Original Study

Reliability of Self-reported Treatment Data by Patients With Breast Cancer Compared With Medical Record Data

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Abstract

The reliability of self-reported treatment data is unclear. Therefore 350 (58% response) breast cancer patients completed a questionnaire to compare self-reported data with data from medical records. Agreement was good for type of surgery, receiving chemotherapy, endocrine and radiation therapy. Only moderate agreement was seen for sentinel node biopsy, pathological results an axillary lymph node dissection.

Objectives: Medical records are considered the gold standard for accurate treatment information. However, treatment data are increasingly obtained from questionnaires. It can be questioned whether self-reported treatment data are reliable, particularly because patients have to process a lot of information during their diagnosis and treatment process. The present study assesses the reliability of self-reported treatment data compared with medical records. **Methods:** All patients with stage I, II, and III breast cancer (n = 606) in 5 hospitals in the west of the Netherlands were invited to complete a questionnaire 9 to 18 months after surgery. We calculated kappa statistics, proportion correct, sensitivity, specificity, and positive and negative predictive values to assess agreement. **Results:** Three hundred fifty patients completed the questionnaire (58%). Agreement was good for type of surgery and receiving chemotherapy, endocrine therapy, and radiation therapy, with sensitivity and specificity of 95% or higher and kappa above 0.90. However, only moderate agreement was seen for sentinel node biopsy, including the pathologic results and axillary lymph node dissection (kappa between 0.60 and 0.80). Lack of agreement was more often found for patients who had received endocrine therapy (odds ratio, 1.85; 95% confidence interval, 1.11-3.10) but not influenced by age (odds ratio, 1.00; 95% confidence interval, 0.98-1.02). **Conclusion:** Accuracy of self-reported data is high for type of surgery, chemotherapy, endocrine therapy, and radiation therapy, but much lower for sentinel node biopsy including the pathologic results and axillary lymph node dissection. This is relevant for clinicians given the time spent explaining these procedures, and for researchers to help decide what information to obtain from patients or medical records.

Background

Medical records are still considered the gold standard to obtain reliable information on breast cancer treatment data. However, this is time consuming, and, with increased use of Patient Reported

Outcome Measures as part of routine clinical practice as well as for research, self-reported treatment data could be a feasible alternative if the self-reported information is sufficiently reliable. Previous studies suggest that self-reported treatment data are accurate for broad categories of treatment such as chemotherapy and surgery.[1-5]

However, since these studies were conducted, some things have changed in clinical practice that may influence the results. Treatment decisions at present are more frequently made by doctor and patient together.[6] As a result, patients receive more and more information about their disease, especially in oncology.[7-9] Various studies among patients with (breast) cancer showed that patients want to be fully informed and share decision-making responsibility.[6-9] This may result in better recall of this information by patients, because of their

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involvement in the decision-making. On the other hand, there is an increased number of choices to make during the treatment period, and therefore, patients with breast cancer receive even more information to process than they did in the past,[5] which may limit the accurateness by which patients recall their treatment data. In addition, past studies did not assess the accurateness of self-reported sentinel node biopsy data, in part because these were not available at the time. Only 1 previous study assessed the accurateness of self-reported data about axillary lymph node dissections being performed,[2] describing a high proportion of agreement on this treatment regimen (97%; kappa 0.89).

Therefore, the present study aims to assess the agreement between self-reported data collected using a questionnaire, and clinical data of these patients collected using the hospital information systems on different breast cancer treatments including the sentinel node biopsy being performed, the pathologic result, and having received an axillary lymph node dissection.

Methods

The Importance for Mamma patients of PAtient reported outcomes in Choice of Therapy (IMPACT) study is an internet-based questionnaire study, investigating which outcomes of treatment for breast cancer are most important to patients in their judgement for good quality of care by using conjoint analysis. Details of the design and data collection have been described previously.[10] Within this study, patients reported data about the treatment they received; we also collected this treatment data from the medical records.

Ethics

The study was approved by the Medical Ethics Committee of the Leiden University Medical Center (project number P13.211).

Patients

All patients (n = 606) with stage I, II, and III breast cancer were selected in 5 hospitals in the western part of the Netherlands and invited to participate. Patients were selected if they were at least 18 years of age, and underwent surgery for breast cancer 9 to 18 months ago. The invitations and informed consent forms were sent by mail. Reminders were sent after 3 weeks.

Questionnaire

The first part of the questionnaire consisted of questions about the respondent and her diagnosis with and treatment for breast cancer. Questions about the received treatment included: (1) Type of surgery: breast conserving therapy versus mastectomy; (2) Sentinel node biopsy: performed versus not performed; (3) Patients who underwent a sentinel node procedure also answered a question about the pathologic results from this procedure: tumor-positive or tumor-negative; (4) Axillary lymph node dissection: performed versus not performed; (5) Chemotherapy: received versus not received; (6) Endocrine therapy: received versus not received; and (7) Radiation therapy: received versus not received.

Clinical Data

Clinical data of all invited patients were collected from the medical records. The collected data included: type of surgery (breast-conserving therapy or mastectomy), sentinel node procedure (performed or not performed), axillary lymph node dissection (performed or not performed), chemotherapy (received or not received), endocrine therapy (received or not received), radiation therapy (received or not received), and pathologic result from sentinel node procedure (tumor-positive or tumor-negative).

Statistical Analysis

Baseline characteristics were compared between respondents and nonrespondents, using χ^2 and t tests. This was done to assess whether the respondents were representative for the total population of patients with breast cancer. In case of expected counts less than 5, the Fisher exact test was used.

Agreement between self-reported treatment data and medical records was first assessed by calculating the kappa statistic. Next, agreement was analyzed by calculating the proportion of correct answers and sensitivity and specificity, as well as the positive and negative predictive values. In all these analyses, the medical records data were considered as the gold standard.

Multiple logistic regression analysis were conducted to examine whether lack of agreement between self-reported treatment and the medical records was influenced by age, receiving chemotherapy, and receiving endocrine therapy because these treatment regimens are known to influence the cognition of patients.[11] Receiving chemotherapy or endocrine therapy as noted in the medical records were included as independent variables besides age. This was done for the different types of treatment separately as well as overall, using lack of agreement on (at least 1) treatment (yes/no) as the dependent variable.

All data were analyzed using the statistical package SPSS for Windows 17.0 (SPSS Inc, Chicago, IL). Descriptive data are given as a mean (SD) or median (range). In all analyses, $P < .05$ was considered statistically significant.

Results

In total, 350 patients returned a complete questionnaire (response rate, 58%).

Respondents are, on average, 7 years younger than nonrespondents (Table 1). Among the respondents, there were more patients who received chemotherapy (50% vs. 31%) and radiation therapy (72% vs. 60%) than among the nonrespondents.

Overall, 2334 questions were answered by these 350 patients, and 138 questions were answered incorrectly compared with the medical records (5.9%). In total, 108 patients answered 1 or more questions incorrectly (31%), 83 patients answered 1 question incorrectly, 21 patients answered 2 questions incorrectly, 3 patients answered 3 questions incorrectly, and 1 patient answered 4 questions incorrectly.

Agreement by type of treatment is summarized in Table 2. The proportion of patients who correctly reported type of surgery, having chemotherapy, endocrine therapy, and radiation therapy was 95% or higher. Sensitivity and specificity along with positive and negative predictive values were also above 95%, and the kappa statistic was above 0.90 for each of these treatments, indicating good agreement. However, agreement was lower for sentinel node biopsy including the pathologic result and axillary lymph node dissection. The proportion of patients who correctly reported a sentinel node biopsy being performed, the pathologic results of the sentinel node biopsy, and undergoing axillary lymph node dissection were all below 90%, with the kappa statistic showing moderate agreement (between 0.60 and 0.80).

| Table 1 | Differences in Baseline Characteristics Between Respondents and Nonrespondents |

	Respondents, N = 350 (%)	Nonrespondents, N = 256 (%)	Differences Between Respondents and Nonrespondents
Mean age, y (SD)	59.3 (11.6)	66.3 (13.8)	$t = -6.49$
Range	27-93	31-95	**P <.01**
Tumor			
Invasive ductal carcinoma	230 (66)	149 (59)	
Invasive lobular carcinoma	61 (18)	44 (17)	
Ductal carcinoma in situ	40 (11)	34 (13)	
Other (pre)malignant	16 (5)	24 (10)	$\chi^2 = 7.96$
Benign	1 (0)	2 (1)	$P = .14$
Type of surgery			
Mastectomy	142 (41)	116 (45)	$\chi^2 = 1.36$
Breast-conserving therapy	208 (59)	140 (55)	$P = .24$
Axillary lymph node dissection			
Yes	88 (25)	73 (29)	$\chi^2 = 0.88$
No	261 (75)	182 (71)	$P = .35$
Chemotherapy			
Yes	169 (50)	76 (31)	$\chi^2 = 21.15$
No	172 (50)	172 (69)	**P <.01**
Endocrine therapy			
Yes	170 (50)	130 (52)	$\chi^2 = 0.30$
No	169 (50)	118 (48)	$P = .59$
Radiation therapy			
Yes	252 (72)	151 (60)	$\chi^2 = 10.39$
No	97 (28)	102 (40)	**P <.01**
Intraoperative radiation therapy			
Yes	69 (20)	39 (15)	$\chi^2 = 5.75$
No	281 (80)	215 (85)	$P = .10$

Significant differences are indicated in bold.

Age does not have an influence on the lack of agreement between self-reported data and the medical records, when adjusted for the effects of receiving chemotherapy and endocrine therapy (Table 3).

The same is true for receiving chemotherapy. However, among patients who received endocrine therapy, more often lack of agreement was found for any treatment (odds ratio, 1.95; 95%

| Table 2 | Agreement Between Self-reported Treatment and Medical Records |

	Proportion Correct,[a] %	Sensitivity, %	Specificity, %	PPV, %	NPV, %	Kappa
Surgery						
Lumpectomy	97.6	97.6	99.3	99.5	96.6	0.97
Mastectomy	99.3	99.3	97.6	96.6	99.5	0.97
Sentinel node	89.1	95.9	66.7	90.5	83.1	0.67
Pathologic result sentinel node						
Positive	85.9	85.9	94.6	85.9	94.6	0.77
Negative	94.2	94.6	85.9	94.6	85.9	0.77
ALND proceeded	86.8	93.2	84.7	67.2	97.4	0.69
Chemotherapy	97.7	98.2	97.1	97.1	98.8	0.95
Endocrine therapy	96.2	95.9	96.4	96.4	96.4	0.92
Radiation therapy	97.7	98.8	94.8	98.0	96.8	0.94

Abbreviations: ALND = axillary lymph node dissection; NPV = negative predictive value; PPV = positive predictive value.
[a]Using medical records as the gold standard.

Table 3 Influence of Age, Receiving Chemotherapy, and Receiving Endocrine Therapy on Lack of Agreement Between Self-reported Treatment and Medical Records

	Age		Chemotherapy		Endocrine Therapy	
	OR	95% CI	OR	95% CI	OR	95% CI
Any treatment	1.00	0.98-1.02	1.32	0.73-2.38	**1.85**	**1.11-3.10**
Type of surgery	1.02	0.94-1.10	0.75	0.10-5.93	0.56	0.09-3.52
SN performed	1.00	0.97-1.04	1.66	0.69-3.99	1.05	0.49-2.24
Pathology SN	0.97	0.92-1.02	3.32	0.78-14.09	1.85	0.60-5.68
ALND	0.98	0.95-1.02	0.64	0.28-1.46	**2.75**	**1.31-5.79**
Chemotherapy	0.97	0.91-1.04	0.29	0.05-1.76	2.57	0.53-12.52
Endocrine therapy	1.05	0.99-1.11	1.42	0.34-5.84	1.13	0.34-3.70
Radiation therapy	1.01	0.93-1.08	0.89	0.14-1.08	0.78	0.15-4.07

Significant differences are indicated in bold.
Abbreviations: ALND = axillary lymph node dissection; CI = confidence interval; OR = odds ratio; SN = sentinel node.

confidence interval, 1.11-3.10). This seems to be owing to the lack of agreement on reporting axillary lymph node dissection, which was observed more often in the group of patients who received endocrine therapy (odds ratio, 2.75; 95% confidence interval, 1.31-5.79) (Table 3). For all other treatment regimens, there were no differences in lack of agreement by age, receiving chemotherapy, and receiving endocrine therapy.

Discussion

The present study has shown that most women correctly answered type of surgery received, as well as chemotherapy and endocrine and radiation therapy, with sensitivity and specificity of 95% or higher and kappa above 0.90. However, sentinel node biopsy, including the positive or negative pathologic result, and an axillary lymph node dissection being performed were reported with only moderate agreement (kappa between 0.60 and 0.80). A lack of agreement was more often found for patients who had received endocrine therapy, specifically regarding axillary lymph node dissection, but not influenced by age. Overall, about one-third (31%) of patients answered 1 or more questions regarding treatment incorrectly.

These results confirm that the accuracy of self-reported data compared with medical records was high for most broad categories of treatment received, as found in previous studies.[1-5] However, the accuracy reported for axillary lymph node dissection in the current study was much lower than in a previous study.[7] Agreement regarding sentinel node biopsy and pathologic results of the biopsy was not investigated before, given that these became part of routine practice in recent years, but also showed moderate agreement. Age did not influence the lack of agreement between self-reported data and the medical records, but receiving endocrine therapy did, particularly regarding axillary lymph node dissection. This could be explained by the previously proven effect of endocrine therapy on cognition and memory.[12-14] The question is whether information about these treatment regimens is not remembered well by patients, or not understood, or not explained correctly by doctors. This should be investigated in future studies to get clues on how this can be improved so that these can be reliably assessed using self-reported data.

Study Limitations

Our sample may have been a selected population, as it was shown that respondents were younger than nonrespondents. Therefore, response bias may have occurred, but this will only affect the results

if the lack of agreement was also influenced by age. Age did not influence the lack of agreement; thus, our younger sample is likely to give results representative for the total population. Similarly, more responding patients received radiation therapy and chemotherapy, but there was no difference in the lack of agreement between patients who did or did not receive radiation therapy or chemotherapy, so this will not have affected the results. Finally, a limitation of the study is that we did not have data available on patient characteristics like education, income, and literacy or on stage of cancer, so that the influence of these variables on agreement could not be assessed.

Conclusion

In conclusion, the current study confirms previous studies concluding that the accuracy of self-reported data is high for most broad categories of treatment. The present study adds that the accuracy of self-reported data about sentinel node biopsy, pathologic results of the biopsy, and axillary lymph node dissection is much lower and shows only moderate agreement. This is relevant for clinicians, given the time spent explaining these procedures, and for researchers to help them decide what information to obtain from patients or medical records. Future studies should investigate the causes for such lack of agreement, and whether this is owing to information not being understood by patients, not being well-explained by doctors, or the large amount of information that needs to be processed. This is likely to improve both the information provision to patients and to contribute to patients being able to participate in shared decision-making.

Clinical Practice Points

- Medical records are still considered the golden standard to obtain reliable information on breast cancer treatment data.
- However, this is time consuming and self-reported treatment data could be a feasible alternative if the self-reported information is sufficiently reliable.
- Previous studies suggest that self-reported treatment data are accurate for broad categories of treatment such as chemotherapy and surgery.
- Past studies did not assess the accurateness of self-reported sentinel node biopsy data, in part because these were not available at the time.

- Only one previous study assessed the accurateness of self-reported data about axillary lymph node dissections being performed.
- The current results confirms previous studies concluding accuracy of self-reported data is high for most broad categories of treatment.
- The present study adds that accuracy of self-reported data about sentinel node biopsy, pathological results of the biopsy and axillary lymph node dissection is much lower and shows only moderate agreement.
- This is relevant for clinicians given the time spent explaining these procedures, and for researchers to help them decide which information to obtain from patients or medical records.
- Future studies should investigate the causes for such lack of agreement, and whether this is due to information not being understood by patients, not well explained by doctors or due to the large amount of information that needs to be processed.
- This is likely to improve both the information provision to patients and likely to contribute to patients being able to participate in shared decision making.

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Disclosure

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