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Elderly Breast Cancer Survivors Accurately Self-Report Key Treatment Information

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To the Editor: Prior studies have shown that both tumor registry and administrative databases, including the National Cancer Institute's Surveillance Epidemiology End Results (SEER) registry and Medicare data, provide valid, accurate and complete information on various treatment modalities for women with breast cancer.^{1–3} Another alternative to obtain this information is patient self-report. Three studies have shown that breast cancer survivors can accurately recall key treatment information.^{4–6} However, these studies are relatively small and include largely younger women. Validation of self-report of breast cancer treatments specifically in elderly women is important as over 40% of women with breast cancer are diagnosed at age 65 or older. We sought to determine whether a population-based cohort of older breast cancer survivors could accurately recall key treatment information.

Our study cohort consisted of 3,083 community-dwelling women (65–89 years) residing in 4 states (CA, FL, IL, NY), who underwent initial breast cancer surgery in 2003 and completed a telephone survey at approximately 30 months after breast cancer surgery.⁷ Self-reported data regarding treatment (breast surgery, radiation therapy, chemotherapy, and reconstructive surgery) were validated against Medicare claims data dated from 1 month prior to breast cancer diagnosis until the time of the survey.⁸ Agreement was assessed by Cohen's kappa statistic.⁹

The mean age of the women when they completed the survey was 76 years (sd 5.5; range, 67–93 years); 94% were Caucasian and the majority were healthy (65% with no comorbidities). Half were married and 92% had at least a high school degree. The median annual household income in 2004 was \$29,000. According to Medicare claims, 66% underwent breast-conserving surgery (BCS), 67% underwent radiation therapy, and 21% received chemotherapy. Only 4.6% (n = 143) of the cohort underwent breast reconstruction surgery.

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Author Contributions: Indicate authors' role in study concept and design, acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript. (See section on "Authorship and Duplicate Publication").

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Assuming Medicare claims as the gold standard, the validation of each item on the self-report questionnaire is summarized in Table 1. Overall, agreement was excellent for the four treatments examined. Kappa values varied between 0.83 for type of breast surgery and 0.95 for receipt of radiation therapy. Sensitivity (80%–99%), specificity (98%–99%), positive and negative predictive values (90%–99%) for self-report were high for all four treatments. Accuracy of self-report was not significantly affected by proxy response, patient age group, or educational status (data not shown).

The agreement for type of breast surgery is likely higher than what is reported. Of the 2,207 women who self-reported undergoing BCS, 214 had Medicare claims for mastectomy; 171 (80%) of these 214 women also had claims for BCS. Therefore, these 171 women presumably underwent initial BCS followed by mastectomy at a later date and were identified by our Medicare claims algorithm⁸ as total mastectomy cases. Our survey did not capture these 171 women as undergoing eventual mastectomy since a positive response to the BCS survey item was erroneously programmed to skip the next item about mastectomy. Therefore, these 171 women were placed in the BCS self-report group. If these 171 women are re-categorized as self-reported total mastectomy cases, then the sensitivity of self-report for mastectomy increases from 79.7% to 95.9% and the kappa improves from 0.83 to 0.96 (95% CI: 0.95 – 0.97). These values would represent the “best case” scenario and the true agreement likely falls somewhere between those reported in Table 1 and this “best case” scenario.

Our results confirm the validity of self-report described in previous smaller studies in elderly breast cancer survivors⁶ and younger women.^{4, 5} Several factors may explain the disagreement between self-report data and Medicare claims in our study. From a survey standpoint, errors may be attributed to biased self-report, women’s recall, or unclear wording of the survey items. We attempted to limit this bias by providing brief descriptions of each type of treatment, referencing the time frame of treatment, and wording questions at the 8th-grade level. Although we assumed that the Medicare claims data were correct, there are limitations of Medicare data regarding accuracy of coding, completeness of claims, and the potential for underreporting due to care provided by other agencies.^{1, 3}

In summary, this study demonstrates that general information regarding several key cancer treatments was accurately reported 2–3 years later by a population-based cohort of over 3,000 elderly breast cancer survivors. Details regarding stage of disease and treatment would likely still need to be obtained from other sources. However, for investigators performing survey studies in breast cancer survivors which require only broad key treatment information (i.e. quality of life or patient satisfaction studies), patient self-report appears to be an excellent, lower-cost alternative for obtaining this information.

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Table 1

Agreement between Self-report and Medicare Claims for Initial Treatment of Breast Cancer*

Treatment	Proportion correct (%)	Kappa (95% CI)	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
Receipt of radiation therapy	97.9	0.95 (0.94 – 0.96)	97.6	98.6	99.3	95.3
Receipt of chemotherapy	96.8	0.90 (0.88 – 0.92)	90.0	98.6	94.5	97.4
Type of breast surgery [†]	92.8	0.83 (0.81 – 0.85)				
Breast-conserving			99.5	79.7	90.3	98.7
Mastectomy			79.7	99.5	98.7	90.3
Receipt of breast reconstructive surgery	99.1	0.90 (0.86 – 0.94)	90.2	99.6	90.8	99.5

Abbreviations: CI, confidence interval; NPV, negative predictive value; PPV, positive predictive value

* Excludes missing values: 3 for radiation therapy, 6 chemotherapy, 25 for type of breast surgery, and 5 for reconstructive surgery

[†] “Best case” scenario for type of breast surgery (see text for explanation): Proportion correct = 98.2%, Kappa = 0.96 (95% CI: 0.95 – 0.97), sensitivity for mastectomy = 95.9%, PPV for mastectomy = 98.9, PPV for BCS = 97.9.