An Analysis of the Association Between Cancer-Related Information Seeking and Adherence to Breast Cancer Surveillance Procedures

Andy S.L. Tan, Mihaela Moldovan-Johnson, Stacy W. Gray, Robert C. Hornik, and Katrina Armstrong

Abstract

**Background:** Breast cancer surveillance is important for women with a known history of breast cancer. However, relatively little is known about the prevalence and determinants of adherence to surveillance procedures, including associations with seeking of cancer-related information from medical and nonmedical sources.

**Methods:** We conducted a longitudinal cohort study of breast cancer patients diagnosed in Pennsylvania in 2005. Our main analyses included 352 women who were eligible for surveillance and participated in both baseline (~1 year after cancer diagnosis) and follow-up surveys. Outcomes were self-reported doctor visits and physical examination, mammography, and breast self-examination (BSE) at 1-year follow-up.

**Results:** Most women underwent two or more physical examinations according to recommended guidelines (85%). For mammography, 56% of women were adherent (one mammogram in a year) while 39% reported possible overuse (two or more mammograms). Approximately 60% of respondents reported regular BSE (≥5 times in a year). Controlling for potential confounders, higher levels of cancer-related information seeking from nonmedical sources at baseline was associated with regular BSE (OR, 1.52; 95% CI, 1.01–2.29; P, 0.046). There was no significant association between information-seeking behaviors from medical or nonmedical sources and surveillance with physical examination or mammography.

**Conclusions:** Seeking cancer-related information from nonmedical sources is associated with regular BSE, a surveillance behavior that is not consistently recommended by professional organizations.

**Impact:** Findings from this study will inform clinicians on the contribution of active information seeking toward breast cancer survivors’ adherence to different surveillance behaviors. Cancer Epidemiol Biomarkers Prev; 22(1); 167–74. ©2012 AACR.

Introduction

Based on recent estimates, there are more than 2.6 million women alive in the United States who have a history of breast cancer (1). With a rapidly aging population, increased detection of early-stage tumors, and improved treatment procedures, the population of breast cancer survivors is projected to grow even further.

Improvements in diagnostic technologies and treatment delivery make breast cancer surveillance following women’s initial cancer treatment even more essential. Given the increased risk of second cancers in breast cancer survivors, routine surveillance is important for diagnosing early local recurrences and second primary breast tumors. Considerable evidence supports routine surveillance through regular physician examination and screening mammography (2–9); both are recommended by the American Society of Clinical Oncology (ASCO), National Comprehensive Cancer Network (NCCN), and other national or international professional agencies (10–17). In contrast, evidence supporting breast self-examinations (BSE) is absent. Thus far, no controlled trials have shown improved patient survival with BSE surveillance. Accordingly, only a handful of advisory organizations provide guidance about BSE for breast cancer surveillance (11, 12, 18).

Research suggests that many breast cancer survivors do not receive mammography and clinical examination as recommended or conduct BSE (19–22). One survey found only about 60% of breast cancer survivors underwent surveillance mammography in the first year after their...
treatment, with fewer doing so in the second year after treatment and beyond (21). Adherence to surveillance mammography and clinical examination is lower among women of older age, ethnic minorities, women suffering from comorbid conditions, and those who underwent certain types of treatment (19–21, 23–26). However, relatively little attention has been paid to potentially modifiable factors that may influence breast cancer surveillance adherence, including the level of cancer-related information seeking.

Cancer patients are interested in obtaining information about a variety of topics related to their disease and from a multitude of sources (27–29). While health professionals are the key information source for most cancer survivors, nonmedical information sources including interpersonal contacts (e.g., family members, friends, support groups, etc.) and media sources (e.g., printed materials such as books, brochures, magazines and newspapers and other forms of mass media such as TV, radio, and the Internet) play an increasingly important role for cancer patients (27). Active seeking of cancer-related information from medical and nonmedical sources have been linked to various patient behaviors and health outcomes. For instance, studies report patients’ active seeking of cancer-related information is associated with use of targeted therapy, treatment decision satisfaction, nutrition behaviors, patient-reported quality-of-life, and emotional well-being (30–35). Given this background, we analyzed longitudinal survey data from a population sample of breast cancer survivors to determine the associations between information seeking from medical and nonmedical sources measured at baseline and subsequent breast cancer surveillance.

Materials and Methods

Study population and procedure

This analysis was part of a larger study involving a randomly selected sample of 2,013 patients diagnosed with breast, prostate, or colorectal cancers between January 2005 and December 2005, as reported to the Pennsylvania Cancer Registry. The larger study aimed to examine the influence of information-seeking behaviors of patients with cancer on a variety of health behaviors and outcomes. We included participants who were diagnosed with breast cancer in the current analyses. The baseline survey was conducted in September 2006 with a follow-up survey in September 2007. We oversampled cancer patients with stage IV disease and African-American patients to facilitate planned subgroup analyses (not part of this present study). Further details are described elsewhere (36).

Of 679 patients diagnosed with breast cancer at baseline, 450 completed the follow-up survey. The response rate for participants with breast cancer at baseline was 68% (American Association for Public Opinion Research response rate 4; ref. 37). At follow-up, the raw response rate among those who agreed to be recontacted was 79%.

We excluded patients who did not complete the second survey (n = 229), those with metastatic disease as they were not eligible for surveillance testing (n = 81), and those with unknown cancer stage (n = 17), leaving 352 patients in the analysis (Fig. 1).

We developed the survey questionnaire following a literature review, expert consultation, and a pilot study involving in-depth interviews among 43 patients diagnosed with breast, prostate, or colorectal cancer in the greater Philadelphia area (38). Participants in the pilot study were not part of the longitudinal survey. Data collection was based on Dillman’s tailored design method for mail surveys (39). First, we mailed notice letters to sampled participants to inform them about the study objectives and instructions for opting out. Next, participants received the survey, a small monetary incentive (either $3 or $5 at baseline and $3 at follow-up), and stamped return envelopes. Participants who did not opt out or return the survey within 2 weeks were sent an additional letter and survey. The instructions for completing the survey indicated that participation was voluntary and submitting a completed questionnaire implied informed consent. The University of Pennsylvania Institutional Review Board approved the study procedure and materials.

Outcome measures – cancer surveillance procedures

The outcomes were based on self-reported use of surveillance procedures by patients during the 12 months preceding the survey at follow-up (~2 years after being diagnosed with breast cancer). The item asked, “How often have you done the following things in the past 12 months, as part of your routine cancer follow-up? Do not include the times that you have done things because of a new symptom or health concern.” Participants indicated
the frequency across 5 response options, ranging from "0 times" to "5 or more times" of: (i) doctor visit and physical exam; (ii) mammogram; and (iii) breast self-exam. The baseline survey omitted these adherence measures because some patients might not have completed treatment. The outcome of doctor visit and physical exam was dichotomized to "less than two times" compared with "two or more times" in the past 12 months on the basis of typical recommendations for 6-monthly routine physical exams or more (11–17). Because of the high prevalence of receiving 1 or more mammograms in this study population and growing concern about possible overuse, we categorized the responses for the mammography measure as nonadherent (0 times in the past year), adherent (1 time in the past year), or overusing (≥2 times in the last year). As the highest frequency of all surveillance behaviors was "5 or more times" in the past 12 months, BSE was dichotomized to "less than five times" compared with "five or more times". We further analyzed BSE as a continuous variable across the 5 response categories.

**Predictor measure – information seeking from nonmedical sources (Seeking)**

To measure information seeking by patients from nonmedical sources, we asked participants to think back to the first few months of their cancer diagnosis and to recall whether they sought information (yes/no) about treatments, information related to their cancer, and information about quality-of-life issues from a variety of interpersonal and media sources as described in previous research (32, 33). These different sources included: (i) television or radio; (ii) books, brochures, or pamphlets; (iii) newspapers or magazines; (iv) the Internet other than personal e-mail; (v) family members, friends, or coworkers; (vi) other cancer patients; (vii) support groups; and (viii) telephone hotlines from the American Cancer Society, comprising 24 items across 3 topic domains. Of these sources, previous research from this study population indicated that the main nonmedical sources of information that breast cancer survivors sought from included (from most frequent to least frequent) books, brochures, or pamphlets; family, friends, coworkers; other cancer patients; and the Internet (40). Responses were summed within each topic domain (i.e., treatment, cancer information, and quality of life) and the summed scores were standardized and averaged to form the scale on seeking from nonmedical sources (Cronbach α, 0.81).

**Predictor measure – Patient–Clinician Information Engagement**

Seeking cancer-related information from medical sources was measured using the Patient–Clinician Information Engagement (PCIE) scale as described by Martinez and colleagues (31). Briefly, the scale comprised 8 survey items (yes/no) that asked participants to think back to the first few months of their cancer diagnosis and to recall whether they: (i) sought information about treatments from their treating physician; (ii) sought treatment information from other physicians or health professionals; (iii) actively looked for information about their cancer from their treating physician; (iv) looked for cancer information from other physicians or health professionals; (v) discussed information from other sources with their treating physician; (vi) received suggestions from their treating physician to get information from other sources; (vii) actively looked for information about quality-of-life issues from their treating physician; and (viii) actively looked for quality-of-life information from other physicians or health professionals. Each item was standardized and the average of these 8 standardized items formed the PCIE scale. This measure showed reasonable internal consistency in the analyzed sample (Cronbach α, 0.80).

**Potential confounder variables**

Informed by previous literature, the analysis controlled for demographic variables (age in years, gender, education level, marital status, and race/ethnicity), indication of concern by respondents at baseline about how to reduce their chances of cancer recurrence (yes/no), their tendency to follow recommendations by doctors for tests to monitor their cancer (ranging from ‘Never’ to ‘Always’), cancer-related worry (Lerman Cancer Worry Scale; ref. 41), and other clinical characteristics including the American Joint Committee on Cancer/International Union Against Cancer TNM stage at diagnosis (derived from the PCR data and ranging from stage 0 to III; ref. 42), treatment received (i.e., self-reported type of surgery, radiation therapy, and systemic therapy), and self-reported health status (ranging from ‘Poor’ to ‘Excellent’). All confounder variables were assessed at baseline.

**Statistical analysis**

We conducted the analyses using Stata Release 12 (43). On the basis of initial descriptive analyses, 50% of the analyzed sample had missing data on 1 or more variables. The majority of missing values (39%) occurred in the covariate measure of tendency of patients to follow recommendations by doctors for tests because 84 cases were randomly selected to receive the short form of the survey and were, therefore, not asked this item (44). Excluding this control variable from the analysis did not alter the substantive findings of the study and the final model retained this variable. Additional missing cases were due to missing values on 1 or more of the 3 individual items that asked about adherence to mammography (29 cases), BSE (50 cases), and physical examinations (12 cases). Missing values for the PCIE and information seeking from nonmedical sources were minimal in this analysis, only 1 respondent had missing values for PCIE while 2 had missing values on the information seeking from nonmedical sources. We carried out multiple imputations to address missing data only for predictor variables using the Stata MI program.
according to recommended procedures (45, 46) to generate 30 datasets with imputed values of predictor variables. To analyze the associations between the information-seeking measure and surveillance behaviors, we used binary logistic regression to predict physical examinations and BSE and multinomial logistic regressions to predict mammography, controlling for potential confounders.

Results

Among the analyzed sample, the mean age of participants at diagnosis was 62 years, 50% had some college education or higher, and 87% were white (Table 1). At follow-up, the majority of participants reported 2 or more doctor visits and physical examination (84.7%). For mammography surveillance, 4% were not adherent (no mammogram in the past year), 56% of women were adherent (1 mammogram), while 39% were categorized as overusers (≥2 mammograms). Therefore, the majority of women received at least 1 mammogram for surveillance in this study sample. In addition, 60% of participants reported having conducted BSE 5 or more times in the past year.

Table 2 presents the results of the binary logistic regressions predicting physical examination and BSE surveillance behaviors. Seeking from medical or non-medical sources did not significantly predict physical examination (≥2 vs. <2 physical examinations). Seeking from nonmedical sources was associated with conducting BSE 5 or more times in the past year at follow-up [OR, 1.52; 95% confidence interval (CI), 1.01 to 2.29; \( P = 0.046 \)], controlling for potential confounders (Table 2). This association held when considering frequency of BSE as a continuous variable (Spearman \( r \), 0.194, \( P = 0.001 \); Kendall \( \tau \), 0.150, \( P = 0.001 \)). Using multinomial logistic regressions, information seeking from medical and nonmedical sources was not associated with overuse of routine mammography (vs. being adherent and vs. non-adherence) or with adherence to surveillance mammography (vs. non-adherence; Table 3).

Discussion

Active seeking of cancer information represents a strategy for patients with cancer to cope with breast cancer (47, 48). Previous studies have found linkages between information-seeking behaviors and various important behavioral outcomes among cancer survivors, including a positive association between information seeking and participation in shared decision-making about their care (48) and adoption of healthier lifestyle practices such as fruit and vegetable intake (49). In contrast to previous studies, this present research did not find an association between seeking cancer-related information from medical and nonmedical sources and adherence to physical examination and mammography surveillance.

Several observations arising from the study findings deserve further discussion. First, the majority of breast cancer survivors in this study reported undergoing mammography (95.7%) and physical examinations (84.7%) at or above the recommended levels. This finding compares favorably with other studies which typically described underuse of surveillance mammography or clinical visits for follow-up among women diagnosed with breast cancer (19, 20, 25). Although direct comparisons across studies are not possible due to differences in study populations.

Table 1. Characteristics of analyzed sample (n = 352)

<table>
<thead>
<tr>
<th>Participant characteristic</th>
<th>Range</th>
<th>Mean (SD)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs)</td>
<td>29–90</td>
<td>62.2 (12.9)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school and below</td>
<td>176 (50.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some college and above</td>
<td>175 (49.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>307 (87.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>36 (10.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or other</td>
<td>9 (2.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>130 (36.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>222 (63.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking of cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>from medical sources</td>
<td>-1.15–2.84</td>
<td>0.25 (0.87)</td>
<td></td>
</tr>
<tr>
<td>from nonmedical sources</td>
<td>-1.22–1.24</td>
<td>0.12 (0.63)</td>
<td></td>
</tr>
<tr>
<td>Concern about reducing chances of recurrence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>70 (20.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>276 (79.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer stage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0</td>
<td>67 (19.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>153 (43.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage II</td>
<td>111 (31.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage III</td>
<td>21 (6.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health status</td>
<td>1–5</td>
<td>3.86 (1.12)</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>217 (61.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td>109 (31.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>25 (7.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>96 (27.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>255 (72.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systemic therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>58 (16.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (chemotherapy, hormonal therapy, or biologics)</td>
<td>293 (83.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Followed doctor’s</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>recommendations for tests</td>
<td>1–5</td>
<td>4.57 (0.94)</td>
<td></td>
</tr>
<tr>
<td>Lerman Cancer Worry Scale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–5</td>
<td>2.41 (0.91)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
and study designs, possible reasons for the higher adherence in this present analysis may be because of the study population who were more recently diagnosed (within the last 2 years) or secular trends over time of survivors being more adherent for follow-up with physical examinations and mammography. This present study also found that approximately 40% of participants reported undergoing 2 or more mammograms in the previous year, which exceeded the typical recommendations of conducting annual mammography for surveillance purposes. While we did not detect significant associations between information-seeking behaviors and what might be considered overuse of mammography, the prevalence of overuse of mammography may warrant further study of the underlying reasons.

This research has several strengths. The sample was population-based, representing a broader range of demographic characteristics. Moreover, the present study used longitudinal data analysis, which enabled us to establish temporal precedence of information-seeking predictor variables at baseline in relation to surveillance at follow-up. Although we were not able to conduct a true lagged analysis to control for previous adherence to surveillance procedures, we controlled for the tendency of

<table>
<thead>
<tr>
<th>Sources of cancer-related information seeking</th>
<th>Physical examination (≥2 visits in the past 12 months)</th>
<th>BSE (≥5 times in the past 12 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nonmedical</td>
<td>Unadjusted OR (95% CI)</td>
<td>1.43 (1.00–2.05)</td>
</tr>
<tr>
<td>Medical</td>
<td>Adjusted OR (95% CI)</td>
<td>1.15 (0.67–1.97)</td>
</tr>
<tr>
<td>Medical</td>
<td>1.56 (0.97–2.51)</td>
<td>1.02 (0.50–2.10)</td>
</tr>
</tbody>
</table>

NOTE. Adjusted ORs controlled for baseline confounder variables (age, education, ethnicity, marital status, concern about recurrence, cancer stage, health status, surgery, radiation therapy, systemic therapy, following doctors’ recommendations for tests, and Lerman Cancer Worry scale). OR, odds ratio; 95% CI, 95% confidence interval.

<table>
<thead>
<tr>
<th>Sources of cancer-related information seeking</th>
<th>Adherence to mammography (Once in the past 12 months vs. none)</th>
<th>Overuse of mammography (≥2 times in the past 12 months vs. none)</th>
<th>Overuse of mammography (≥2 times in the past 12 months vs. once)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nonmedical</td>
<td>Unadjusted RRR (95% CI)</td>
<td>0.90 (0.48–1.68)</td>
<td>Unadjusted RRR (95% CI)</td>
</tr>
<tr>
<td>Medical</td>
<td>Adjusted RRR (95% CI)</td>
<td>1.14 (0.38–3.45)</td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>0.70 (0.29–1.70)</td>
<td>0.40 (0.11–1.54)</td>
<td></td>
</tr>
</tbody>
</table>

NOTE. Adjusted RRRs controlled for baseline confounder variables (age, education, ethnicity, marital status, concern about recurrence, cancer stage, health status, surgery, radiation therapy, systemic therapy, following doctors’ recommendations for tests, and Lerman Cancer Worry scale). RRR, relative risk ratio; 95% CI, 95% confidence interval.
patients to follow their doctor’s recommendations for tests to monitor their disease at baseline. While this precludes a claim that information seeking produced a change in individual adherence to surveillance over time, this study compares favorably with previous observational research limited by cross-sectional data with all measures collected simultaneously.

The study was limited in terms of relying on self-reported engagement by patients with cancer information and receipt of cancer surveillance. Self-reported measures of these variables may be subject to recall or social desirability bias. Although self-reported adherence was not validated against administrative or medical records in this study, validation studies on screening mammography have found self-reported screening to be reasonably accurate (50–52). Because the information-seeking measures were not specific to patients actively searching for information about surveillance procedures, we were not able to perfectly match the behavior of interest (information seeking) to the outcomes of surveillance adherence. However, the information-seeking measures do provide valuable indications of overall information seeking by patients about various cancer topics (treatments, information related to cancer, quality-of-life issues, etc.), which routine surveillance is a component of. Furthermore, the items asked about information-seeking behaviors of patients in the first few months after diagnosis; this is a stressful time period for most patients and they may have difficulty recalling their information-seeking behaviors. In addition, despite the longitudinal analysis, the observational design is unable to prove a causal relationship between information seeking and adherence. As our study population was confined to patients from the Pennsylvania Cancer Registry, the inferences from this study may not generalize to breast cancer survivors in other geographic areas. Finally, we cannot know exactly if, or when, the study participants have ended their active treatment for breast cancer. For instance, some women may be undergoing hormonal therapy, which typically lasts for 5 years and would, therefore, be continuing with clinic visits and physical examinations as part of their treatment. In this analysis, we controlled for receipt of systemic therapy by patients to partially address the potential threat that ongoing hormonal therapy would confound the observed association between information engagement and adherence.

The clinical implications of the discovery that cancer-related information seeking is associated with regular BSE, a surveillance behavior that is not widely recommended for breast cancer survivors, remain unknown and deserve further research and discussion. In view of the findings from this research, a practice implication is how should clinicians communicate with their patients about information from nonmedical sources that may be overemphasizing the benefits of BSE or other surveillance procedures that are not widely recommended? More rigorous research on whether BSE influences meaningful outcomes, including early detection and survival, may be necessary before advocating (or discouraging) practice of BSE by patients for routine surveillance. Another implication for future research would be to assess whether other nonrecommended surveillance procedures that may entail higher costs or adverse effects (e.g., advanced imaging procedures such as positron emission tomography or computed tomography) are similarly associated with active information seeking from nonmedical sources. Forthcoming research from this team is addressing these specific research questions.

Disclosure of Potential Conflicts of Interest
No potential conflicts of interest were disclosed.

Authors’ Contributions
Conception and design: A.S.L. Tan, M. Moldovan-Johnson, S.W. Gray, R.C. Hornik, K. Armstrong
Development of methodology: A.S.L. Tan, S.W. Gray, R.C. Hornik, K. Armstrong
Acquisition of data (provided animals, acquired and managed patients, provided facilities, etc.): S.W. Gray, R.C. Hornik
Analysis and interpretation of data (e.g., statistical analysis, biostatistics, computational analysis): A.S.L. Tan, S.W. Gray, R.C. Hornik, K. Armstrong
Writing, review, and/or revision of the manuscript: A.S.L. Tan, M. Moldovan-Johnson, S.W. Gray, R.C. Hornik, K. Armstrong
Administrative, technical, or material support (i.e., reporting or organizing data, constructing databases): A.S.L. Tan, S.W. Gray
Study supervision: R.C. Hornik, K. Armstrong

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