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A FEASIBILITY STUDY TO EVALUATE BREAST CANCER PATIENTS' KNOWLEDGE OF THEIR DIAGNOSIS AND TREATMENT

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Abstract

Objective—To evaluate the feasibility of an electronic survey to assess patients' knowledge of their breast cancer and treatment, and interest in receiving a medical summary.

Methods—Women undergoing breast cancer treatment completed an interviewer-administered electronic survey in person or by telephone. Medical records were abstracted to evaluate knowledge accuracy.

Results—Among 38 eligible patients approached for the study, 35 (92%) participated and 33 (94%) completed the survey. Participants' perceived knowledge tended to be greater than their actual knowledge. Reporting of clinicopathologic features was most accurate for stage (91%) and lymph node status (88%), and least accurate for tumor size (61%), type (61%), and grade (33%). Accurate reporting of tumor receptor over-expression varied from 76% (estrogen receptor) to 39% (progesterone receptor). Many patients correctly recalled general treatment modalities and details of surgery; fewer recalled details of radiation and chemotherapy. Importantly, nearly all (32/33) were interested in receiving a breast cancer medical summary.

Conclusion—An electronic survey is feasible to assess breast cancer patients' knowledge. This data suggests that patients have gaps in knowledge and would like a personalized medical summary.

Practice Implications—Larger studies are needed to validate and characterize knowledge gaps, and test interventions to improve physician-patient information sharing.

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STATEMENT OF PATIENT INFORMATION

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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1. Introduction

Approximately 2.5 million women in the United States are alive with a history of breast cancer (1). Advances in diagnosis and treatment have improved survival while introducing more treatment options for patients. A growing emphasis has been placed on informed decision-making, physician-patient communication, and information sharing. Breast cancer patients' information needs vary according to different phases of diagnosis, treatment, and survivorship, as well as personal preference (2, 3). Many patients prefer to receive information from their health care provider (4) and most utilize additional sources of information, including print media, broadcast media, the Internet, and personal contacts (5, 6), in search of verification, clarification, and elaboration of concepts (5). The volume of information can be overwhelming, and there is a need for tools that help patients personalize the information to identify what is relevant (7, 8).

Importantly, patients tend to be more satisfied if their information needs are met (9) and if they feel more informed and have higher levels of patient-clinician information engagement and exchange (10). To date, much emphasis has been placed on educating breast cancer patients about treatment options using decision aids (11, 12), with little attention given to investigating what patients know about their individual cancer diagnosis and treatment. In fact, only one study has systematically assessed adult cancer survivors' knowledge of their diagnosis and treatment (13). Among breast cancer survivors an average of 6.6 years following diagnosis, there was a trend toward decreased knowledge accuracy with increased time since diagnosis (13). However, it is not known whether the knowledge gaps gradually developed over time, or if they had been present throughout earlier phases of diagnosis and treatment.

Patients that are knowledgeable about their individual cancer history, including details of diagnosis, clinical and pathologic features, and treatment, may benefit from: (a) greater patient satisfaction and empowerment, related to increased information engagement and fewer unmet information needs, (b) more effective use of general information resources, such as websites and books, due to increased ability to personalize the topics, and (c) provision of appropriate medical care should care be needed outside of one's treating institution in the absence of universal medical records. Determining the extent to which knowledge gaps are present during diagnosis and treatment, as well as the trajectory of knowledge over time, has important implications for developing educational interventions to improve patient knowledge. In addition, a succinct record of a patient's individual cancer history, such as a survivorship care plan or cancer treatment summary, may promote patient engagement and address ongoing information needs (2, 14, 15). Breast cancer survivors who have completed therapy express a desire to receive these summaries (13, 16–18); whether such a tool would also be useful for patients during treatment has not been assessed.

Given how little is understood about what women who are undergoing treatment for breast cancer know about their cancer, the purpose of this study is twofold: (1) to develop and pilot-test an electronic survey to assess breast cancer patients' knowledge about their diagnosis, clinical and pathologic features, and treatment; and (2) to describe patients' knowledge of their cancer and interest in receiving a breast cancer medical summary.

2. Methods

2.1. Study population

The study population consisted of women with early (non-recurrent, non-metastatic) breast cancer receiving adjuvant treatment from one of three oncologists at Stanford Cancer Center during the enrollment period. Additional eligibility criteria included age > 18 years, English-speaking, access to the Internet, and never having received a diagnosis of more than one primary breast cancer, including bilateral breast cancer.

2.2. Recruitment

A clinic-based recruitment strategy was employed. Eleven clinic days in a four-week period were selected for enrollment based on interviewer availability. All patients on the clinic schedule were pre-screened for eligibility before their appointment. Potentially eligible patients were introduced to study personnel by treating oncologists or nurse practitioners during their appointments. One of three study interviewers (SMS, AF, CN) spoke with potential participants to confirm eligibility, describe the study, and obtain informed consent. The Institutional Review Board approved the research protocol and all participants provided written informed consent.

2.3. Data collection

Upon enrollment, participants provided contact information and demographics (race and ethnicity, primary language, marital status, education level), and scheduled a time to complete a knowledge questionnaire, either in person or by telephone, according to their preference. Study data were collected and managed using REDCap electronic data capture tools hosted at Stanford Medical School (19). REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. The study interviewer administered the knowledge questionnaire to each participant and entered responses into the web-based REDCap Survey form during the interview. The content of the questionnaires given in person and by telephone was identical, and can be viewed in full at <http://redcap.stanford.edu/surveys/?s=ypE52N>

Following completion of the questionnaire, participants' electronic medical records were manually abstracted to compare the gold standard (medical record) with participant responses.

The knowledge questionnaire consisted of four sections: knowledge perceptions, breast cancer knowledge, evaluation of a breast cancer medical summary, and evaluation of the survey.

In the first section, participants were asked to indicate their level of agreement with the following three statements: "I am knowledgeable about (1) the clinical features of my breast cancer, (2) my breast cancer pathology, and (3) my breast cancer treatment". Agreement was

assessed on a 5-point Likert scale, where 1=strongly disagree and 5=strongly agree. Participants were also asked whether they would like to know more about their breast cancer, and if so, what they would like to know (free text).

In the second section of the questionnaire, participants were asked specific questions about their breast cancer. Clinical and pathologic features included age at diagnosis, breast cancer site, type of breast cancer, stage (I-IV), lymph node status, pathologic grade (1–3), tumor size, and tumor expression of estrogen receptor (ER), progesterone receptor (PR), and HER2/neu. Treatment questions included surgery (y/n/not sure), type(s) of surgery, reconstruction (y/n/not sure), type of reconstruction, radiation therapy (y/n/not sure), type of radiation, radiation fields, radiation dose, chemotherapy (y/n/not sure), chemotherapy drugs, chemotherapy dose, hormonal/endocrine therapy (y/n/not sure), medication name(s), biologic/targeted therapy (y/n/not sure), and medication name(s).

For each knowledge item, participants were provided a list of answer choices. Participants were instructed to select the answer that described their cancer, and if they were unsure, to select “not sure” rather than guess. Participants who completed the survey by telephone were given a folder during enrollment that contained reference materials to use during the survey, which were identical to those given to participants who completed the survey in person. All participants were firmly instructed not to consult other resources (medical records, notes, Internet, family, etc).

In the third section of the questionnaire, participants were asked whether they had ever received a written summary of their breast cancer diagnosis, clinical features, pathology, or treatment. If so, they were asked what was included and who provided the summary (free text). Next, they were shown a breast cancer medical summary based on a fictitious patient, and adapted from the American Society of Clinical Oncology (ASCO) treatment summary and survivorship care templates (20) and Children’s Oncology Group treatment summary (21) (Appendix). Participants were asked whether they would be interested in receiving a personalized breast cancer summary like this (y/n/not sure), and, in general, how they would feel about receiving a summary (free text).

Finally, participants were asked to comment on their experiences taking the survey and whether anything had upset them or made them feel anxious, fearful, or overwhelmed (free text).

2.4. Analysis

Descriptive statistics were used to assess feasibility outcomes, including participation rate, completion rate, survey administration time, and medical record abstraction time. Descriptive statistics were also used to describe the study population and knowledge perceptions (“felt knowledgeable” if “agree” or “strongly agree” with each statement). Knowledge accuracy was determined by comparing participant responses with the medical record. Responses were considered accurate if they matched and inaccurate if they did not match (incorrect or not sure). Data was analyzed using SAS version 9.2 (SAS Institute, Cary, NC) and Microsoft Excel (Microsoft Corporation, Redmond, WA).

3. Results

3.1. Participant characteristics

The initial eligibility screen identified 41 women who were approached for the study; of these, 38 were eligible, and 35 (92%) agreed to participate (Figure 1). Two participants withdrew from the study before completing the questionnaire (completion rate, 94%). Reasons for withdrawal included insufficient time and transfer of care to another institution.

Among 33 participants who completed the questionnaire, the median age at study entry was 53 years (range, 24 to 82 years) and the median time since breast cancer diagnosis was approximately 3 years (range, 2 months to 9 years). Participants tended to be non-Hispanic white (61%) or Asian (24%), married (70%), and highly educated, with nearly 40% possessing a master's degree or doctorate (Table 1).

3.2. Feasibility

Two-thirds of participants (22/33) completed the survey in-person, one-third (11/33) by telephone. The median time for survey administration was 16.5 minutes (range, 11 to 25 minutes) and for medical record abstraction was 27 minutes (range, 15 to 45 minutes) per participant. The survey was well received; 32 of 33 participants reported that they did not become upset, anxious, fearful or overwhelmed from the survey. The participant who felt upset explained: "not the survey itself – makes me feel like I don't have that much knowledge about it [my breast cancer]. Knowledge is a lot of blanks for me, a lot more information I need to absorb".

3.3. Knowledge accuracy and perceptions

The clinical and pathologic features of the participants' tumors were heterogeneous (Table 2). Accurate knowledge reporting varied across domains of knowledge, with the most accurate reports for stage (29/32, 91% accurate) and lymph nodes (29/33, 88%). Only 20/33 patients (61%) accurately reported the type of breast cancer (N=7 not sure, N=6 incorrect) and 19/31 patients (61%) accurately reported the tumor size (N=6 not sure, N=4 thought it was smaller, N=2 thought it was larger). Knowledge of pathologic grade was least accurate (11/33, 33%). Approximately three-quarters (25/33, 76%) accurately recalled whether their tumor was ER positive, but only 39% recalled whether it was PR positive (13/33). HER2 over-expression was reported accurately by 67% of patients (22/33); all 3 patients who were HER2 positive reported this accurately. Notably, only 1 of 4 women (25%) with a tumor larger than 5 cm and 3 of 8 women (38%) with a grade 3 tumor reported these high-risk features accurately (Table 2).

Overall, women had nearly complete general knowledge of their treatment: all 33 participants knew whether they had surgery, chemotherapy, and/or radiation therapy. Four participants who received hormonal therapy mistakenly reported not receiving it or were not sure, yielding an overall general treatment accuracy of 29/33, or 88% (Table 3). Interestingly, all four of these women accurately reported the specific hormonal medications they were receiving, though they did not recognize that these were hormonal treatments. As shown in Table 4, the most accurate specific knowledge was type of surgery (30/31) and

type of reconstruction (14/14). Among women who had radiation therapy, 7 of 16 (44%) accurately reported the radiation type and 3 of 17 (18%) accurately reported all radiation fields. Thirty women received chemotherapy, 22 (73%) of whom reported all chemotherapy drug names correctly. Among 27 patients receiving anthracyclines, 22 (81%) reported anthracyclines, and among 24 patients receiving taxanes, 22 (92%) reported taxanes. Of the 22 women who had hormonal therapy, 20 (91%) reported all hormonal medications correctly and 2 (9%) reported some but not all. No participants accurately recalled the dose of radiation therapy or chemotherapy.

Most participants felt knowledgeable about their breast cancer clinical features (30/33, 91%), pathology (28/33, 85%), and treatment (32/33, 97%); yet, 70% wanted to know more. The 5 women who did not feel knowledgeable about their pathology were less accurate in reporting grade (1/5) and ER (2/5), PR (1/5), and HER2 status (3/5), compared to those who felt knowledgeable. Despite this apparent concordance, it is notable that less than half of those who felt knowledgeable accurately reported grade (10/28, 36%) and PR status (12/28, 43%)

3.4. Breast cancer medical summary

Less than one-third of participants (10/33, 30%) recalled ever having received a written summary of their breast cancer clinical features, pathology, or treatment. In most cases, these documents included pathology reports, surgical reports, and information about medications and side effects, but no written summary in lay terms from an oncologist. When shown a sample breast cancer medical summary, nearly all women (32/33, 97%) said they were interested in receiving a summary like this. One participant explained, “I’ve had all this information at some point, but it’s scattered all over. If for any reason I had to change doctors, it would be nice to have it all in one place”. Additional information that participants thought should be included was prognostic and genetic test results (OncoTypeDx, BRCA1/2), adverse treatment reactions, and a glossary explaining each term in the summary. Several mentioned that they would like to have online access to the summary with real-time updates.

4. Discussion and conclusion

4.1. Discussion

4.1.1. Feasibility—This electronic questionnaire is a feasible approach for assessing breast cancer patients’ knowledge of their cancer diagnosis and treatment. On average, survey administration time was only 16 minutes per participant and all participants found the survey acceptable. Two-thirds completed the survey in person at their clinic visit immediately after enrollment, whereas one-third did so by telephone at a later date. The high participation rate in this study may reflect the convenience of flexible scheduling with the telephone survey option. To further improve convenience, based on these pilot data, future iterations of the survey would shorten and simplify knowledge questions.

The survey’s electronic format and linkage with the REDCap database facilitated data management and electronic medical record (EMR) abstraction. Using the REDCap platform,

the survey is formatted for remote use, such that participants may be emailed a secure link to complete the survey from any computer with Internet access. The potential for a web-based self-administration would enable broader dissemination of this tool to other institutions and non-research settings without dedicated study personnel to administer the survey.

4.1.2. Knowledge accuracy—Participants were most knowledgeable about general treatment modalities, specific details of surgery and reconstruction, and clinical features such as stage and lymph node status. Accurate knowledge of surgical treatment may reflect increased use of decision aids to educate breast cancer patients about surgical options once it became clear that patients lacked knowledge about the use of breast conserving surgery vs. mastectomy in early stage breast cancer (22–24). These decision aids are associated with increased understanding of surgical options, less decisional conflict, and more patient satisfaction (11, 12, 25). Although formal decision aids are not used at all cancer treatment centers, information about surgical options may be more widely available on the Internet or in other public sources, compared to other survey items where greater gaps were identified.

Despite accurately reporting general treatment information, many participants were unable to recall specific details of radiation and chemotherapy that have implications for future healthcare. Nearly half of patients could not recall the radiation modality, more than 80% could not recall all radiation fields, and none could recall the dose. This data may be relevant for future radiation or surgery for local recurrence and is important medical history for monitoring for treatment related risks (i.e. secondary malignancy and cardiopulmonary risks). Similarly, exposure to anthracycline chemotherapy increases risk of cardiac disease (26) and cumulative lifetime doses are limited. Thus, it is concerning that 1 in 5 patients receiving anthracyclines could not recall this exposure.

About 90% of participants accurately recalled their clinical stage and whether they had positive lymph nodes, whereas less than 40% knew their pathologic grade. This disparity may reflect the relative amount of time spent counseling patients. Stage and lymph node status are relevant for multidisciplinary treatment planning. In contrast, pathologic grade may be discussed with the patient only once, if ever, when reviewing the pathology report. It is striking that so few patients knew their tumor grade, even though it is correlated with the risk of local and distant recurrence. Tumor size was reported accurately by only 60% of participants, compared to the approximate 90% accuracy for clinical stage. Since tumor size is a component of the TNM final clinical stage, this isolated feature may not be emphasized to patients.

Participants tended to have greater perceived knowledge than actual knowledge. Only 5 participants (15%) did not feel knowledgeable about their breast cancer pathology; yet 40% did not know their tumor size or pathologic type and 67% did not know their pathologic grade. Although these 5 participants with low perceived knowledge also tended to be less accurate than peers, there were substantial knowledge gaps even among those who felt knowledgeable. This discordance between perceived and actual knowledge suggests that it may be important to offer educational interventions to all participants, even those who feel knowledgeable.

Four participants were unaware that their prescribed medication was “hormonal or endocrine therapy”. Perhaps this term was unfamiliar to some patients, or perhaps they did not understand the relationship between the medications and having a hormone receptor positive tumor. Studies demonstrate surprisingly low compliance with adjuvant hormonal therapy, as low as 50% among younger women (27, 28), which is associated with recurrence risk (29). Noncompliance is most commonly due to hormonal side effects, and patients report that they would be more likely to take medications if these effects were better managed and if they knew that it could improve clinical outcomes (27, 30). It is thus important to educate patients about the mechanism of action of these anti-cancer agents, which decrease estrogen or its effects on tumor cells, and the resulting recurrence risk reduction, in order to improve compliance and prevent the use of estrogen-containing medications or supplements that may compromise treatment benefits.

Our study is the first to describe what women who are being treated for breast cancer know about their diagnosis and treatment. Recently, Nissen et al. characterized knowledge gaps among breast cancer survivors (13). Our study, in contrast, characterized breast cancer patients in active treatment. Despite the shorter median time since initial diagnosis, a similar percentage of patients in our study did not know their lymph node status (12% vs. 7% in Nissen et al.) or breast cancer type (39% vs. 43%). Accurate knowledge of ER expression was higher in our study (76% vs. 58%), while knowledge of PR expression was identical (39%). In both studies, some patients who knew they were treated with tamoxifen or an aromatase inhibitor were unaware they had received hormonal therapy. Among patients who were treated with anthracycline chemotherapy, the percentage accurately reporting this exposure was markedly higher in our study (81% vs. 43%), possibly reflecting the proximity of the exposure to the time of the survey and consistent with findings described by Nissen and colleagues that knowledge accuracy tends to decrease with increasing time since diagnosis (13). Our study suggests that even during treatment and among a highly educated population, patients’ knowledge of their diagnosis and treatment is incomplete. These two studies, considered together, underscore the importance of educating patients during treatment and throughout follow-up.

4.1.3. Breast cancer medical summary—The Institute of Medicine and ASCO have both recommended that patients receive summaries of their diagnosis and treatment for education and to improve follow-up care (15, 31). In this study, women on treatment expressed a nearly universal interest in receiving a breast cancer medical summary, signifying that this tool has value beyond the post-treatment survivor population for whom it was initially developed. Medical summaries may allow patients to receive a continuity of care across institutions despite the lack of a universal medical record ((14, 15, 18)). This may become particularly important as traditional oncology-based follow-up shifts toward a primary care follow-up approach.

The feasibility of developing breast cancer medical summaries rests on automation of medical record abstraction. This pilot used manual medical record abstraction, which can be time consuming, inefficient and prone to errors. For institutions with electronic medical records, automated linkage between medical record and medical summary template would enable automatic generation of a medical summary that could be modified in real-time to

reflect ongoing treatment and health changes. However, given the challenge of constantly-changing treatment plans for patients on active therapy, additional collaboration with Information Technology (IT) services at each medical center will be necessary to coordinate this process and assist with challenges. As an intermediate step until automated medical record linkage is consistently available, patients may benefit from receiving a printout, at each clinic visit, stating the treatment they are to receive at that visit. While patients would be responsible for saving and compiling these individual pages, and this would not be as convenient as a concise summary, it may be a more feasible way to improve patient knowledge during active treatment.

4.1.4. Study quality and limitations—Although electronic patient questionnaires have been previously described, this study contributes to a growing body of literature using electronic surveys to assess important clinical questions with implications for patient care. This survey was feasible and lays the groundwork for future studies using web-based administration and automated medical record abstraction to identify knowledge gaps. Future iterations should include fewer answer choices for treatment details, but add “chest wall” as a radiation field. In addition, participants should be asked about their usual and preferred sources of health information, as this could be used to develop future knowledge-based interventions. Additional study limitations include the small sample size and homogeneity of the patient population, as is common for a pilot study. All participants were patients of one of three oncologists at a single comprehensive cancer center, and the majority were patients of a single oncologist. All had early breast cancer and although varying lengths of time had elapsed since diagnosis, all continued to attend clinic for ongoing therapy. Even more knowledge attrition is likely to occur with increasing time since diagnosis, particularly after treatment ends. The post-treatment period is a critical time for patient knowledge, due to increased risk of treatment-associated late effects and the continued risk of recurrence that extends well beyond the usual 5-year course of hormonal therapy. Our participants were highly educated and most spoke English as their primary language, reflecting the socioeconomically advantaged patient population in this geographic area. Thus, the knowledge gaps that were seen are likely to substantially underestimate those that exist in the general population. Furthermore, the use of answer choice recognition, rather than unprompted recall, provides an optimistic view of patient knowledge.

4.2. Conclusion

The questionnaire developed in this study is a feasible, well-accepted approach to measure patients’ knowledge about their breast cancer clinical features, pathology, and treatment. Preliminary data suggests that many breast cancer patients undergoing treatment have incomplete knowledge of their disease, and, like many patients who have completed treatment, would like to receive a concise, comprehensive breast cancer medical summary. Future studies should validate this knowledge questionnaire in a large, diverse population in a variety of settings and languages. Importantly, as in other web-based questionnaires, the electronic format enables remote self-administration and broad dissemination. With electronic medical records and web-based survey platforms such as REDCap, automated linkage between medical record and survey responses may be possible, allowing for real-time identification of patient knowledge gaps. However, further collaborations with IT

services at each medical center will be necessary to develop the infrastructure to generate and update treatment summaries in real-time.

4.3. Practice implications

Historically, efforts to understand patient knowledge have focused on general knowledge about treatment options and disease course, rather than specific information about a patient's diagnosis and treatment history. If validated in future studies, this knowledge questionnaire could be used to shape patient-provider communication and information sharing, and lay the groundwork for targeted educational interventions. The questionnaire could also streamline oncology clinic appointments by identifying patient knowledge gaps before the appointment and enabling providers to tailor medical visits accordingly.

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Figure 1.
Flow diagram of study

Table 1

Characteristics of the study population (N=33)

Characteristics	N	%
Age at time of study		
20–39 years	4	12
40–59 years	18	55
> 60 years	11	33
Median (range)	52.9 (24.9–82.2)	
Time since diagnosis		
< 1 year	9	27
1–3 years	7	21
3–5 years	8	24
5 years	9	27
Median (range)	3.2 (0.2–9.2)	
Race and ethnicity		
White, non-Hispanic	20	61
Black, non-Hispanic	1	3
Asian, non-Hispanic	8	24
Hispanic	4	12
Primary language		
English	29	88
Other	4	12
Marital status		
Single, never married	3	9
Married	23	70
Divorced, separated, widowed	6	18
Declined to answer	1	3
Highest education level		
High school diploma	7	21
2-year college degree	2	6
4-year college degree	11	33
Master’s degree	11	33
Doctorate	2	6

Table 2

Knowledge of clinical and pathologic features

Characteristics	Actual		Reported Correctly		Mistaken Values Reported by Participants	
	N	% *	N	% †		
Type of breast cancer						
Invasive ductal carcinoma	28	85	17	61	DCIS (N=4); Mucinous (N=1); Not sure (N=6)	
Invasive lobular carcinoma	5	15	3	60	Invasive ductal (N=1); Not sure	
Total	33	100	20	61		
Tumor size						
< 1 cm	2	6	1	50	Not sure (N=1)	
1 to < 3 cm	20	61	12	60	< 1 cm (N=2); 3–5 cm (N=1); > 5 cm (N=1); Not sure (N=4)	
3 to 5 cm	5	15	5	100		
> 5 cm	4	12	1	25	< 1 cm (N=1); 3–5 cm (N=1); Not sure (N=1)	
Not yet known§	2	6	N/A			
Total	33	100	19	61§		
Clinical stage						
I	8	24	6	75	Stage II (N=2)	
II	16	49	15	94	Not yet known (N=1)	
III	8	24	8	100		
Not yet known§	1	3	N/A			
Total	33	100	29	91§		
Pathologic grade						

Characteristics	Actual				Reported Correctly			Mistaken Values Reported by Participants	
	N	% *	N	% †	N	% ‡			
1	5	15	2	40				Grade 2 (N=1); Not sure (N=2)	
2	20	61	6	30				Not sure (N=14)	
3	8	24	3	38				Not sure (N=5)	
Total	33	100	11	33					
Lymph nodes									
Any positive	22	67	20	91				None positive (N=2)	
None positive	11	33	9	82				Any positive (N=1); Not sure (N=1)	
Total	33	100	29	88					
Estrogen receptor									
Positive	31	94	24	77				Negative (N=1); Not sure (N=6)	
Negative	2	6	1	50				Positive (N=1)	
Total	33	100	25	76					
Progesterone receptor									
Positive	29	88	12	41				Negative (N=3); Not sure (N=14)	
Negative	4	12	1	25				Positive (N=1); Not sure (N=2)	
Total	33	100	13	39					
HER2									
Positive	3	9	3	100					
Negative	30	91	19	63				Positive (N=3); Not sure (N=8)	
Total	33	100	22	67					

Notes:

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Abbreviations: DCIS = ductal carcinoma in situ

* Column percent;

[†] Row percent

[§] Tumor size (N=2) and clinical stage (N=1) were not yet known for participants who had surgery after the time of the survey, so total percentages were calculated out of 31 and 32, respectively

Table 3

General knowledge of treatment modalities

Treatment modalities [§]		Actual		Reported Correctly		Mistaken Values Reported by Participants	
		N	% [*]	N	% [‡]		
Surg.	Chemo	RT	Horm.				
X	X	X	15	45	13	87	No hormonal therapy (N=1); Not sure of hormonal therapy (N=1)
X	X	--	X	5	15	5	100
X	--	X	X	1	3	0	0
X	X	--	--	8	24	8	100
X	--	X	--	1	3	1	100
X	--	--	X	1	3	0	0
--	X	--	--	2	6	2	100
Total		33	100	29	88		

Notes:

Abbreviations: surg. = surgery; chemo = chemotherapy; RT = radiation therapy; horm. = hormonal therapy

^{*} Column percent;

[‡] Row percent

[§] Treatment modalities based on treatment received up until the time of the study (women were not asked about future planned treatments).

Table 4

Specific knowledge of treatment regimens

Treatment regimen	Actual		Reported Correctly		Mistaken Values Reported by Participants	
	N	%	N	%	N	%
Surgery (N=31)						
Any surgery	31	94	31	100		
Type of surgery						
Lumpectomy only	13	42	13	100		
Mastectomy only	9	29	9	100		
Lumpectomy + mastectomy	2	6	1	50	Double mastectomy (N=1)	
Double mastectomy	7	23	7	100		
Total	31	100	30	97		
Reconstruction (N=14)						
Any reconstruction	14	42	14	100		
Type of reconstruction						
Expander implant	10	71	10	100		
TRAM flap	4	29	4	100		
Radiation therapy (N=17)						
Any radiation therapy	17	52	17	100		
Type of radiation *						
External beam	15	88	6	40	Not sure (N=1); IMRT (N=1); Accelerated RT (N=1)	
Intra-operative	1	6	1	100		

Treatment regimen	Actual		Reported Correctly		Mistaken Values Reported by Participants	
	N	%	N	%	N	%
Field						
Identified all fields			3	18	Missed 1 (N=10); Missed 2 (N=2); Missed 3 (N=2)	
Breast	12	71	12	100		
Axilla	4	24	1	25	Reported other fields (N=3)	
Clavicular (infra, supra)	6	35	2	33	Reported other fields (N=4)	
Chest wall	5	29	0	0	Breast (N=5) [‡]	
Chemotherapy (N=30)						
Any chemotherapy	30	91	30	100		
Medication names						
Identified all medications			22	73		
Anthracyclines	27	90	22	81		
Taxanes	24	80	22	92		
Hormonal therapy (N=22)						
Any hormonal therapy	22	67	18	82		
Medication names						
Identified all medications			20	91		

Notes:

Abbreviations: IMRT = intensity modulated radiotherapy; RT = radiotherapy

* Complete radiation records were not available for 1 patient who received radiation at an outside institution

[‡]All 5 patients who received chest wall radiation reported receiving breast irradiation. Note that chest wall radiation was not provided as an answer choice; however, none of the participants offered this as an "other" field to write in.