ethnic differences in treatment and mortality among women with triple-negative breast cancer. *JAMA Oncol* 7(7):1016–1023. <https://doi.org/10.1001/jamaoncol.2021.1254>
- Ellis L, Canchola AJ, Spiegel D, Ladabaum U, Haile R, Gomez SL (2018) Racial and ethnic disparities in cancer survival: the contribution of tumor, sociodemographic, institutional, and neighborhood characteristics. *J Clin Oncol* 36(1):25–33. <https://doi.org/10.1200/JCO.2017.74.2049>
- Ko NY, Hong S, Winn RA, Calip GS (2020) Association of insurance status and racial disparities with the detection of early-stage breast cancer. *JAMA Oncol* 6(3):385–392. <https://doi.org/10.1001/jamaoncol.2019.5672>
- Stringer-Reasor EM, Elkhanany A, Khoury K, Simon MA, Newman LA (2021) Disparities in breast cancer associated with African American identity. *Am Soc Clin Oncol Educ Book* 41:e29–e46. https://doi.org/10.1200/EDBK_319929
- Freedman RA, Revette AC, Hershman DL et al (2017) Understanding breast cancer knowledge and barriers to treatment adherence: a qualitative study among breast cancer survivors. *Biores* Open Access 6(1):159–168. <https://doi.org/10.1089/biores.2017.0028>
- Freedman RA, Kouri EM, West DW, Lii J, Keating NL (2016) Association of breast cancer knowledge with receipt of guideline-recommended breast cancer treatment. *J Oncol Pract* 12(6):e613–e625. <https://doi.org/10.1200/JOP.2015.008508>
- Fagerlin A, Lakhani I, Lantz PM et al (2006) An informed decision? Breast cancer patients and their knowledge about treatment. *Patient Educ Couns* 64(1–3):303–312. <https://doi.org/10.1016/j.pec.2006.03.010>
- Chen JY, Diamant AL, Thind A, Maly RC (2008) Determinants of breast cancer knowledge among newly diagnosed, low-income, medically underserved women with breast cancer. *Cancer* 112(5):1153–1161. <https://doi.org/10.1002/cncr.23262>
- Loh S, Packer TL, Yip CH, Passmore A (2009) Targeting health disparity in breast cancer: insights into women’s knowledge of their cancer profile in Malaysia Comparative Study. *Asian Pac J Cancer Prev* 10(4):631–6
- Lukwago SN, Kreuter MW, Holt CL, Steger-May K, Bucholtz DC, Skinner CS (2003) Sociocultural correlates of breast cancer knowledge and screening in urban African American women. Research Support, US Gov’t. P.H.S. *Am J Public Health* 93(8):1271–4
- Geng C, Lu GJ, Zhu J, Li YY (2021) Patients’ awareness about their own breast cancer characteristics. *World J Clin Cases* 9(24):7043–7052. <https://doi.org/10.12998/wjcc.v9.i24.7043>
- Wing SE, Hu H, Lopez L et al (2021) Recall of genomic testing results among patients with cancer. *Oncologist* 26(12):e2302–e2305. <https://doi.org/10.1002/onco.13928>
- Say RE, Thomson R (2003) The importance of patient preferences in treatment decisions—challenges for doctors. *BMJ* 327(7414):542–545. <https://doi.org/10.1136/bmj.327.7414.542>
- Freedman RA, Kouri EM, West DW, Keating NL (2015) Racial/ethnic disparities in knowledge about one’s breast cancer characteristics. *Cancer* 121(5):724–732. <https://doi.org/10.1002/cncr.28977>
- Boling W, Laufman L, Lynch GR, Weinberg AD (2005) Increasing mammography screening through inpatient education. *J Cancer Educ* 20(4):247–250. https://doi.org/10.1207/s15430154jce2004_14
- Kessler TA (2012) Increasing mammography and cervical cancer knowledge and screening behaviors with an educational program. *Clin Trial Oncol Nurs Forum* 39(1):61–68. <https://doi.org/10.1188/12.ONF.61-68>
- Sabatino SA, Lawrence B, Elder R, et al. Effectiveness of interventions to increase screening for breast, cervical, and colorectal cancers: nine updated systematic reviews for the guide to community preventive services. Research Support, Non-U.S. Gov’t Research Support, U.S. Gov’t, P.H.S. *Am J Prev Med*. Jul 2012;43(1):97–118. doi:<https://doi.org/10.1016/j.amepre.2012.04.009>
- Goodwin JS, Samet JM, Hunt WC (1996) Determinants of survival in older cancer patients. *J Natl Cancer Inst* 88(15):1031–1038
- Samet JM, Hunt WC, Goodwin JS (1990) Determinants of cancer stage. A population-based study of elderly New Mexicans. Research Support, U.S. Gov’t, P.H.S. *Cancer*. 1990;66(6):1302–7
- Bickell NA, Weidmann J, Fei K, Lin JJ, Leventhal H (2009) Underuse of breast cancer adjuvant treatment: patient knowledge, beliefs, and medical mistrust. *J Clin Oncol* 27(31):5160–5167. <https://doi.org/10.1200/JCO.2009.22.9773>
- Sheppard VB, Adams IF, Lamdan R, Taylor KL (2011) The role of patient-provider communication for black women making decisions about breast cancer treatment. *Psychooncology* 20(12):1309–1316. <https://doi.org/10.1002/pon.1852>
- Wheeler SB, Spencer J, Pinheiro LC et al (2019) Endocrine therapy nonadherence and discontinuation in Black and White

- women. *J Natl Cancer Inst* 111(5):498–508. <https://doi.org/10.1093/jnci/djy136>
26. Fallowfield LJ (2008) Treatment decision-making in breast cancer: the patient-doctor relationship. *Breast Cancer Res Treat* 112(Suppl 1):5–13. <https://doi.org/10.1007/s10549-008-0077-3>
 27. Street RL Jr, Voigt B (1997) Patient participation in deciding breast cancer treatment and subsequent quality of life. *Med Decis Making* 17(3):298–306
 28. Winston S (2021) Health Information National Trends Survey (HINTS.gov). *Med Ref Serv Q* 40(2):215–223. <https://doi.org/10.1080/02763869.2021.1912575>
 29. Partridge A, Adloff K, Blood E et al (2008) Risk perceptions and psychosocial outcomes of women with ductal carcinoma in situ: longitudinal results from a cohort study. *J Natl Cancer Inst* 100(4):243–251
 30. Lerman C, Croyle R (1994) Psychological issues in genetic testing for breast cancer susceptibility. *Arch Intern Med* 154(6):609–616
 31. Mandelblatt JS, Sheppard VB, Hurria A et al (2010) Breast cancer adjuvant chemotherapy decisions in older women: the role of patient preference and interactions with physicians. *J Clin Oncol* 28(19):3146–3153. <https://doi.org/10.1200/JCO.2009.24.3295>
 32. Ayanian JZ, Chrischilles EA, Fletcher RH et al (2004) Understanding cancer treatment and outcomes: the Cancer Care Outcomes Research and Surveillance Consortium. *J Clin Oncol* 22(15):2992–2996. <https://doi.org/10.1200/JCO.2004.06.020>
 33. Neugut AI, Hillyer GC, Kushi LH et al (2012) The Breast Cancer Quality of Care Study (BQUAL): a multi-center study to determine causes for noncompliance with breast cancer adjuvant therapy. *Breast J* 18(3):203–213. <https://doi.org/10.1111/j.1524-4741.2012.01240.x>
 34. Neugut AI, Hillyer GC, Kushi LH et al (2012) Non-initiation of adjuvant hormonal therapy in women with hormone receptor-positive breast cancer: The Breast Cancer Quality of Care Study (BQUAL). *Breast Cancer Res Treat* 134(1):419–428. <https://doi.org/10.1007/s10549-012-2066-9>
 35. Neugut AI, Hillyer GC, Kushi LH et al (2016) A prospective cohort study of early discontinuation of adjuvant chemotherapy in women with breast cancer: the breast cancer quality of care study (BQUAL). *Breast Cancer Res Treat* 158(1):127–138. <https://doi.org/10.1007/s10549-016-3855-3>
 36. Brier MJ, Chambless DL, Gross R, Chen J, Mao JJ (2017) Perceived barriers to treatment predict adherence to aromatase inhibitors among breast cancer survivors. *Cancer* 123(1):169–176. <https://doi.org/10.1002/cncr.30318>
 37. Morisky DE, Ang A, Krousel-Wood M, Ward HJ (2008) Predictive validity of a medication adherence measure in an outpatient setting. *J Clin Hypertens (Greenwich)* 10(5):348–354. <https://doi.org/10.1111/j.1751-7176.2008.07572.x>
 38. Sherbourne CD, Stewart AL (1991) The MOS social support survey. *Soc Sci Med* 32(6):705–714
 39. Sherman AC, Simonton S, Adams DC et al (2001) Measuring religious faith in cancer patients: reliability and construct validity of the Santa Clara Strength of Religious Faith questionnaire. *Psychooncology* 10(5):436–443. <https://doi.org/10.1002/pon.523>
 40. Plante TG, Boccaccini M (1997) The Santa Clara strength of religious faith questionnaire. *Pastor Psychol* 45:375–387
 41. Jung M, Ramanadhan S, Viswanath K (2013) Effect of information seeking and avoidance behavior on self-rated health status among cancer survivors. *Patient Educ Couns* 92(1):100–106. <https://doi.org/10.1016/j.pec.2013.02.008>
 42. Hesse BW, Nelson DE, Kreps GL et al (2005) Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med* 165(22):2618–2624. <https://doi.org/10.1001/archinte.165.22.2618>
 43. Nelson DE, Kreps GL, Hesse BW et al (2004) The Health Information National Trends Survey (HINTS): development, design, and dissemination. *J Health Commun.* 9(5):443–60. <https://doi.org/10.1080/10810730490504233>
 44. Williams DR, Yan Y, Jackson JS, Anderson NB (1997) Racial differences in physical and mental health: socio-economic status, stress and discrimination. *J Health Psychol* 2(3):335–351. <https://doi.org/10.1177/135910539700200305>
 45. Lewis TT, Yang FM, Jacobs EA, Fitchett G (2012) Racial/ethnic differences in responses to the everyday discrimination scale: a differential item functioning analysis. *Am J Epidemiol* 175(5):391–401. <https://doi.org/10.1093/aje/kwr287>
 46. Chew LD, Griffin JM, Partin MR et al (2008) Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med* 23(5):561–566. <https://doi.org/10.1007/s11606-008-0520-5>
 47. McNaughton CD, Cavanaugh KL, Kripalani S, Rothman RL, Wallston KA (2015) Validation of a short, 3-item version of the subjective numeracy scale. *Med Decis Making* 35(8):932–936. <https://doi.org/10.1177/0272989X15581800>
 48. Yabroff KR, Dowling E, Rodriguez J et al (2012) The Medical Expenditure Panel Survey (MEPS) experiences with cancer survivorship supplement. *J Cancer Surviv* 6(4):407–419. <https://doi.org/10.1007/s11764-012-0221-2>
 49. Agency for Healthcare Research and Quality Medical Expenditure Panel Survey. <http://www.meps.ahrq.gov/mepsweb>. Accessed 14 April 2022
 50. Gershon RC, Rothrock N, Hanrahan R, Bass M, Cella D (2010) The use of PROMIS and assessment center to deliver patient-reported outcome measures in clinical research. *J Appl Meas* 11(3):304–314
 51. Ware JE Jr, Sherbourne CD (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care.* 30(6):473–83
 52. The American Association for Public Opinion Research. 2016. Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. 9th edition. AAPOR. <https://www.aapor.org>. Accessed 14 April 2022
 53. Hershman DL, Unger JM, Hillyer GC et al (2020) Randomized Trial of Text Messaging to Reduce Early Discontinuation of Adjuvant Aromatase Inhibitor Therapy in Women With Early-Stage Breast Cancer: SWOG S1105. *J Clin Oncol* 38(19):2122–2129. <https://doi.org/10.1200/JCO.19.02699>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.