

# Factors That Affect Intention to Avoid Strenuous Arm Activity After Breast Cancer Surgery

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**L**ymphedema is feared by many women after breast cancer surgery (Collins, Nash, Round, & Newman, 2004). Generally chronic and incurable, lymphedema is characterized by swelling and symptoms of discomfort, pain, and heaviness in the upper limb, affecting normal functional use of the arm (Armer, Fu, Wainstock, Zagar, & Jacobs, 2004; Baron et al., 2002; Ridner, 2005; Schrenk, Rieger, Shamiyeh, & Wayand, 2000). The visibility of the swollen arm also adversely affects body image and may cause psychological distress, anxiety, and poor self-esteem for breast cancer survivors (Greenslade & House, 2006; Tobin, Lacey, Meyer, & Mortimer, 1993). Together, these symptoms greatly reduce quality of life (Ridner, 2005).

It makes sense that women would fear lymphedema and want to protect their arms from known risk factors, such as skin infection (Soran et al., 2006). However, why some women consider strenuous forms of arm activity a risk factor for lymphedema is unknown (Karki, Simonen, Malkia, & Selfe, 2004), particularly when the evidence shows no association between the two (Ahmed, Thomas, Yee, & Schmitz, 2006; Kilbreath, Refshauge, Beith, & Lee, 2006; McKenzie & Kalda, 2003) and actually supports the use of resisted arm exercise to aid recovery (Ahmed et al.; Kilbreath et al.; McKenzie & Kalda). In fact, evidence suggests that arm exercises may reduce the risk of lymphedema as a result of enhanced lymphatic return and regeneration of secondary lymphatic channels (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002; Johansson, Tibe, Weibull, & Newton, 2005; Lane, Dolan, Worsley, & McKenzie, 2007; Moseley, Piller, & Carati, 2005). Conversely, failure to exercise and inactivity of the affected arm may result in poor lymphatic clearance and stasis of the lymphatic system in the affected arm (Trettin, 1992). Considering that pain and shoulder restriction are more prevalent than lymphedema 6–12 months after surgery (Thomas-Maclean et al., 2008), prevention through exercise and activity is recommended. In

**Purpose/Objectives:** To explore the factors that contribute to women's intention to avoid strenuous arm activity after breast cancer surgery.

**Design:** Cross-sectional survey.

**Setting:** Three hospitals located in eastern Australia.

**Sample:** 175 patients with breast cancer.

**Methods:** A survey, based on Protection Motivation Theory, was used to assess whether treatment variables, demographic variables, arm advice, fear, or coping attributes predicted women's intentions to avoid strenuous arm activity.

**Main Research Variables:** Intention to avoid strenuous arm activity, presence of arm or chest symptoms, receipt of arm care advice, and fear of lymphedema.

**Findings:** Seventy percent of participants reported an intention to avoid strenuous activity with their affected arm and reported more arm and chest symptoms than participants who did not avoid strenuous arm activity. Women who perceived that they were vulnerable to lymphedema and women who received advice about arm care were more likely to avoid strenuous arm activity.

**Conclusions:** Fear of lymphedema and receipt of arm care advice motivated women's intention to avoid strenuous arm activity.

**Implications for Nursing:** Information about lymphedema distributed to patients by healthcare professionals should be updated to reflect evidence and address the risk of developing lymphedema relevant to the patients' surgery.

particular, strenuous arm exercises against resistance are necessary for recovery of arm strength and may even counteract the effects of bone mineral loss caused by adjuvant therapy for breast cancer (Cheema, Gaul, Lane, & Fiatarone Singh, 2008). Avoidance of such activity may result in prolonged arm weakness, scapula-humeral dysfunction, osteopenia, and, potentially, lymphedema (Cheema et al.).

Protection Motivation Theory (PMT) (Rogers, 1983) is a social cognition model chosen for this study to explore why some women intend to avoid strenuous

activities with their affected arm 6–15 months after breast cancer treatment. Intention represents the motivating factors behind the adoption of behavior and has been shown to correlate with actual behavior in other health-related studies using this theory (Milne, Sheeran, & Orbell, 2000). PMT proposes that the intention to protect oneself depends on four factors: perceived vulnerability of the individual to the health risk, perceived severity of a health risk, perceived efficacy of the preventive behavior (response efficacy), and perceived self-efficacy (i.e., level of confidence by an individual to perform such behavior). The factors can be grouped into two components: perceived threat and perceived coping. Perceived threat refers to the extent to which people perceive they are vulnerable to a health risk and their perception of the severity of the health risk. Perceived coping refers to the extent to which people feel that a particular behavior will protect them from the health risk (response efficacy) and whether they feel they are able to perform such behavior (self-efficacy). The combination of threat and coping influences intention, which is posited to influence behavior.

The potential consequences of arm inactivity after breast cancer treatment are unfavorable for breast cancer survivors. Why women continue to avoid strenuous arm activity despite evidence showing no association between this type of activity and lymphedema is unknown; therefore, the primary aim of this study was to explore factors that contribute to women's intention to avoid strenuous arm activity after breast cancer surgery. The secondary aims were to identify the prevalence and the severity of self-reported arm and chest symptoms in the participants at the time of survey administration.

## Methods

### Participants

Ethical approval was obtained from the institution's human ethics committee. The aim was to detect a difference in women's intention to avoid strenuous activities with the affected arm. A sample size of 170 was determined prior to study commencement to ensure sufficient power to detect a 25% (95% confidence interval [CI] 0.1–0.4) difference in intention, allowing for 10% missing data. Women were eligible to enter the study if they had surgery for breast cancer 6–15 months previously, had no recurrence since surgery, and could read and comprehend English. This time interval was selected because women were likely to have completed adjuvant treatment and resumed normal arm function and employment following the breast cancer treatment. Recruitment sites included two metropolitan public hospitals and one private

suburban hospital in Sydney, Australia, ensuring a mix of public and private patients. Participants were asked to complete the survey in the waiting room of their doctors' clinics because they were likely to have ample time to devote to the survey prior to or following their appointment with their doctor. A researcher was present and available to provide clarification if required by the participant. The majority of patients completed the survey independently. The few patients who required the researcher's help were offered the use of a treatment room for discussion. No identifying information was recorded about participants. If participants did not complete the survey in the waiting room, a postage-paid envelope was provided.

### Instrument

The development of this survey has been previously described (Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2007). A pilot survey was tested on seven patients who had been treated for breast cancer. Revisions to the survey were made based on their responses and tested on three additional patients. Face validity of the questions and inter-item reliability were checked by the authors. Questions were altered to ensure that the final survey was interpreted accurately by the participants and was feasible in application. The entire survey can be viewed at [www.fhs.usyd.edu.au/phy/pdf/post\\_bc\\_survey8.pdf](http://www.fhs.usyd.edu.au/phy/pdf/post_bc_survey8.pdf).

The survey included questions relating to the following areas.

- Demographic characteristics (employment, education, age, ethnicity, postcode, weight, and height)
- Information about the cancer and treatment received (affected side, time since surgery, size of tumor, cancer surgery, axillary surgery, reconstructive surgery, radiotherapy, and chemotherapy)
- Arm or chest symptoms (discomfort, pain, pins and needles, numbness, movement restriction, stiffness, arm weakness, swelling, arm heaviness, and previous symptoms)
- Arm function (single arm or hand activities if affected arm dominant and bimanual activities)
- Arm care and exercise advice, including advice received from clinicians, allied health, nursing, brochures, and the Internet
- Fear of developing lymphedema, arm protection, and intention to avoid arm activities, including strenuous arm activities
- Fear of musculoskeletal symptoms, strenuous activity, or exercise, and intention to perform strenuous arm exercise

For questions related to perceptions and intentions, participants expressed their agreement with a statement (e.g., "The possibility of developing or worsening arm swelling worries me.") using a five-point Likert scale

ranging from 1 (strongly agree) to 5 (strongly disagree). Women's intentions to avoid strenuous arm activity were measured by the statement, "I plan to avoid any strenuous arm activities." Participants responded to this item using the Likert scale.

## Data Analysis

A series of independent tests were conducted to determine if any significant differences existed in demographic and treatment variables between women who avoided strenuous activities with their affected arm and women who did not for use in the subsequent regression analysis. Chi-square tests were conducted for nominal data (age, occupation, education, ethnicity, affected arm dominant, size of tumor, type of breast surgery, extent of axillary surgery, reconstructive surgery, chemotherapy, radiotherapy, receipt of arm care advice, and none or mild and moderate or severe symptoms) and independent sample *t* tests were conducted for continuous data (body mass index [BMI], time since surgery, and perceptions). Similarly, a series of independent tests were performed to determine whether any significant differences existed between women who reported arm or chest swelling and women who did not. To control for type I errors generated by multiple tests, the significance level was reduced by dividing  $p < 0.05$  by the number of tests performed according to the Bonferroni method (Abdi, 2007) ( $p < 0.05/5 = 0.01$  for demographic variables,  $p < 0.05/9 = 0.01$  for cancer and treatment variables,  $p < 0.05/3 = 0.02$  for perception variables). Cases with more than 5% missing data for the questions related to fear of developing lymphedema and intention to avoid strenuous arm activities ( $n = 14$ ) were excluded from analysis. Variables that significantly differentiated women who intended to avoid strenuous arm activities from women who did not were entered into a sequential logistic regression to determine the independent predictors of intention to avoid strenuous arm activity. Tests for collinearity were performed to ensure that predictor variables were not highly correlated.

Factor analysis was used to summarize women's fears of developing lymphedema. As PMT assumes a strong relationship between some of the constructs, oblique rotation specifically designed to maximize the correlation among factors was selected to extract factors (Tabachnick & Fidell, 2007). Factors with Eigen values greater than one were examined. Consistent with the methods described by Tabachnick and Fidell, each factor was analyzed if it consisted of two or more items with factor loadings of 0.5 or higher. The internal consistency of factors was examined using Cronbach  $\alpha$ . Factors with Cronbach  $\alpha = 0.6$ – $0.9$  were considered to have acceptable reliability (Kaiser, 1974), and a summed factor score was created for each of the

factors. All factors were linearly transformed to a 10-point scale.

## Results

### Subjects

In total, 175 of 180 surveys (97%) were returned. All surveys distributed in the waiting room were returned to the researchers ( $n = 114$ ), and 92% of surveys distributed through the mail ( $n = 61$ ) were returned. The majority (91%) of participants were from metropolitan Sydney, with a minority (9%) from nonmetropolitan regions of New South Wales, Australia. Most frequently, participants identified themselves as being from Australia or New Zealand, aged 50–59 years, employed either as a professional or not working, and had a college education (see Table 1). Mean ( $\pm$  standard deviation [SD]) time since surgery was  $10.3 \pm 2.9$  months, and mean BMI ( $\pm$  SD) was  $25.4 \pm 4.6$  kg/m<sup>2</sup>. Most women had tumors that were less than 5 cm (73%) and had undergone lumpectomies (53%) or mastectomies (45%) followed by chemotherapy (64%) and radiotherapy (71%). Fifty-two percent of the participants underwent sentinel lymph node biopsy (SLNB), and the remainder underwent axillary lymph node dissection (ALND) (37%) or no axillary surgery (8%).

### Intention to Avoid Strenuous Arm Activity

Of the participants, 112 (70%) were classified as intending to avoid strenuous arm activity. Five women (3%) had arm or chest symptoms prior to breast cancer surgery. The variables discriminating these women from those not intending to avoid strenuous arm activity were the extent of axillary surgery, receipt of arm care advice, perceived vulnerability, and perceived coping ability (see Table 2). The majority of patients received information from a combination of sources, including nurses, physiotherapists, occupational therapists, doctors, brochures, and the Internet. The authors were unable to explore the exact source(s) of specific items of advice. The groups did not differ in age, BMI, occupation, education, ethnicity, dominance of affected arm, type of cancer surgery, size of tumor, reconstructive surgery, time since surgery, chemotherapy, radiotherapy, and perceived severity of lymphedema. Ninety-one percent of women who intended to avoid strenuous arm activity and 80% of women who did not reported at least one arm or chest symptom, and intensity ranged from mild to severe (see Figure 1). Overall, the prevalence of moderate to severe symptoms of arm or chest discomfort, movement restriction, stiffness, swelling, and heaviness was significantly higher in women who intended to avoid strenuous arm activity than in women who did not.

**Table 1. Demographic and Treatment Characteristics**

| Characteristic                       | $\bar{X}$ | SD   |
|--------------------------------------|-----------|------|
| Body mass index (kg/m <sup>2</sup> ) | 25.37     | 4.64 |
| Time since surgery (months)          | 10.31     | 2.96 |
| Characteristic                       | n         | %    |
| <b>Age (years)</b>                   |           |      |
| 30–39                                | 18        | 10   |
| 40–49                                | 45        | 26   |
| 50–59                                | 57        | 33   |
| 60–69                                | 36        | 21   |
| 70 and older                         | 16        | 9    |
| Missing                              | 3         | 2    |
| <b>Treatment site</b>                |           |      |
| Suburban private hospital            | 63        | 36   |
| Metropolitan public hospital 2       | 58        | 33   |
| Metropolitan public hospital 1       | 54        | 31   |
| <b>Occupation</b>                    |           |      |
| Professional                         | 66        | 38   |
| Not working                          | 64        | 37   |
| Clerical and service                 | 30        | 17   |
| Trade and labor                      | 9         | 5    |
| Other                                | 6         | 3    |
| <b>Education</b>                     |           |      |
| Below primary school                 | 11        | 6    |
| High school                          | 50        | 29   |
| College                              | 106       | 61   |
| Other or missing                     | 8         | 4    |
| <b>Ethnicity</b>                     |           |      |
| Australian or New Zealander          | 128       | 73   |
| Asian or Middle Eastern              | 22        | 13   |
| European                             | 16        | 9    |
| Other or missing                     | 9         | 5    |
| <b>Affected arm dominant</b>         |           |      |
| Yes                                  | 89        | 51   |
| No                                   | 82        | 47   |
| Missing                              | 4         | 2    |
| <b>Size of tumor</b>                 |           |      |
| Less than 2 cm                       | 61        | 35   |
| 2–5 cm                               | 67        | 38   |
| More than 5 cm                       | 16        | 9    |
| Do not know                          | 27        | 15   |
| Missing                              | 4         | 2    |
| <b>Type of surgery</b>               |           |      |
| Lumpectomy                           | 92        | 53   |
| Mastectomy                           | 79        | 45   |
| Other                                | 2         | 1    |
| Unknown or missing                   | 2         | 1    |
| <b>Type of axillary surgery</b>      |           |      |
| Sentinel lymph node biopsy           | 92        | 53   |
| Axillary lymph node dissection       | 66        | 38   |
| No surgery                           | 14        | 8    |
| Unknown                              | 3         | 1    |
| <b>Reconstructive surgery</b>        |           |      |
| No                                   | 154       | 88   |
| Yes                                  | 18        | 10   |
| Do not know or missing               | 3         | 1    |
| <b>Chemotherapy</b>                  |           |      |
| Yes                                  | 112       | 64   |
| No                                   | 63        | 36   |
| <b>Radiotherapy</b>                  |           |      |
| Yes                                  | 124       | 71   |
| No                                   | 51        | 29   |

N = 175

Note. Because of rounding, not all percentages total 100.

Specifically, women who reported arm or chest swelling were more likely to have undergone mastectomy (odds ratio [OR] = 3.64, 95% CI 1.81–7.29,  $p = 0$ ), ALND (OR = 2.42, 95% CI 1.2–4.87,  $p = 0.01$ ), and have higher mean BMI ( $\bar{X} \pm SE = 26.3 \pm 0.45$ ,  $\bar{X}$  difference =  $1.6 \pm 0.8$ ,  $p = 0.048$ ), compared to women who reported no arm or chest swelling.

### Fear of Developing Lymphedema and Coping Ability

Three factors explained 46% of the variance in the 18 items that were based on fear of developing lymphedema (see Table 3). The items, factor loadings, and Cronbach  $\alpha$  for these factors are presented in Table 4.

**Perceived vulnerability to lymphedema:** The five items included in this factor referred to women's fears of developing lymphedema and included items related to feelings about their perceived risk of developing lymphedema (Cronbach  $\alpha = 0.844$ ). This factor also assessed the extent to which women worried about developing lymphedema and whether women felt that others who have had the same breast cancer treatment as the participant also were vulnerable to developing lymphedema.

**Perceived severity of lymphedema:** The four items included in this factor referred to women's perceptions about the physical and psychological consequences of having lymphedema and included items about appearance, perceived suffering, and affects on lifestyle (Cronbach  $\alpha = 0.714$ ).

**Perceived coping ability:** The four items included in this factor referred to women's perceptions of the extent to which they could use their affected arm (Cronbach  $\alpha = 0.725$ ). This included items about women's perceived ability to carry out avoidance behaviors and their perception about the effectiveness of avoiding strenuous arm activity. Women's perceptions of the advice they were given from their healthcare professionals also were included.

The three factors are generally consistent with the concepts of PMT. Factor analysis identified two components of fear: perceived vulnerability to lymphedema and perceived severity of lymphedema. PMT describes perceived coping as reflecting perceived response and self-efficacy, but these did not emerge as independent components in the factor analysis.

### Variables Associated With Intention to Avoid Strenuous Arm Activities

Variables that were potentially associated with the women's intention to avoid strenuous activities with the affected arm were entered into a logistic regression in three steps: extent of axillary surgery, receipt of arm care advice, and perceived vulnerability to lymphedema and perceived coping ability. Variables were entered in

this order based on the assumption that treatment factors occurred first, followed by the advice received by women, and it was the combination of the two elements that were likely to affect perceptions about arm use.

The extent of axillary surgery alone accounted for 96% of women who intended to avoid strenuous activities but only accounted for 17% of women who did not avoid strenuous activities with their arm. Women who underwent SLNB were more likely to avoid strenuous arm activity (OR = 3.47, 95% CI 0.962–12.49,  $p = 0.062$ ) than women who did not have axillary surgery, and women who underwent ALND were more likely to avoid strenuous arm activity (OR = 3.12, 95% CI 1.385–7.008,  $p = 0.005$ ) than women who underwent SLNB. The addition of arm care advice improved the predictive accuracy to 40% for women who did not intend to avoid strenuous arm activity, but reduced accuracy to 89% for women who intended to avoid strenuous arm activity. Addition of perceived vulnerability and coping ability created the most accurate model overall, correctly predicting 60% of women who did not intend to avoid strenuous arm activity and 91% of women who intended to avoid strenuous arm activity.

Receipt of arm care advice, perceived vulnerability to lymphedema, and perceived coping ability were significant predictors of the intention to avoid strenuous arm activity (see Table 5). Women who received any arm care advice were about five times more likely to avoid strenuous arm activity. Only 23% of women who received arm care advice after surgery perceived that their healthcare professional approved of strenuous arm exercises to strengthen their arm. For every 1-point increase on the 10-point perceived lymphedema vulnerability factor score, women were 1.59 times more likely to avoid strenuous arm activity. For every 1-point increase on the 10-point perceived coping ability score, women were half as likely to avoid strenuous arm activity.

Women who completed the survey at home using the mail option did not have immediate onsite assistance from the researcher compared to women who completed the survey in the waiting room. Analysis of the results indicated no significant difference in the primary outcome of intention to avoid strenuous arm activity and the secondary outcomes of arm and chest symptoms between mail and waiting room participants. The authors also analyzed participants' cancer and treatment details and no difference was found between mail and waiting room participants.

## Discussion

Some women are unable to participate in strenuous arm activity in the immediate postoperative period as a result of pain, scar formation, and swelling. However, 6–15 months following breast cancer surgery usually is

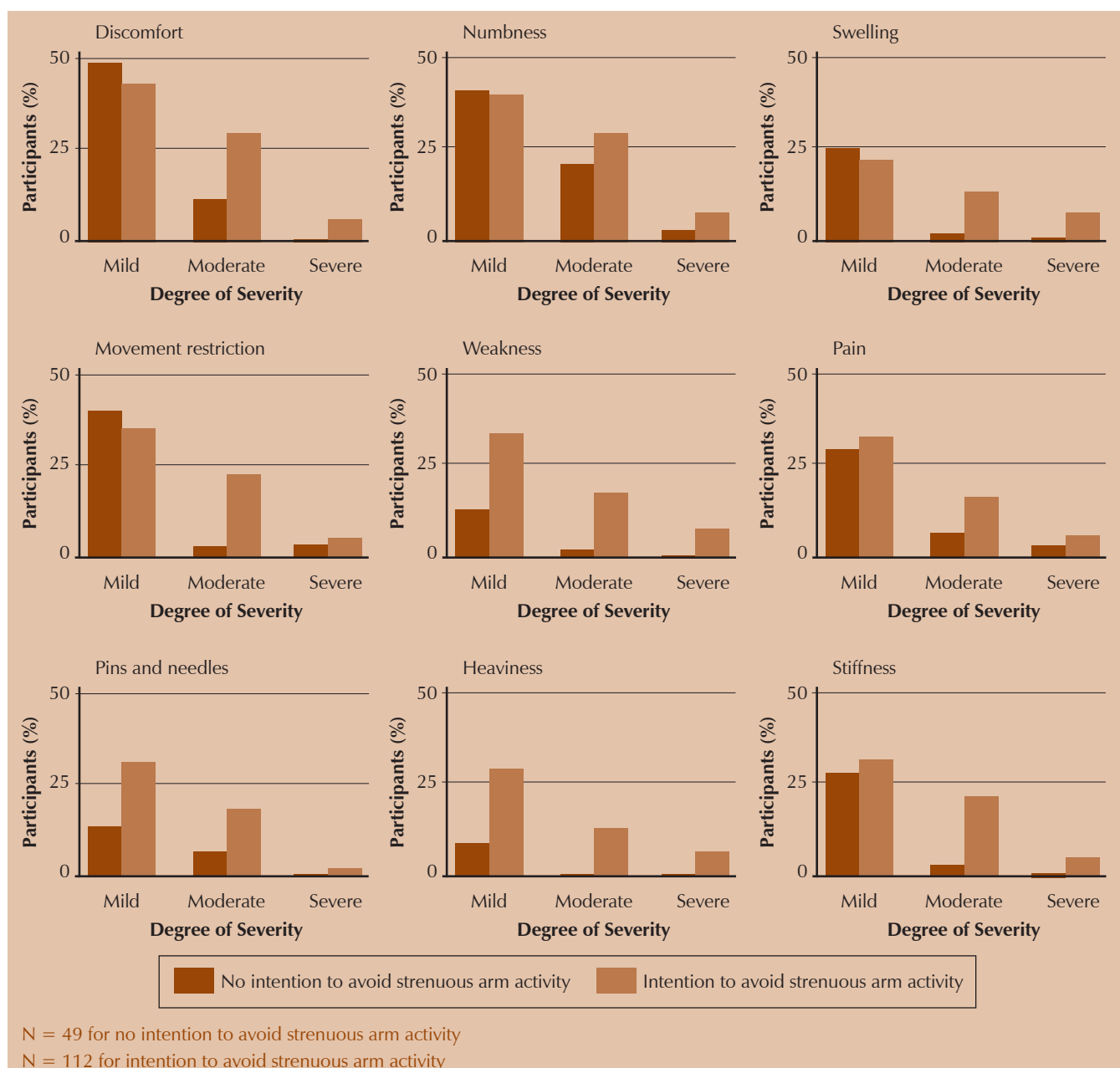
enough time for women to have regained normal use of the affected arm and be able to participate in an activity that involves strenuous arm work. Reasons that may explain why women intend to avoid strenuous arm activity include extensive axillary surgery, inaccurate

**Table 2. Comparison of Cancer and Treatment Variables Between Women Who Did and Did Not Intend to Avoid Strenuous Arm Activity**

| Variable                             | No Intention to Avoid Activity (N = 49) |      | Intention to Avoid Activity (N = 112) |      |
|--------------------------------------|-----------------------------------------|------|---------------------------------------|------|
|                                      | $\bar{X}$                               | SD   | $\bar{X}$                             | SD   |
| Time since surgery (months)          | 10.16                                   | 2.91 | 10.37                                 | 3    |
| Body mass index (kg/m <sup>2</sup> ) | 25.31                                   | 5.14 | 25.45                                 | 4.63 |

| Variable                           | n  | %  | n  | %  |
|------------------------------------|----|----|----|----|
| <b>Age (years)</b>                 |    |    |    |    |
| Younger than 50                    | 19 | 40 | 43 | 39 |
| 50–59                              | 15 | 31 | 37 | 33 |
| 60 or older                        | 14 | 29 | 31 | 28 |
| <b>Occupation</b>                  |    |    |    |    |
| Professional                       | 24 | 49 | 40 | 38 |
| Nonprofessional                    | 10 | 20 | 25 | 23 |
| Not working                        | 15 | 31 | 41 | 39 |
| <b>Education</b>                   |    |    |    |    |
| High school or below               | 18 | 39 | 35 | 32 |
| College or above                   | 28 | 61 | 74 | 68 |
| <b>Ethnicity</b>                   |    |    |    |    |
| Australian or New Zealander        | 40 | 87 | 78 | 72 |
| Other                              | 6  | 13 | 30 | 23 |
| <b>Affected arm dominant</b>       |    |    |    |    |
| Yes                                | 22 | 46 | 59 | 54 |
| No                                 | 26 | 54 | 50 | 46 |
| <b>Size of tumor</b>               |    |    |    |    |
| Less than 2 cm                     | 16 | 39 | 39 | 42 |
| 2 cm or more                       | 25 | 61 | 53 | 58 |
| <b>Type of surgery</b>             |    |    |    |    |
| Lumpectomy                         | 32 | 67 | 51 | 47 |
| Mastectomy                         | 16 | 33 | 58 | 53 |
| <b>Extent of axillary surgery*</b> |    |    |    |    |
| Sentinel lymph node biopsy         | 30 | 63 | 52 | 47 |
| Axillary lymph node dissection     | 10 | 21 | 54 | 49 |
| None                               | 8  | 16 | 4  | 4  |
| <b>Reconstructive surgery</b>      |    |    |    |    |
| Yes                                | 7  | 14 | 10 | 9  |
| No                                 | 42 | 86 | 99 | 91 |
| <b>Chemotherapy</b>                |    |    |    |    |
| Yes                                | 27 | 55 | 81 | 72 |
| No                                 | 22 | 45 | 31 | 28 |
| <b>Radiotherapy</b>                |    |    |    |    |
| Yes                                | 39 | 24 | 74 | 46 |
| No                                 | 10 | 6  | 38 | 24 |
| <b>Arm care advice*</b>            |    |    |    |    |
| Received                           | 29 | 59 | 97 | 88 |
| Not received                       | 20 | 41 | 13 | 12 |

N = 175  
\*  $p < 0.01$   
Note. N values represent the number of responses for that variable excluding missing data.



**Figure 1. Prevalence of Arm or Chest Symptoms Categorized According to Intensity**

advice, misinterpretation of arm care advice and, as suggested by PMT, high fear of lymphedema and low coping ability.

PMT was confirmed as a useful predictive model in identifying intention to avoid strenuous arm activity in breast cancer survivors. Perceived “coping” was found to be a stronger predictor than perceived “threat” or vulnerability. The results indicate that, despite a fear of lymphedema, women would benefit from balanced advice that empowers them to be active and in control of their bodies. Factors external to the theory, such as extent of axillary surgery and receipt of arm care advice, also were strong contributors to women’s intentions to avoid strenuous arm activity. Given these results, the theory

could possibly be strengthened by the examination of external factors, such as degree of incident (i.e., cancer pathological classification, exact number of lymph nodes removed, and number of positive lymph nodes), receipt of protection advice, and content of the advice received.

Women may intend to avoid strenuous arm activity simply because healthcare professionals have given them this information. Prior to the update of the National Lymphedema Network position statement about risk reduction practices and exercise (National Lymphedema Network, 2008a, 2008b), women were advised to avoid strenuous activity such as heavy lifting (Ridner, 2002). Therefore, the assumption can be made that some healthcare professionals do not have knowledge of

**Table 3. Comparison of Perceptions Between Women Who Did and Did Not Intend to Avoid Strenuous Arm Activity**

| Variable                              | No Intention to Avoid Activity |      | Intention to Avoid Activity |      | t       |
|---------------------------------------|--------------------------------|------|-----------------------------|------|---------|
|                                       | $\bar{X}$                      | SE   | $\bar{X}$                   | SE   |         |
| Perceived vulnerability to lymphedema | 12.9                           | 0.64 | 17.7                        | 0.39 | -6.601* |
| Perceived severity of lymphedema      | 14.84                          | 0.52 | 15.6                        | 0.28 | -1.392  |
| Perceived coping ability              | 14.08                          | 0.4  | 10.37                       | 0.3  | 7.106*  |

\*  $p < 0.02$  (two-tailed)

SE—standard error

updated information that shows strenuous arm activity does not cause or exacerbate lymphedema. Also possible is that breast cancer survivors misinterpret healthcare professionals' advice and information from hospital brochures. Women may not recall or comprehend the arm care and exercise advice they were given because of the shock of cancer diagnosis and surgery (Arder-Jones, Kenen, & Eeles, 2005; Hallowell, Green, Statham, Murton, & Richards, 1997). Generally, advice on lymphedema risk reduction focuses on promoting avoidance behavior, including avoidance of sunburn, cuts, insect bites, venopuncture, injections, and tourniquets to the affected arm (NSW Breast Cancer Institute, 2006; Ridner, 2002). The emphasis on avoidance may lead women to mistakenly believe strenuous arm activity to be a risk factor for lymphedema.

Some women may misinterpret acute postoperative advice and think that the advice still is applicable 6–15 months after surgery. Failure to inform women about the expected function for time points after surgery may lead to an extended period of avoiding strenuous arm

activity. Because postoperative arm care advice after breast cancer surgery focuses largely on lymphedema, women may think that this is the only side effect to affect the upper limb and they may not be aware of the potential for musculoskeletal issues. This lack of awareness may result in a lack of motivation to progress from gentle arm exercise to strenuous arm exercise and gives

them no reason to question why avoidance of strenuous arm activity is detrimental to their health. Fear of lymphedema appeared to drive women's intentions to avoid strenuous arm activity. Lymphedema is not a life-threatening condition, but its detrimental effects on body image appears to generate a fear that results in a high compliance to avoidance behavior. In comparison, other fear campaigns used for health promotion, such as smoking cessation (Hastings & MacFadyen, 2002; MacAskill, Will, Hughes, & Eadie, 1993), have been less successful even when failure to comply with the avoidance behavior may result in death. Although it remains unclear how the fear of lymphedema is learned or adopted, fear of lymphedema is not innate and possibly stemmed from information sources such as healthcare professionals, other breast cancer survivors, advocacy groups, and the media.

Hospital brochures often provide the same information about the risk of developing lymphedema to all women, regardless of the type of axillary surgery they have undergone. Generalized information about

**Table 4. Factor Analysis of Survey Items and Item Loadings**

| Survey Statement                                                                                          | Factor Loadings                       |                                  |                          |
|-----------------------------------------------------------------------------------------------------------|---------------------------------------|----------------------------------|--------------------------|
|                                                                                                           | Perceived Vulnerability to Lymphedema | Perceived Severity of Lymphedema | Perceived Coping Ability |
| Having arm swelling would or does significantly alter my lifestyle.                                       | —                                     | 0.806                            | —                        |
| Arm swelling is a minor side effect.                                                                      | —                                     | -0.699                           | —                        |
| People with arm swelling suffer a lot.                                                                    | —                                     | 0.756                            | —                        |
| Swelling in the arm can look very severe.                                                                 | —                                     | 0.531                            | —                        |
| The possibility of developing or worsening arm swelling worries me.                                       | 0.533                                 | —                                | —                        |
| I am not at risk for developing or worsening arm swelling.                                                | -0.79                                 | —                                | —                        |
| My chance of developing or worsening arm swelling is low.                                                 | -0.801                                | —                                | —                        |
| People who have had the same breast cancer treatment as me are vulnerable to arm swelling.                | 0.762                                 | —                                | —                        |
| It is unlikely that swelling will occur or worsen in my arm.                                              | -0.87                                 | —                                | —                        |
| Doing strenuous activities with my affected arm puts me at risk for developing or worsening arm swelling. | —                                     | —                                | 0.587                    |
| I am confident in my ability to avoid strenuous work.                                                     | —                                     | —                                | 0.801                    |
| I will rest and protect my affected arm even though it may be inconvenient.                               | —                                     | —                                | 0.698                    |
| Health professionals have told me to be protective of my arm and avoid strenuous arm work.                | —                                     | —                                | 0.523                    |

**Table 5. Variables Associated With the Intention to Avoid Strenuous Arm Activity**

| Independent Variable                  | B     | Wald   | Significant | OR    | 95% CI Lower | 95% CI Upper |
|---------------------------------------|-------|--------|-------------|-------|--------------|--------------|
| Extent of axillary surgery            | 0.278 | 0.405  | 0.524       | 1.321 | 0.561        | 3.113        |
| Arm care advice                       | 1.596 | 8.921  | 0.003       | 4.933 | 1.731        | 14.058       |
| Perceived vulnerability to lymphedema | 0.467 | 9.114  | 0.003       | 1.595 | 1.178        | 2.16         |
| Perceived coping ability              | −0.6  | 14.933 | —           | 0.549 | 0.45         | 0.744        |

CI—confidence interval; OR—odds ratio

lymphedema is likely to engender fear in many women, whether or not they have undergone ALND, which increases the likelihood of this condition. Provision of standardized advice may engender fear needlessly in women who have none or few lymph nodes removed.

To reduce this unnecessary fear, it may be more appropriate to target lymphedema information specifically to women who are known to be at high risk for the condition rather than to all women after breast cancer surgery. Women known to be at high risk for developing lymphedema include women who are obese (Werner et al., 1991), who undergo ALND (Herd-Smith, Russo, Muraca, Del Turco, & Cardona, 2001; Lee, Kilbreath, Refshauge, Herbert, & Beith, 2008), or who undergo radiotherapy to the axilla (Nagel, Bruggink, Wobbes, & Strobbe, 2003). Clinical pathways after ALND could include screening for upper-limb impairments by a breast cancer nurse or allied healthcare provider several weeks after surgery. Additionally, all women, regardless of the type of surgery they have undergone, could be offered an educational session so that the risks of lymphedema may be explained in the context of surgical procedures.

A self-monitoring checklist of functional milestones is recommended to ensure women progress beyond their acute postoperative functional ability. Although this type of checklist requires additional study, one example may be the ability to reach for the top shelf of a cupboard by four weeks after removal of drains for women who have undergone SLNB, and by eight weeks for women who have undergone ALND. Hospital brochures about upper-limb recovery should not only emphasize avoidance behavior for lymphedema, but also promote activity and exercise to prevent cancer recurrence, shoulder restriction, arm weakness, and osteopenia after breast cancer treatment. In this way, women may receive a balanced view on precautions as well as activity. Finally, healthcare professionals may need a change in their own perceptions toward strenuous arm activity after breast cancer. To address this, commitment is required from their affiliated department and professional organizations. The National Lymphedema Network (2008a, 2008b) has led the way in providing renewed position statements about risk reduction and exercise. Healthcare professionals and advocacy groups have a duty to access this information

to ensure advice and practice is based on the updated position statements and guidelines.

### Limitations

Not surprisingly, this study found a strong association between women who intended to avoid strenuous arm activity and those who reported upper-limb symptoms. However, noting that this was a cross-sectional survey is important. Based on the results, whether symptoms are a risk factor for arm protection or the result of arm inactivity is uncertain. Women who experience greater frequency or intensity of symptoms may intend to avoid strenuous activities more than women who experience fewer or milder symptoms because their symptoms prevent them from participating in such activities. Alternatively, women who protect their arm excessively may develop secondary musculoskeletal symptoms caused by disuse and deconditioning of the upper limb. If symptoms are a risk factor, then appropriate prevention and treatment strategies should be implemented to avoid chronic issues. However, if symptoms are secondary to avoidance behaviors, then resumption of normal activities with the affected arm after breast cancer surgery should be recommended. Regardless of the cause of upper-limb symptoms, early intervention is recommended. Consistent with the aims of common rehabilitation protocols, the goal for all women after breast cancer treatment should be to return to normal function.

Although it was not possible to ascertain the specific source and content of information received by the participants of the survey, the results provide an interesting overview of the discord that is evident between the number of women undergoing “at risk” surgery for lymphedema and the number of women who report a “fear” of lymphedema. It allows a strong conclusion to be drawn about the need for targeted advice to patients who are actually at risk for developing lymphedema.

In summary, the fear of developing lymphedema and the receipt of any arm care advice contribute to women’s intentions to avoid strenuous arm activity after breast cancer treatment. To address these issues, it should be made clear to women that the risk of developing lymphedema is dependent on the type of surgery they have undergone. Arm care advice should be updated and reflect a balance between precaution and exercise promotion.

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Digital Object Identifier: 10.1188/09.ONF.454-462

## References

- Abdi, H. (Ed.). (2007). *Bonferroni and Sidak corrections for multiple comparisons*. Thousand Oaks, CA: Sage.
- Ahmed, R.L., Thomas, W., Yee, D., & Schmitz, K.H. (2006). Randomized controlled trial of weight training and lymphedema in breast cancer survivors. *Journal of Clinical Oncology*, 24(18), 2765–2772.
- Ardern-Jones, A., Kenen, R., & Eeles, R. (2005). Too much, too soon? Patients and health professionals' views concerning the impact of genetic testing at the time of breast cancer diagnosis in women under the age of 40. *European Journal of Cancer Care*, 14(3), 272–281.
- Armer, J., Fu, M.R., Wainstock, J.M., Zagar, E., & Jacobs, L.K. (2004). Lymphedema following breast cancer treatment, including sentinel lymph node biopsy. *Lymphology*, 37(2), 73–91.
- Baron, R.H., Fey, J.V., Raboy, S., Thaler, H.T., Borgen, P.I., Temple, L.K., et al. (2002). Eighteen sensations after breast cancer surgery: A comparison of sentinel lymph node biopsy and axillary lymph node dissection. *Oncology Nursing Forum*, 29(4), 651–659.
- Box, R.C., Reul-Hirche, H.M., Bullock-Saxton, J.E., & Furnival, C.M. (2002). Physiotherapy after breast cancer surgery: Results of a randomized controlled study to minimize lymphedema. *Breast Cancer Research and Treatment*, 75(1), 51–64.
- Cheema, B., Gaul, C., Lane, K., & Fiatarone Singh, M. (2008). Progressive resistance training in breast cancer: A systematic review of clinical trials. *Breast Cancer Research and Treatment*, 109(1), 9–26.
- Collins, L.G., Nash, R., Round, T., & Newman, B. (2004). Perceptions of upper-body problems during recovery from breast cancer treatment. *Supportive Care in Cancer*, 12(2), 106–113.
- Greenslade, M.V., & House, C.J. (2006). Living with lymphedema: A qualitative study of women's perspectives on prevention and management following breast cancer-related treatment. *Canadian Oncology Nursing Journal*, 16(3), 165–171.
- Hallowell, N., Green, J., Statham, H., Murton, F., & Richards, M. (1997). Recall of numerical risk estimates and counselees' perceptions of the importance of risk information following genetic counseling for breast and ovarian cancer. *Psychology Health and Medicine*, 2(2), 149–159.
- Hastings, G., & MacFadyen, L. (2002). The limitation of fear messages. *Tobacco Control*, 11(1), 73–75.
- Herd-Smith, A., Russo, A., Muraca, M.G., Del Turco, M.R., & Cardona, G. (2001). Prognostic factors for lymphedema after primary treatment of breast carcinoma. *Cancer*, 92(7), 1783–1787.
- Johansson, K., Tibe, K., Weibull, A., & Newton, R.C. (2005). Low intensity resistance exercise for breast cancer patients with arm lymphedema with or without compression sleeve. *Lymphology*, 38(4), 167–180.
- Kaiser, H. (1974). An index of factorial simplicity. *Psychometrika*, 39(1), 31–36.
- Karki, A., Simonen, R., Malkia, E., & Selfe, J. (2004). Postoperative education concerning the use of the upper limb, and exercise and treatment of the upper limb: Cross-sectional survey of 105 breast cancer patients. *Supportive Care in Cancer*, 12(5), 347–354.
- Kilbreath, S.L., Refshauge, K.M., Beith, J.M., & Lee, M.J. (2006). Resistance and stretching shoulder exercises early following surgery for breast cancer: A pilot study. *Rehabilitation Oncology*, 24(1), 9–14.
- Lane, K.N., Dolan, L.B., Worsley, D., & McKenzie, D.C. (2007). Upper extremity lymphatic function at rest and during exercise in breast cancer survivors with and without lymphedema compared with healthy controls. *Journal of Applied Physiology*, 103(3), 917–925.
- Lee, T.S., Kilbreath, S.K., Refshauge, K.M., Herbert, R.D., & Beith, J.M. (2008). Prognosis of the upper limb following surgery and radiation for breast cancer. *Breast Cancer Research and Treatment*, 110(1), 19–37.
- Lee, T.S., Kilbreath, S.K., Sullivan, G., Refshauge, K.M., & Beith, J.M. (2007). The development of an arm activity survey for breast cancer survivors using the Protection Motivation Theory. *BMC Cancer*, 7(1), 75.
- MacAskill, S., Will, V., Hughes, K., & Eadie, D. (1993). *The Health Education Board for Scotland's 1992 anti-smoking initiative*. Glasgow, Scotland: University of Strathclyde.
- McKenzie, D.C., & Kalda, A. (2003). Effect of upper extremity exercise on secondary lymphedema in breast cancer patients. A pilot study. *Journal of Clinical Oncology*, 21(3), 463–466.
- Milne, S., Sheeran, P., & Orbell, S. (2000). Prediction and intervention in health-related behavior: A meta-analytic review of protection motivation theory. *Journal of Applied Social Psychology*, 30(1), 106–143.
- Moseley, A.L., Piller, N.B., & Carati, C.J. (2005). The effect of gentle arm exercise and deep breathing on secondary arm lymphedema. *Lymphology*, 38(3), 136–145.
- Nagel, P.H., Bruggink, E.D., Wobbes, T., & Strobbe, L.J. (2003). Arm morbidity after complete axillary lymph node dissection for breast cancer. *Acta Chirurgica Belgica*, 103(2), 212–216.
- National Lymphedema Network. (2008a). *Position statement: Exercise*. Oakland, CA: Author.
- National Lymphedema Network. (2008b). *Position statement: Lymphedema risk reduction practices*. Oakland, CA: Author.
- NSW Breast Cancer Institute. (2006). *Lymphedema: An information guide for patients*. Westmead, Australia: Author.
- Ridner, S.H. (2002). Breast cancer lymphedema: Pathophysiology and risk reduction guidelines. *Oncology Nursing Forum*, 29(9), 1285–1293.
- Ridner, S.H. (2005). Quality of life and a symptom cluster associated with breast cancer treatment-related lymphedema. *Supportive Care in Cancer*, 13(11), 904–911.
- Rogers, R. (1983). Cognitive and physiological process in fear appeals and attitude change: A revised theory of protection motivation. In J. Cacioppo & R. Petty (Eds.), *Social psychophysiology* (pp. 153–174). New York: Guildford Press.
- Schrenk, P., Rieger, R., Shamiyeh, A., & Wayand, W. (2000). Morbidity following sentinel lymph node biopsy versus axillary lymph node dissection for patients with breast carcinoma. *Cancer*, 88(3), 608–614.
- Soran, A., D'Angelo, G., Begovic, M., Ardic, F., Harlak, A., Samuel Wieand, H., et al. (2006). Breast cancer-related lymphedema—What are the significant predictors and how do they affect the severity of lymphedema? *Breast Journal*, 12(6), 536–543.
- Tabachnick, B., & Fidell, L. (2007). Principal components and factor analysis. In B. Tabachnick & L. Fidell (Eds.), *Using multivariate statistics* (5th ed., pp. 607–675). Boston: Pearson Education.
- Thomas-Maclean, R.L., Hack, T., Kwan, W., Towers, A., Miedema, B., & Tilley, A. (2008). Arm morbidity and disability after breast cancer: New directions for care. *Oncology Nursing Forum*, 35(1), 65–71.
- Tobin, M.B., Lacey, H.J., Meyer, L., & Mortimer, P.S. (1993). The psychological morbidity of breast cancer-related arm swelling: Psychological morbidity of lymphedema. *Cancer*, 72(11), 3248–3252.
- Trettin, H. (1992). Neurologic principles of edema in inactivity. *Journal of Lymphology*, 16(1), 14–16.
- Werner, R.S., McCormick, B., Petrek, J., Cox, L., Cirrincione, C., Gray, J.R., et al. (1991). Arm edema in conservatively managed breast cancer: Obesity is a major predictive factor. *Radiology*, 180(1), 177–184.