Eighteen Sensations After Breast Cancer Surgery: A Two-Year Comparison of Sentinel Lymph Node Biopsy and Axillary Lymph Node Dissection

Roberta H. Baron, RN, MSN, AOCN®, Jane V. Fey, MPH, Patrick I. Borgen, MD, and Kimberly J. Van Zee, MS, MD

Purpose/Objectives: To evaluate the prevalence, severity, and level of distress of 18 sensations at baseline (3–15 days) and 24 months after breast cancer surgery and to compare sensations after sentinel lymph node biopsy (SLNB) with those after SLNB plus immediate or delayed axillary lymph node dissection (ALND).

Design: Prospective, descriptive.

Setting: Evelyn H. Lauder Ambulatory Breast Center at Memorial Sloan-Kettering Cancer Center in New York, NY.

Sample: 294 women with breast cancer; 214 had undergone breast conserving therapy, and 80 had undergone total mastectomy; 197 had had SLNB, and 97 had had SLNB and ALND.

Methods: Patients completed the Breast Sensation Assessment Scale© (BSAS©) at baseline and 3, 6, 12, and 24 months after surgery.

Main Research Variables: Prevalence, severity, and level of distress of sensations in patients who had undergone breast cancer surgery.

Findings: Sensations were less prevalent, severe, and distressing in patients undergoing SLNB than those undergoing ALND. This difference appeared to be limited to those undergoing breast conserving therapy. Most sensations after SLNB and ALND, even if prevalent, were not very severe or distressing. Some sensations persisted as long as two years. These included tenderness after SLNB and numbness after ALND. Patients often reported phantom sensations after total mastectomy.

Conclusions: Overall, prevalence, severity, and level of distress were lower after SLNB compared to ALND, but some morbidity existed after SLNB. Certain sensations remained prevalent in both groups for as long as 24 months.

Implications for Nursing: Nurses can use information from this study to provide more accurate education and support to patients.

Key Points . . .

➤ Overall, prevalence, severity, and level of distress of sensations are lower after sentinel lymph node biopsy (SLNB) compared to axillary lymph node dissection (ALND), but some morbidity exists after SLNB.

➤ The majority of sensations after SLNB and ALND, even if prevalent, are not very severe or distressing.

➤ Some sensations persist up to two years.

Patients with breast cancer frequently experience postoperative sensations in and around the axilla, breast, and chest wall of the affected side after breast cancer surgery. These sensations, at times, can be severe and distressing to patients, who often are experiencing general emotional upheaval. If not adequately prepared prior to surgery, patients can interpret postoperative sensations as an indication that something is wrong. This, in turn, adds uncertainty and anxiety to an already stressful event. Healthcare professionals should learn about these sensations and how they affect patients to provide adequate pre- and postoperative education and support.

Axillary lymph node dissection (ALND) traditionally has been the standard surgical procedure performed to determine a patient’s disease stage and treatment plan. Because injury or resection of specific nerves and lymphatic pathways in the operative field often occurs with ALND, this procedure is associated with considerable morbidity. Several studies have documented long-term morbidity, including numbness, pain, arm swelling, and decreased arm mobility (Kuehn et al., 2000; Warmuth et al., 1998). In eligible patients, sentinel lymph node biopsy (SLNB) has become an attractive alternative to ALND to stage the disease and is becoming the standard of care at many institutions. SLNB is the resection of the first lymph node or nodes (more than one sentinel node may exist) in the lymphatic basin that receives lymph flow from a primary tumor (Hill et al., 1999). Disruption of the axillary nerves and lymphatics is believed to be less with SLNB than with ALND. Therefore, postoperative sensations are expected to be less extensive and severe than those seen in patients after ALND. This hypothesis must be tested to ensure that patients have accurate information.
Literature Review

Few studies have been conducted to evaluate the morbidity associated with SLNB. In particular, to the best of the authors' knowledge, no studies have followed this phenomenon as long as two years after surgery.

Swenson et al. (2002) found that patients who had undergone SLNB (n = 169) had fewer side effects at 1, 6, and 12 months after surgery than those who had undergone ALND (n = 78). At 1 month, SLNB patients had less pain, numbness, and limitation in range of motion (ROM). At 6 months, they had less pain, numbness, and arm swelling. At 12 months, they had less numbness, arm swelling, and limitation in ROM.

Schrenk, Rieger, Shamiyeh, and Wayand (2000) evaluated patients 4–28 months after surgery and found a significantly higher rate of subjective lymphedema, pain, numbness, and decreased arm mobility in patients after ALND (n = 35) compared with SLNB (n = 35). Patients in the study also had significant increases in upper arm and forearm circumferences of the operated arm after ALND. No difference between the two groups was evident with regard to arm stiffness or strength.

In a retrospective study, Haid et al. (2002) found that patients who had undergone ALND (n = 140) had significantly more pain, numbness, swelling, and limited ROM compared with those who had undergone SLNB (n = 57). Burak et al. (2002) interviewed 48 patients who had undergone ALND and 48 who had undergone SLNB 8–29 months after surgery. ALND patients had significantly more subjective arm complaints, arm numbness, and swelling of the midbicep and antecubital fossa. These studies all contributed important information; however, several were retrospective, had a small sample size, used variable time points after surgery, or used no reliable instrument.

Little is known about patient perceptions of sensory changes after breast cancer surgery. Several years ago, the authors initiated a long-term investigation of the prevalence, severity, and level of distress of 18 sensations in a large population of women undergoing SLNB or SLNB in conjunction with ALND at baseline (3–15 days), 3 (±1) months, 6 (±1) months, 12 (±2) months, and 24 (±3) months after breast cancer surgery. Previous publications have reported the results through 6 months (Baron et al., 2002) and 12 months (Temple et al., 2002). The present article provides follow-up through the 24-month period.

Patients who had undergone SLNB as their only axillary procedure were compared with patients who had undergone SLNB with immediate or delayed ALND (usually indicated if the sentinel node is positive for malignancy). The conceptual framework for this study was based on the University of California, San Francisco, Model of Symptom Management (University of California, San Francisco, School of Nursing Symptom Management Faculty Group, 1994). The premise of this model is that careful symptom assessment is a prerequisite for effective symptom management.

Methods

Sample and Setting

The sample population for the 24-month study was comprised of 294 individuals who met all initial eligibility criteria and completed the questionnaire at all five time points. Researchers recruited patients between November 1999 and November 2000 at the Evelyn H. Lauder Ambulatory Breast Center at Memorial Sloan-Kettering Cancer Center in New York, NY. Eligible patients included those who

- Had undergone SLNB with breast conserving therapy
- Had undergone SLNB with total mastectomy (with or without immediate reconstruction)
- Had had any of the above two surgeries followed by immediate or delayed ALND
- Were at least 18 years old.

Patients were excluded if they had undergone breast conserving therapy or total mastectomy without SLNB. To avoid variables that may have confounded patient responses, patients also were excluded if they had no cancer found or had undergone surgery for prior breast cancer, bilateral breast surgery, or preoperative chemotherapy.

Instrument

Researchers measured sensations using the Breast Sensation Assessment Scale© (BSAS©) (Baron et al., 2002). The BSAS was used to measure the prevalence (presence or absence) of 18 sensations. If a sensation was present, Likert-type scales were used to rate the severity (1 = slight, 2 = moderate, 3 = severe, and 4 = very severe) and level of distress (0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, and 4 = very much) that the sensation caused. An additional question measured the prevalence of phantom sensations in patients after total mastectomy. The BSAS has been demonstrated to have good internal consistency, test-retest reliability, and validity (Baron et al., 2000, 2002; Temple et al., 2002).

Procedure

After institutional review board approval, a full-time research assistant identified eligible patients and recruited them in person during the initial postoperative visit (3–15 days after surgery). After providing an explanation of the study and obtaining written informed consent, the research assistant gave the BSAS to each patient and explained how to complete it. Patients completed the instrument during the initial visit. The research assistant then reviewed the instrument in person with each patient to ensure accuracy and completeness. Each patient also completed a form requesting demographic information, type and side of surgery, type of reconstruction (if applicable), and side of her dominant hand. The research assistant reviewed the medical records and completed a form documenting stage of disease and number and status (positive or negative) of nodes removed.

Subsequent questionnaires were mailed to patients at 2, 5, 10, and 21 months after surgery, along with a form to ascertain treatment information (e.g., chemotherapy, radiation) and status of breast reconstruction, if applicable. If the questionnaire was not returned a month after it was mailed, the research assistant made a reminder phone call. The questionnaire then had to be returned within one to three months (depending on the time period) or researchers considered the data for the time period ineligible. If the reminder call elicited no response, the research assistant asked the patient at her next appointment if she wished to continue in the study. The research assistant contacted patients by telephone as many as five times to obtain missing data. In the end, less than 1% of the items on the mailed questionnaires remained unanswered.

Patients who required delayed ALND because of the identification of a positive SLNB completed a second baseline questionnaire 3–15 days after the second surgical procedure. Researchers removed the results of their first questionnaire from
data analysis. The date of the second surgical procedure served as the new baseline date for completion of future questionnaires.

**Statistical Analysis**

Given the number of sensations measured and multiple time points involved, all analyses were considered to be significant only if the value was less than 0.01. Statistical software SPSS® 10 for Windows (SPSS Inc., Chicago, IL) and StatXact 5 (Cytel Software Inc., Cambridge, MA) were used for all statistical analyses. Fisher’s exact test was used to compare the proportion of each group (SLNB versus ALND) reporting individual sensations and high levels of severity and distress at different time points. Student t tests and Wilcoxon rank-sum tests were used to determine age differences between the SLNB and ALND groups.

**Results**

**Sample**

Of the 399 patients initially enrolled in the study, 294 completed the questionnaires at all five time points and met all study criteria throughout the study (a final completion rate of 74%). Overall, 364 patients completed the 3-month questionnaire, 344 completed the 6-month questionnaire, 334 completed the 12-month questionnaire, and 312 completed the 24-month questionnaire. Eighteen patients who completed the questionnaire at all time points were deemed ineligible for data analyses for reasons that included late data and additional breast surgery during the 24-month study period.

Table 1 shows the clinical and demographic characteristics of the study population. Twice as many patients who had undergone SLNB compared with ALND. Significantly more patients who had SLNB without ALND underwent breast conserving therapy and had early-stage breast cancer. Accepted medical practice for patients with breast cancer includes ALND for those with axillary nodal metastases. Because breast cancer staging is defined by tumor size and status of the axillary nodes, by definition, the ALND population is overwhelmingly stage II, and the SLNB population is overwhelmingly stage I (or 0). Similarly, breast conserving therapy more often is a surgical option in those with smaller primary tumors, and smaller primary tumors have axillary metastases less frequently. Therefore, breast conserving therapy cases are more likely to receive only SLNB. By the very definition of the patient populations (ALND and SLNB), the type of surgery and stage of disease are often different for the two populations.

The majority of patients in both groups were married, Caucasian, and well educated (i.e., postsecondary education). Patients who had undergone SLNB were significantly older than those who had undergone ALND (p < 0.01).

**Sensations**

Table 2 compares the prevalence, severity, and associated level of distress of sensations after SLNB and ALND for the total population at baseline and 24 months. Overall prevalence of sensations was determined using percentages of patients reporting the sensation as “present.” The severity of each sensation and the level of distress that it caused were determined using the percentages of patients reporting the sensation as “severe” or “very severe” and as causing “quite a bit” or “very much” distress; p values were recorded only for significant differences (p < 0.01).

The most prevalent sensation in both groups at baseline was tenderness. Surprisingly, 24 months later, more than 40% of the population still experienced tenderness, and it remained the most prevalent sensation in patients after SLNB. Also, 36% of SLNB patients still reported soreness and 37% reported twinges at 24 months. Soreness and tenderness were the most severe and distressing sensations for SLNB patients at baseline, but the percentage dropped off noticeably at 24 months.

Patients who had undergone ALND experienced significantly more tightness, numbness, pain, and stiffness at baseline than those who had undergone SLNB. Tightness and numbness remained significantly more prevalent at 24 months, as did pulling and tingling.

Overall, for both groups, the percentages of patients reporting severity and distress were small when compared with those reporting prevalence. Numbness was the most severe sensation in ALND patients at baseline (described by 40% of patients) and remained so (in 20%) 24 months later. It was also the most distressing of the sensations at 24 months.

Figure 1 shows the trend over all five time points for the three most prevalent baseline sensations in patients who had SLNB only and compares them with trends for the same sensations after ALND. Although tenderness, soreness, and pulling persisted even until 24 months, the biggest drop in prevalence was between baseline and 3 months in both groups. A similar drop in severity (see Figure 2) and level of distress (see Figure 3) of sensations also was seen between baseline and 3 months. Overall, the severity and level of distress of sensations were greater after ALND compared to SLNB, particularly at baseline. Also of interest to note is that, across time points, the prevalence of tenderness was slightly higher in SLNB patients than in their ALND counterparts.

To explore the influence of the type of breast surgery on sensations, the researchers separated the populations into breast conserving therapy and total mastectomy. They then compared the prevalence rates of sensations in SLNB and ALND for the breast conserving therapy population (see Figure 4) and the total mastectomy population (see Figure 5) at baseline and 24 months.

The overall trend in prevalent sensations for the breast conserving therapy population was similar to that of the total

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<th>Table 1. Characteristics of the Patient Sample</th>
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ALND—axillary lymph node dissection; SLNB—sentinel lymph node biopsy
population (see Table 2). Tenderness was the most prevalent sensation in both groups at baseline and remained so in the SLNB group at 24 months. Several sensations both at baseline and 24 months were significantly more prevalent in the ALND patients. Even if not significant, most of the sensations were reported more often in the patients who had undergone ALND.

In the total mastectomy population, tenderness was the most prevalent sensation in both groups at baseline but was surpassed by tightness at 24 months. The only sensation that was significantly more prevalent after SLNB than ALND in this group at baseline was stiffness. Most of the other sensations, although not significant, were reported with greater frequency in the SLNB population, particularly at baseline.

The researchers examined the incidence of phantom sensations in the patients who had undergone total mastectomy. Table 3 shows the percentage of patients who reported a feeling that the breast or nipple still was present. For those who experienced phantom sensations, the severity and level of distress that they caused were determined using the numbers of patients reporting the sensation as “severe” or “very severe” and as causing “quite a bit” or “very much” distress. Also reported was the number of patients who experienced phantom sensations for the first time at each time point.

A total of 77 patients completed information about phantom sensations. Although the percentages among the time points did not vary greatly, each time point did not include the same patients in every case. Some patients experienced phantom sensations at baseline only, whereas others developed them for the first time at 3, 6, 12, or even 24 months. Forty-three (56%) of the 77 patients reported phantom sensations during at least one time period. Eighteen patients reported that the sensations “came and went” and were experienced at nonconsecutive time intervals. Overall, the levels of severity and distress were low.

Figure 1. Prevalence at All Time Points of Three Reported Baseline Sensations
The effect of age on the prevalence of sensations in the total population also was examined. Women aged 50 or younger reported significantly more sensations at both baseline and 24 months than did women older than 50. Younger women reported significantly more severe sensations at baseline only, and no difference was found between the two groups in terms of level of distress at either time point (see Table 4).

Discussion

Results demonstrate that in the total study population, most sensations are less prevalent, severe, and distressing after SLNB compared to ALND in the initial period following surgery and throughout the first 24 months. However, some morbidity is associated with SLNB even two years after surgery. Patients who had undergone SLNB consistently reported tenderness as the most prevalent sensation throughout all time points. Several other sensations remained highly prevalent as well. These findings suggest that SLNB often requires a significant dissection, which, surprisingly, was reported more by those who had undergone SLNB. The authors propose several hypotheses for these findings. Perhaps because total mastectomy is a more invasive procedure than breast conserving therapy, it may be associated with more discomfort or numbness around the area, thus masking any differences that would be seen between SLNB and ALND. Rowland et al. (2000) found that patients who underwent total mastectomy experienced more physical symptoms and more discomfort around the surgical site, including the sensation of “pins and needles” and numbness, than did patients who underwent breast conserving therapy. In addition, patients who undergo total mastectomy often have more advanced disease than those who undergo breast conserving therapy; perhaps these patients are more worried about prognosis and may not be focusing on the sensations they are experiencing. This area warrants further study.

In the current study, the incidence of phantom sensations remained fairly constant throughout the first 12 months and dropped off minimally at 24 months. A higher percentage of the patient population reported phantom sensations than in a study by Kroner, Knudsen, Lundby, and Hvid (1992). Kroner et al. reported that the incidence of phantom sensations was 26% three weeks after surgery (n = 120), 25% one year after surgery (n = 110), and 26% six years later (n = 69). In both studies, not only did phantom sensations persist over time, but patients developed them at variable time points, including more than a year after surgery.

The authors arbitrarily divided the population into two age groups: those 50 or younger and those older than 50. Overall, few studies have assessed the impact of breast conserving therapy and total mastectomy on the prevalence of sensations in regard to SLNB compared with ALND. Swenson et al. (2002) reported that the advantage of SLNB over ALND was independent of whether women had undergone breast conserving therapy or total mastectomy. The current study showed that with breast conserving therapy, certain sensations were significantly more prevalent after ALND than after SLNB. With total mastectomy, no significant differences were found between SLNB and ALND groups in terms of any sensation except stiffness, which, surprisingly, was reported more by those who had undergone SLNB. The authors propose several hypotheses for these findings. Perhaps because total mastectomy is a more invasive procedure than breast conserving therapy, it may be associated with more discomfort or numbness around the area, thus masking any differences that would be seen between SLNB and ALND. Rowland et al. (2000) found that patients who underwent total mastectomy experienced more physical symptoms and more discomfort around the surgical site, including the sensation of “pins and needles” and numbness, than did patients who underwent breast conserving therapy. In addition, patients who undergo total mastectomy often have more advanced disease than those who undergo breast conserving therapy; perhaps these patients are more worried about prognosis and may not be focusing on the sensations they are experiencing. This area warrants further study.

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The authors arbitrarily divided the population into two age groups: those 50 or younger and those older than 50. Overall,
younger women reported more sensations at both baseline and 24 months compared with older women. Similar results have been found in other studies (Swenson et al., 2002; Temple et al., 2002; Warmuth et al., 1998). The reason for this is not clear, but perhaps younger women are more active, are more sensitive to changes in their bodies, or have not yet developed as high a threshold of pain. Although the sensations were more prevalent in younger women, few sensations were re-reported as severe, and no difference existed in the level of distress between the two age groups.

To the best of the authors’ knowledge, this is the first study to use a psychometrically validated instrument to evaluate sensations after axillary surgery with follow-up 24 months after surgery. Other researchers mainly evaluated pain, numbness, swelling, and ROM; however, the BSAS includes 18 different descriptors to help clinicians pinpoint what a patient is feeling. The current study showed that at baseline, significantly more pain occurred after ALND compared to SLNB. This finding concurs with other studies that compared SLNB and ALND (Haid et al., 2002; Schrenk et al., 2000; Swenson et al., 2002). By providing a variety of descriptors, the researchers were able to ascertain that, although the most prevalent sensation reported by SLNB patients was not pain, the patients did report a high percentage of tenderness and soreness, both of which are pain-like sensations. This knowledge takes on special importance when educating patients about what to expect. Receiving this information will help patients differentiate between what is considered normal and what may be a potential problem after surgery.

**Limitations**

Potential confounding variables included patients’ stage of disease, type of surgical procedure, and emotional status. By definition, the treatment groups differed from each other: The majority of SLNB patients had early-stage breast cancer and
underwent breast conserving therapy, whereas this was not the case in the ALND group. Therefore, patients with more advanced disease may have been more concerned about their prognosis and minimized the sensations they were feeling, whereas patients with early-stage breast cancer may have been more attuned to sensory morbidity. Patients also were not asked to complete any instruments related to mood or quality of life; therefore, the researchers could not assess whether any additional factors were partially responsible for the differences between groups. Patients were not asked to identify the exact location of the sensations they were feeling (i.e., breast or chest wall, axilla, upper-inner arm). In the pilot study (Baron et al., 2000), the researchers asked this question, and patients reported that this detail was time-consuming and difficult to specify. This information would have helped the researchers to better explain the findings when they stratified the samples.

The researchers did not objectively measure the sensory and mobility deficits reported by patients, nor did they keep a record of the integrity of the intercostal brachial nerve after the surgical procedure. Although this information might have helped to explain some of the morbidity reported in patients, the focus was on patient perceptions of sensory changes and the distress experienced as a result of the perceptions. Finally, the patient population consisted predominately of Caucasian, married, and educated women, thus limiting generalization to all demographic groups.

**Implications for Nursing**

The findings from this study provide valuable information for nurses to use when educating their patients both pre- and postoperatively. The following points, based on the results of the research, should be kept in mind when planning patient education.

- Although overall prevalence, severity, and level of distress of sensations are lower in patients who have undergone...
SLNB compared with ALND, some sensory morbidity does exist with SLNB. The difference appears limited to those undergoing breast conserving surgery.

- Common sensations after SLNB include tenderness and soreness. Tenderness, tightness, and numbness are common with ALND.
- The majority of sensations with SLNB and ALND, even if prevalent, are not very severe or distressing.
- The most noticeable improvement in prevalence, severity, and distress of sensations occurs during the first three months. Some sensations, however, may persist for as long as two years.
- Phantom breast and nipple sensations may be reported by as many as 50% of patients at some time point after total mastectomy. They may begin immediately after surgery and persist over a long period of time (e.g., two years), they may come and go, or, in some cases, they may be felt for the first time as long as two years after surgery.
- Sensations are more prevalent in younger women than in older women.

Providing information to patients about sensations can help them to understand what is considered a normal and expected part of the healing process, alleviate unnecessary anxiety and distress, and avoid misconceptions. Nurses can use the BSAS as an evaluation tool in their own practices.

### Conclusions

To the best of the authors’ knowledge, this is the first large, prospective study over a two-year time period that used a validated instrument to systematically evaluate patients undergoing SLNB and ALND. Nurses can use the information from this study to provide more accurate education and support to patients, with the goal of minimizing their distress and making their experience more positive.

**Author Contact:** Roberta H. Baron, RN, MSN, AOCN®, can be reached at baronr@mskcc.org, with copy to editor at rose_mary@earthlink.net.

### References


