Published in final edited form as:

J Cancer Surviv. 2008 December ; 2(4): 233–242. doi:10.1007/s11764-008-0065-y.

Arm/Hand Swelling and Perceived Functioning among Breast Cancer Survivors 12 Years Post-diagnosis: CALGB 79804

Jill M. Oliveri¹, Jeannette M. Day², Catherine M. Alfano^{1,3}, James E. Herndon II², Mira L. Katz^{1,3}, Marisa A. Bittoni¹, Kathleen Donohue², and Electra D. Paskett^{1,3}

¹ Comprehensive Cancer Center, The Ohio State University, Columbus, OH, supported by CA77658

² CALGB Statistical Center, Duke University Medical Center, Durham, NC, supported by CA33601

³ College of Public Health, The Ohio State University, Columbus, Ohio

Abstract

Introduction—Lymphedema is an under-reported and debilitating consequence of axillary node dissection among breast cancer survivors. This study describes the characteristics of arm and hand swelling in relation to perceived physical and mental health functioning among breast cancer survivors 9–16 years post-diagnosis who previously participated in a clinical trial coordinated by the Cancer and Leukemia Group B (CALGB 8541).

Methods—Eligible survivors of CALGB 8541 completed questionnaires assessing demographics, arm/hand swelling, perceived physical functioning, and mental health.

Results—245 women (94% white, mean age=63, on average 12.4 years post-diagnosis) completed questionnaires (participation rate=78%). Seventy-five women (31%) reported arm/hand swelling since their surgery. Of these women, 76% reported current swelling and half reported constant swelling, mainly in the upper arm. Swelling was reported as mild or moderate in 88% of the women. Women who reported severe swelling had significantly worse physical functioning and trended toward worse depressive symptoms and poorer mental health (lower mental SF-36 scores) as well. Activity-limiting swelling was also significantly associated with worse physical functioning. Although swelling interfered with wearing clothing (36%) and perceptions about general appearance (32%), only 37% of women sought treatment for swelling.

Conclusions—Arm/hand swelling is a chronic problem for a subgroup of long-term survivors of breast cancer, negatively affecting physical functioning.

Implications for Cancer Survivors—Educational efforts are needed as part of a comprehensive survivorship care plan to raise awareness about lymphedema so that survivors may identify this complication, seek treatment early, and potentially improve their physical functioning.

Keywords

lymphedema; swelling; breast cancer; physical functioning; mental health

Reprint requests should be sent to the corresponding author: Electra D. Paskett, PhD, OSU Comprehensive Cancer Center, A356 Starling-Loving Hall, 320 W. 10th Avenue, Columbus, OH 43210. Electra.Paskett@osumc.edu..

A portion of these study results were presented at the 8th World Congress of Psycho-Oncology, Venice, Italy, October 21, 2006, and the 135th Annual Meeting of the American Public Health Association, Washington, D.C., November 5, 2007.

INTRODUCTION

Breast cancer is the most common non-skin cancer and a leading cause of cancer mortality among women in the United States (1). Because of early detection and advances in breast cancer treatment, both incidence and mortality rates have declined in recent decades (1). The 5-year survival rate among women with breast cancer, all stages combined, is 89%, while the 10-year survival rate is 80% (2). The National Cancer Institute estimated that more than 2 million breast cancer survivors were alive in January 2004 (2).

Given the growing number of breast cancer survivors who are living years beyond their disease, greater attention is being paid to the long-term effects of cancer treatment among these women. One common complication of cancer treatment is lymphedema, which is characterized by an accumulation of lymphatic fluid in the interstitial tissue that causes swelling, most often in the arms, hands or legs. Lymphedema can occur anywhere lymph nodes have been surgically removed or lymph flow has been disturbed (3). An unwanted consequence of cancer treatment (4), lymphedema can be especially concerning to patients who think they have been cured of their cancer (5).

Lymphedema has been studied by many investigators seeking to find accurate estimates of incidence and prevalence, as well as its effects on physical and mental health and quality of life. From past research, the overall incidence of arm lymphedema can range from 8% to 56% within 3 years following surgery, depending on the extent of axillary dissection and the use of radiotherapy (6-15). Lymphedema usually develops within the first 12 – 14 months following surgery (16, 17); however, some women develop lymphedema decades post-surgery (18, 19).

Lymphedema commonly causes limitations in range of motion, pain, and weakness or stiffness in the affected extremity (20, 21). In addition, lymphedema has been associated with poorer mental health including anxiety, depression, sexual dysfunction, social avoidance, and exacerbation of existing psychiatric illness (22).

The body of research on the prevalence and physical/psychological effects of lymphedema continues to grow; however, little is known about these issues in the increasing population of long-term breast cancer survivors, defined here as living five or more years after diagnosis. While others have studied health-related quality of life in long-term breast cancer survivors (10), this study is the first to explore the association among specific swelling characteristics, physical functioning and mental health in this population of long-term breast cancer survivors. Understanding these relationships is essential to developing truly informed and helpful survivorship care plans for survivors to manage their health in the years after treatment. Specifically, the goals of this study were to (1) describe the prevalence and characteristics of swelling (e.g., onset, duration, severity) and (2) document the impact of swelling on perceived physical functioning and mental health (depression, breast cancer anxiety, body satisfaction, and general mental health).

METHODS

Procedures and Participants

Study methods have been published elsewhere (23, 24). Briefly, data for this study are from participants recruited to Cancer and Leukemia Group B (CALGB) 79804, a cross-sectional study that examined health status, cancer-related symptoms and lifestyle behaviors among long-term breast cancer survivors who participated in a treatment trial (CALGB 8541) from 1985 to 1991 (25). When the current study began in 1999, 618 of the 1,572 women who were randomized in CALGB 8541 were identified by the CALGB Statistical Center as alive,

disease-free, and potentially eligible for participation. However, 304 of these 618 women were deemed ineligible by participating CALGB institutions due to death or disease recurrence, or non-approval for the study by the physician. Of the 314 eligible women invited to participate, 245 women (participation rate = 78%) completed the surveys. Participating women did not differ significantly from survivors who did not participate (N=373) by age, treatment arm, number of positive lymph nodes, or year of entry in CALGB 8541 (data not shown), except that more white survivors participated compared to non-white survivors (93% versus 81%, respectively, $p<0.0001$). CALGB 79804 was approved by the Institutional Review Board of each participating institution.

Data Collection

Patient registration and data collection were managed by the CALGB Statistical Center. Clinical Research Associates at CALGB treating institutions were notified of patient eligibility and selection for potential participation by the CALGB Statistical Center. Women who agreed to participate were asked to complete the questionnaire, sign a consent form, and return both in a provided postage-paid addressed envelope. Non-respondents were contacted by phone, and, if necessary, the survey was conducted by phone (n=8). Upon questionnaire completion, the research interviewer registered the patient with the CALGB Statistical Center.

Measures

Demographics were obtained both from the CALGB 8541 database and from self-report. This information included age, race, marital status, educational status, family income, and primary occupational status.

Clinical variables were obtained from the CALGB 8541 database including time since diagnosis, number of nodes removed, and number of positive nodes.

Self-reported swelling characteristics, measured by the Lymphedema and Pain Questionnaire, assessed self-report of current and past swelling, as well as pain. This self-report instrument documents the occurrence, duration, perceived cause and other characteristics of any breast cancer treatment-related swelling and pain in the arms and hands and was created for use in a previous study to describe the characteristics of lymphedema (4). Definitions of swelling severity (mild, moderate and severe) were not provided since the instrument was designed to capture women's perceptions of severity, and standardized definitions of severity do not exist.

Perceived physical functioning was assessed with the physical component summary scale of the Medical Outcomes Study Short Form 36 (SF-36) health status measure. Created to measure physical and mental health functioning in healthy populations (26, 27), this 36-item measure is scored into eight subscales and summarized into a physical component and a mental health component summary scale. The physical component summary scale ranged from zero to 100 with increasing scores indicating better functioning, per standard coding protocol. Considerable psychometric analyses have been published on the SF-36 and its multiple components (28, 29).

Mental health was assessed via several measures. *Depression* was measured with the Center for Epidemiologic Studies-Depression (CES-D) 20-item short form, which assesses depressive symptoms during the past week, has been used with a variety of populations, and has documented reliability and validity as a depression screening tool (30, 31). The total score was used to assess participants' overall level of depression and was coded with higher scores indicating worse depression symptomology. *Breast Cancer Anxiety* was assessed with

a modified form of the Breast Cancer Anxiety and Screening Behavior Scale, a 21-item reliable and valid scale that assessed the intrusive and avoidant thoughts related to breast cancer as well as fears of recurrence (32). We used 14 of the items relevant to breast cancer survivors, omitting 7 items relevant only to high-risk women or to breast cancer screening. Higher scores indicated more frequent breast cancer anxiety. *Body satisfaction* was assessed with the Self-Concept Scale, which consists of 10-items that assessed the participants' satisfaction with different areas of their body and their overall weight (33). Body satisfaction was measured by taking the sum of the eight items (scored 1-5) assessing satisfaction with seven areas of the body and with the body overall. Higher body satisfaction scores indicated greater satisfaction with the body. *General mental health* was assessed with mental health component summary scale of the Medical Outcomes Study Short Form 36 (SF-36) health status measure described above. The mental health component summary scale ranged from zero to 100 with increasing scores indicating better mental health, per standard coding protocol.

Analytic Methods

Descriptive statistics were calculated to describe participants' demographic, clinical and arm/hand swelling characteristics, as well as variables assessing swelling-related pain, interference with activities, and treatment. Demographic and clinical differences between women who reported swelling since surgery and those who did not were tested using Wilcoxon's rank sum test (34) and Fisher's Exact test (35). Differences in perceived physical functioning and mental health among those who reported swelling since surgery and those who did not were examined with t-tests. These results were verified by non-parametric tests including the Wilcoxon rank sum test. Non-parametric results were similar to t-test results; thus, results of t-tests are presented.

Analysis of variance (ANOVA) models tested the relationships between specific swelling characteristics and perceived physical functioning and mental health among those participants who reported any swelling since surgery. Weighted least squares estimates were calculated for ordered data. These results were verified by non-parametric Kruskal Wallis tests(36), Wilcoxon rank sum tests, or the Jockheere-Terpstra test for ordered data (37). Where results were similar, only p values for the ANOVA are presented. Where results differed between parametric and non-parametric tests, p values are indicated for the non-parametric test. Statistical tests were two-sided, with level of significance set at 5%. Statistical analyses were performed by statisticians at the CALGB Statistical Center.

RESULTS

Characteristics of the Participants

The demographic and clinical characteristics of the 245 participants stratified by reported arm/hand swelling status are presented in Table I. The mean age of all women was 63 years (range=35-85). Participants were on average 12.5 years post-diagnosis, and most were white (94%). About half of the women had a high school degree or less and reported an annual household income under \$45,000. Most women (82%) had between one and four positive lymph nodes, and 13% had between five and nine positive nodes. There were 75 (31%; 95% confidence interval: 25% - 39%) women who reported a history of ever swelling of the affected arm or hand since their breast cancer surgery. There were no differences in any demographic or clinical characteristics between women who reported a history of ever having arm/hand swelling compared to women who did not report swelling.

Characteristics of Arm and/or Hand Swelling

The swelling characteristics noted by the participants who reported a history of arm/hand swelling (N=75) are presented in Table II. More than half (55%) of the women reported that they noticed their first episode of swelling within two years of their surgical treatment for breast cancer, and approximately half (49%) of the women reported constant arm/hand swelling since its onset. One-third (33%) of the women experienced swelling in their upper arm only, while 21% experienced swelling the entire length of their arm and hand. Among the women who reported ever having arm/hand swelling, 76% reported currently experiencing swelling. While half (51%) of the women described their swelling as mild, 37% described their swelling as moderate, and 9% reported severe swelling. A majority (69%) of the participants reported that swelling interfered with daily activities, particularly with respect to clothing properly fitting and perceived image about appearance. Forty-three percent (n=32) of the women experienced arm and/or hand pain in addition to swelling. These women reported a mean pain severity score of 5.3 out of 10 (higher scores indicating worse pain) and half reported that this pain interfered with their daily activities.

Only 73% of women who reported ever swelling attributed their swelling to the surgical removal of their lymph nodes. Twenty-three percent of the women believed their arm/hand swelling was a result of general arm use. Other perceived causes of swelling included infection or injury to the arm/hand, weather changes, exercise, radiation treatment, airplane travel, and breast reconstruction. More than half (60%) of the participants did not seek medical treatment at the time of their arm/hand swelling.

Relationship between Swelling, Perceived Physical Functioning, and Mental Health

The relationships between arm/hand swelling, perceived physical functioning, and mental health are presented in Table III. There were no significant differences in physical functioning, depression, breast cancer anxiety, body satisfaction, or general mental health between women who reported arm/hand swelling and those who did not.

The relationships between specific swelling characteristics (i.e., onset, frequency, severity, interference, treatment-seeking) and perceived physical functioning and mental health among women who reported any swelling since surgery are presented in Table IV. Women who reported swelling that was not constant reported significantly more breast cancer anxiety compared to women who had swelling that was constant ($p = 0.006$). Women who reported severe swelling had significantly worse physical functioning (lower physical SF-36 scores) compared to women who reported mild or moderate swelling ($p = 0.008$), and there were nonsignificant trends toward worse depressive symptoms and poorer mental health (lower mental SF-36 scores) as well. Women reporting that their arm/hand swelling interfered with their daily activities reported worse physical functioning compared to those who reported that swelling did not interfere with their daily activities ($p = 0.01$). In addition, there was a trend for women who reported not seeking treatment for swelling to report worse physical functioning ($p = 0.06$). There were no significant relationships between onset of swelling or having single or multiple sources of interference with daily life (e.g., clothing, appearance, exercise) with any outcome, nor between characteristics of swelling and body satisfaction.

DISCUSSION

This study describes the prevalence and characteristics of arm/hand swelling and the effects of swelling on perceived physical functioning and mental health among long-term breast cancer survivors. The prevalence of swelling since surgery in these long-term survivors was 31%, which is strikingly similar to the prevalence of lymphedema reported in several studies

that have measured these outcomes earlier in the postoperative period (~ 32%) (38, 39) and within the range of prevalence estimates (8% - 56%) reported by other studies that evaluated women 2-3 years post-surgery (6-15). The swelling prevalence in these 12-year survivors was lower than the 49% estimate reported in the one other study of long-term (20-year) breast cancer survivors (19), possibly due to improvements in breast cancer treatment (e.g., fewer nodes removed) at the time of the CALGB 8541 (conducted 1985-1991) compared to the older study by Petrek and colleagues (conducted 1976-1978).

Two reviews of the sequelae of lymphedema have shown swelling to be associated with poor mental health, reductions in physical functioning, and social and occupational problems (40, 41). The primary take home message from this study is that while many long-term survivors with swelling reported doing quite well in terms of physical functioning and mental health, there was a subgroup of long-term survivors who reported high rates of persistent severe swelling, pain, and interference with daily activities. Moreover, the current study suggests that it is not simply the presence of lymphedema, but rather specific swelling characteristics (namely severe or activity-limiting swelling), that are negatively associated with perceived physical functioning and trends toward worse mental health. This adds to the increasing evidence (39, 42-44) that for some women, lymphedema becomes a chronic condition after breast cancer, interfering with their ability to engage in activities and self-care, even 12 years after diagnosis. While previous studies have shown lymphedema to be associated with poorer physical functioning and mental health and with greater depression and distress (9, 15, 38, 42, 45-47), we know of no previous studies that have shown this relationship with lymphedema severity. These results suggest that interventions to reduce swelling severity may improve physical functioning.

Activity limitations from lymphedema symptoms were not related to mental health, inconsistent with previous work documenting that such limitations can lead to a loss of independence and problems with social, work and sexual relationships (39, 42, 43). Since almost 70% of women who reported swelling also reported activity limitations, it may be that there was too little variation among the women in this study to detect a significant relationship between activity limitations and mental health. Alternatively, it may be that if these survivors have struggled with activity limitations for 12 years, they have successfully adapted to their limitations such that the limitations do not affect mental health. Similarly, women with constant swelling reported less breast cancer anxiety than did women with intermittent swelling. This may occur because women who have come to expect the daily swelling as a chronic condition may be more likely to successfully adapt to it.

The survey used in this study also queried women about perceptions of the causes of swelling. Only 73% of the women who reported swelling since surgery attributed swelling to surgical treatment of breast cancer and removal of lymph nodes. Nearly 25% believed swelling resulted from general arm use, which has been shown in a qualitative study as well (48). This underscores the need for educational efforts, which should be directed at both survivors and health care providers since women report being poorly informed about the prevention and treatment of lymphedema before surgery (44), and providers report not routinely counseling women about lymphedema (4).

Another concerning result is that despite living with this chronic swelling condition that was related to interference with daily activities, few women reported seeking treatment. This points again to the need for a multi-level educational intervention. Efforts should be directed at healthcare providers to underscore the importance of patient education and early detection and treatment of lymphedema and to increase their communication skills about lymphedema. Educational programs need to be developed for breast cancer survivors that provide information about the causes of lymphedema and treatment options. This

information should be included as part of comprehensive survivorship care plans to help survivors maintain their health in the post-treatment period. In addition, breast cancer survivors should be encouraged to talk with their healthcare providers about arm/hand swelling or pain.

There are certain factors that limit the conclusions from this study. Data on arm/hand swelling were obtained via self-report rather than from medical chart review or a standardized objective clinical evaluation. Further, although used in previous work, this self-report instrument has not been subjected to rigorous psychometric testing and shown to be reliable and valid. Additionally, the occurrence of missing data may have biased the results, and the predominance of white women in the sample limits the generalizability of these findings to all women. Additionally, weight or body mass index data were not available, so analyses could not explore whether swelling or the relationships between swelling, physical functioning, or mental health differed by body mass index. Finally, the small number of women reporting severe swelling likely limited the ability to detect significant relationships with mental health and depression.

Despite these limitations, this study provides a unique contribution to the existing literature by reporting data on arm/hand swelling prevalence and characteristics, and on the impact of this swelling on the physical functioning and mental health of long-term breast cancer survivors. Among these long-term survivors, it was not the presence of swelling, but rather the presence of severe or activity-limiting swelling that was related to physical functioning and a trend toward worse mental health. Results have clear implications for the development of educational programs for both healthcare providers and survivors included as part of a comprehensive survivorship care plan to prevent or successfully manage lymphedema and limit the effects of this treatment-related complication on survivors' lives.

Acknowledgments

The research for CALGB 79804 was supported, in part, by grants from the National Cancer Institute (CA31946) to the Cancer and Leukemia Group B (Richard L. Schilsky, MD, Chairman) and to the CALGB Statistical Center (Stephen George, PhD, CA33601). The content of this manuscript is solely the responsibility of the authors and does not necessarily represent the official views of the National Cancer Institute. In addition this research was funded by the National Institutes of Health Grants: AG16602, CA79883, CA57707, and CA131029.

CALGB Statistical Office, Durham, NC — Stephen George, Ph.D.; supported by CA33601

Christiana Care Health Services, Inc. CCOP, Wilmington, DE—Irving M. Berkowitz, D.O.; supported by CA45418

Dana Farber Cancer Institute, Boston, MA—George P Canellos, M.D.; supported by CA32291

Dartmouth Medical School - Norris Cotton Cancer Center, Lebanon, NH—Marc S. Ernstoff, M.D.; supported by CA04326

Duke University Medical Center, Durham, NC—Jeffrey Crawford, M.D.; supported by CA47577

Massachusetts General Hospital, Boston, MA—Michael L. Grossbard, M.D.; supported by CA12449

Mount Sinai School of Medicine, New York, NY—Lewis R. Silverman, M.D.; supported by CA04457

North Shore - Long Island Jewish Medical Center, Manhasset, NY, Daniel R Budman, M.D., supported by CA35279

Rhode Island Hospital, Providence, RI—Louis A. Leone, M.D.; supported by CA08025

Roswell Park Cancer Institute, Buffalo, NY—Ellis Levine, M.D.; supported by CA02599

Southeast Cancer Control Consortium Inc. CCOP, Goldsboro, NC—James N. Atkins, M.D.; supported by CA45808

Southern Nevada Cancer Research Foundation CCOP, Las Vegas, NV–John Ellerton, M.D.; supported by CA35421

SUNY Upstate Medical University, Syracuse, NY–Stephen L. Graziano, M.D.; supported by CA21060

Syracuse Hematology-Oncology Assoc. CCOP, Syracuse, NY, Jeffrey Kirshner, M.D., supported by CA45389

University of California at San Diego, San Diego, CA–Stephen L Seagren, M.D.; supported by CA11789

University of Chicago Medical Center, Chicago, IL–Gini Fleming, M.D.; supported by CA41287

University of Maryland Cancer Center, Baltimore, MD–David Van Echo, M.D.; supported by CA31983

University of Massachusetts Medical Center, Worcester, MA, Mary Ellen Taplin, M.D., supported by CA37135

University of Minnesota, Minneapolis, MN–Bruce A Peterson, M.D.; supported by CA16450

University of Missouri/Ellis Fischel Cancer Center, Columbia, MO–Michael C Perry, M.D.; supported by CA12046

University of North Carolina at Chapel Hill, Chapel Hill, NC–Thomas C. Shea, M.D.; supported by CA47559

Wake Forest University School of Medicine, Winston-Salem, NC–David D Hurd, M.D.; supported by CA03927

Walter Reed Army Medical Center, Washington, DC–Joseph J. Drabek, M.D.; supported by CA26806

Washington University School of Medicine, St. Louis, MO, Nancy Bartlett, MD, supported by CA77440

REFERENCES

1. American Cancer Society. Cancer Facts and Figures 2007. American Cancer Society, Inc.; Atlanta: 2007.
2. Ries, LAG.; Melbert, D.; Krapcho, M.; Mariotto, A.; Miller, BA.; Feuer, EJ., et al. SEER Cancer Statistics Review, 1975–2004. National Cancer Institute; Bethesda: 2007.
3. Guralnik JM, LaCroix AZ, Abbott RD, Berkman LF, Satterfield S, Evans DA, et al. Maintaining mobility in late life: demographic characteristics and chronic conditions. *Am J Epidemiol.* 1993; 137:845–857. [PubMed: 8484376]
4. Paskett ED, Stark NN. Lymphedema: knowledge, treatment and impact among breast cancer survivors. *Breast J.* 2000; 6:373–378. [PubMed: 11348395]
5. Petrek JA, Pressman PI, Smith RA. Lymphedema: current issues in research and management. *CA Cancer J Clin.* 2000; 50:292–307. [PubMed: 11075239]
6. Engel J, Kerr J, Schlesinger-Raab A, Sauer H, Holzel D. Axilla surgery severely affects quality of life: results of a 5-year prospective study in breast cancer patients. *Breast Cancer Res Treat.* 2003; 79:47–57. [PubMed: 12779081]
7. Ozaslan C, Kuru B. Lymphedema after treatment of breast cancer. *Am J Surg.* 2004; 187:69–72. [PubMed: 14706589]
8. Kwan W, Jackson J, Weir LM, Dingee C, McGregor G, Olivotto IA. Chronic arm morbidity after curative breast cancer treatment: prevalence and impact on quality of life. *J Clin Oncol.* 2002; 20:4242–4248. [PubMed: 12377968]
9. Velanovich V, Szymanski W. Quality of life of breast cancer patients with lymphedema. *American Journal of Surgery.* 1999; 177:184–188. [PubMed: 10219851]
10. Kornblith AB, Herndon JE, Weiss RB, Zhang C, Zuckerman EL, Rosenberg S, et al. Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy. *Cancer.* 2003; 98:679–689. [PubMed: 12910510]
11. Petrek JA, Heelan MC. Incidence of breast carcinoma-related lymphedema. *Cancer.* 1998; 83:1776–1781.
12. Swedborg I, Wallgren A. The effect of pre- and post-mastectomy radiotherapy on the degrees of edema, shoulder-joint mobility, and gripping force. *Cancer.* 1981; 47:877–881. [PubMed: 7013962]

13. Kissin MW, Quero Della Rovere G, Easton D, Westbury G. Risk of lymphedema following the treatment of breast cancer. *Br J Surg.* 1986; 73:580–584. [PubMed: 3730795]
14. Gerber L, Lampert M, Wood C, Duncan M, D'Angelo T, Schain W, et al. Comparison of pain, motion, and edema after modified radical mastectomy vs. local excision with axillary dissection and radiation. *Breast Cancer Res Treat.* 1992; 21:139–145. [PubMed: 1627817]
15. Paskett ED, Naughton MJ, McCoy TP, Case LD, Abbott JM. The epidemiology of arm and hand swelling in premenopausal breast cancer survivors. *Cancer Epidemiol Biomarkers Prev.* 2007; 16:775–782. [PubMed: 17416770]
16. Werner RS, McCormick B, Petrek J, Cox L, Cirrincione C, Gray JR, et al. Arm edema in conservatively managed breast cancer: obesity is a major predictive factor. *Radiology.* 1991; 180:177–184. [PubMed: 2052688]
17. Guedes Neto HI. Arm edema after treatment for breast cancer. *Lymphology.* 1997; 30:35–36. [PubMed: 9106138]
18. Runowicz CD. Lymphedema: patient and provider education. *Cancer.* 1998; 83:2874–2876. [PubMed: 9874414]
19. Petrek JA, Senie RT, Peters M, Rosen PP. Lymphedema in a cohort of breast carcinoma survivors 20 years after diagnosis. *Cancer.* 2001; 92:1368–1377. [PubMed: 11745212]
20. Sneeuw KC, Aaronson NK, Yarnold JR, Broderick M, Regan J, Ross G, et al. Cosmetic and functional outcomes of breast conserving treatment for early stage breast cancer: relationship with psychosocial functioning. *Radiother Oncol.* 1992; 25:160–166. [PubMed: 1470692]
21. Maunsell E, Brisson J, Deschenes L. Arm problems and psychological distress after surgery for breast cancer. *Can J Surg.* 1993; 36:315–320. [PubMed: 8370012]
22. Passik S, Newman M, Brennan M, Holland J. Psychiatric consultation for women undergoing rehabilitation for upper-extremity lymphedema following breast cancer treatment. *J Pain Symptom Manage.* 1993; 8:226–233. [PubMed: 7963764]
23. Hensley ML, Dowell JM, Herndon II JE, Winer E, Stark N, Weeks JC, et al. Economic outcomes of breast cancer survivorship: CALGB study 79804. *Breast Cancer Res Treat.* 2005; 91:153–161. [PubMed: 15868443]
24. Paskett ED, Herndon II JE, Day JM, et al. Applying a conceptual model for examining health-related quality of life in long-term breast cancer survivors: CALGB study 79804. *Psychooncology.* 2008 in press.
25. Wood WC, Budman DR, Korzun AH, Cooper MR, Younger J, Hart RD, et al. Dose and dose intensity of adjuvant chemotherapy for stage II, node-positive breast carcinoma. *N Engl J Med.* 1994; 330:1253–1259. [PubMed: 8080512]
26. Rubin HR, Gandek B, Rogers WH, Kosinski M, McHorney CA, Ware JE Jr. Patients' rating of outpatient visits in different practice settings: Results from the Medical Outcomes Study. *JAMA.* 1993; 270:835–840. [PubMed: 8340982]
27. Stewart, AL.; Ware, J. *Measure of Functioning and Well-being: The Medical Outcomes Study Approach.* Duke University Press; Durham: 1992.
28. McHorney CA, Ware JE Jr, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Med Care.* 1993; 31:247–263. [PubMed: 8450681]
29. McHorney CA, Ware JE Jr, Lu JFR, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions and reliability across diverse patient groups. *Med Care.* 1994; 32:40–66. [PubMed: 8277801]
30. Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Appl Psychol Meas.* 1977; 1:385–401.
31. Andersen EM, Malmgren JA, Carter WB, Partrick DL. Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *Am J Prev Med.* 1994; 10:77–84. [PubMed: 8037935]
32. Kash, KM.; Jacobsen, PB.; Holland, JC.; Osborne, MP.; Miller, DG. 42nd Annual Meeting of the Academy of Psychosomatic Medicine. Palm Springs; 1995. Measuring breast cancer anxiety..
33. Polivy J. Psychological effects of mastectomy on a woman's feminine self-concept. *J Nerv Ment Dis.* 1977; 164:77–87. [PubMed: 836487]

34. Wilcoxon F. Individual comparisons by ranking methods. *Biometrics Bull.* 1945; 1:80–83.
35. Fisher, R. *The Design of Experiments.* Oliver and Boyd; Edinburg, Scotland: 1935.
36. Kruskal W, Wallis W. Use of ranks in a one-criterion analysis of variance. *J Am Stat Assoc.* 1952; 47:583–621.
37. Jonckheere A. A distribution-free k-sample test against ordered alternatives. *Biometrika.* 1954; 41:133–145.
38. Pyszel A, Malyszczak K, Pyszel K, Andrzejak R, Szuba A. Disability, psychological distress and quality of life in breast cancer survivors with arm lymphedema. *Lymphology.* 2006; 39:185–192. [PubMed: 17319631]
39. Bani HA, Fasching PA, Lux MM, Rauh C, Willner M, Eder I, et al. Lymphedema in breast cancer survivors: assessment and information provision in a specialized breast unit. *Patient Educ Couns.* 2007; 66:311–318. [PubMed: 17331692]
40. McWayne J, Heiney SP. Psychologic and social sequelae of secondary lymphedema: a review. *Cancer.* 2005; 104:457–466. [PubMed: 15968692]
41. Morgan PA, Franks PJ, Moffatt CJ. Health-related quality of life with lymphoedema: a review of the literature. *Int Wound J.* 2005; 2:47–62. [PubMed: 16722853]
42. Carter BJ. Women's experiences of lymphedema. *Oncol Nurs Forum.* 1997; 24:875–882. [PubMed: 9201739]
43. Radina ME, Armer JM. Post-breast cancer lymphedema and the family: a qualitative investigation of families coping with chronic illness. *J Fam Nurs.* 2001; 7:281–299.
44. Thomas-MacLean R, Miedema B, Tatemichi SR. Breast cancer-related lymphedema: women's experiences with an underestimated condition. *Can Fam Physician.* 2005; 51:246–247. [PubMed: 16926934]
45. Tobin MB, Lacy HJ, Meyer L, Mortimer PS. The psychological morbidity of breast cancer related arm swelling. *Cancer.* 1993; 72:3248–3252. [PubMed: 8242549]
46. Ridner SH. Quality of life and a symptom cluster associated with breast cancer treatment-related lymphedema. *Support Care Cancer.* 2005; 13:904–911. [PubMed: 15812652]
47. Beaulac SM, McNair LA, Scott TE, La Morte WW, Kavanah MT. Lymphedema and quality of life in survivors of early-stage breast cancer. *Arch Surg.* 2002; 137:1253–1257. [PubMed: 12413312]
48. Radina ME, Armer JM, Culbertson SD, Dusold JM. Post-breast cancer lymphedema: understanding women's knowledge of their condition. *Oncol Nurs Forum.* 2004; 31:97–104. [PubMed: 14722593]

Table IDemographic and clinical characteristics of study participants by arm/hand swelling status (N = 245)^a

Characteristic	Swelling Since Surgery n = 75	No Swelling Since Surgery n = 170	All Participants ^b n = 245
	n (%)	n (%)	n (%)
<u>Age (years)</u>			
30 -49	10 (13)	13 (8)	23 (9)
50 -59	24 (32)	54 (32)	78 (32)
60 -69	30 (40)	62 (36)	92 (38)
70	11 (15)	41 (24)	52 (21)
Mean (SD)	61 (9)	63 (10)	63 (10)
<u>Race</u>			
White	69 (92)	160 (90)	229 (94)
Other	6 (8)	10 (6)	16 (7)
<u>Marital Status</u>			
Single	5 (6)	10 (6)	15 (6)
Married/living as married	50 (67)	113 (67)	163 (67)
Separated/divorced/widowed	20 (27)	46 (27)	66 (27)
<u>Education</u>			
< High school	39 (54)	83 (52)	122 (53)
Some college	28 (33)	56 (35)	84 (36)
Post-graduate	5 (7)	20 (13)	25 (11)
<u>Annual Household Income</u>			
< \$30,000	26 (39)	46 (32)	72 (34)
\$30,000 - \$44,999	10 (15)	28 (20)	38 (18)
\$45,000 - \$59,999	9 (13)	17 (12)	26 (12)
\$60,000	22 (33)	52 (36)	74 (35)
<u>Occupational Status</u>			
Employed full-time	23 (31)	54 (32)	77 (32)
Employed part-time	7 (9)	25 (15)	32 (13)
Retired	28 (37)	57 (34)	85 (35)
Homemaker	11 (15)	24 (14)	35 (14)
Other ^c	6 (8)	8 (5)	14 (6)
<u>Time (years) since Diagnosis</u>			
Mean	12.4	12.6	12.5
Range	9.4 - 16.4	9.4 - 16.5	9.4 - 16.5
<u>Number of Nodes Removed</u>			
10	11 (15)	29 (17)	40 (16)
11 - 15	11 (15)	60 (35)	71 (29)
16 -20	23 (31)	37 (22)	60 (24)
21 -25	17 (23)	25 (15)	42 (17)
26	13 (17)	19 (11)	32 (13)

Characteristic	Swelling Since Surgery n = 75	No Swelling Since Surgery n = 170	All Participants ^b n = 245
	n (%)	n (%)	n (%)
<u>Number of Positive Nodes</u>			
1 -4	59 (79)	141 (83)	200 (82)
5 -9	10 (13)	23 (14)	33 (13)
10	6 (8)	6 (4)	12 (5)

^aNote: Frequencies do not sum to sample size total for education level, income, and occupational status due to missing data.

^bThere were no significant demographic differences between survivors who reported swelling and those who did not.

^c“Other” category consists of unemployed persons and students.

Table II

Swelling characteristics of study participants who reported arm/hand swelling since surgery (N = 75)

Characteristic	N (%)
<u>Onset since Surgical Treatment</u> ^a	
< 6 months	27 (36)
6 - 12 months	5 (7)
1 to < 2 years	9 (12)
2 to < 5 years	10 (13)
5 to < 10 years	6 (8)
10 - 15 years	3 (4)
<u>Frequency</u> ^a	
Constantly	37 (49)
Not constantly	31 (41)
<u>Location</u> ^a	
Hand	10 (13)
Upper arm	25 (33)
Lower arm	8 (11)
Hand and lower arm	4 (5)
Hand and upper arm	2 (3)
Upper and lower arm	10 (13)
Entire arm and hand	16 (21)
<u>Severity</u> ^a	
Mild	38 (51)
Moderate	28 (37)
Severe	7 (9)
<u>Perceived Cause</u> ^a (multiple responses permitted)	
Removal of axillary lymph nodes	55 (73)
General use of arm	17 (23)
Infection/injury to arm/hand	13 (17)
Weather changes	9 (12)
Exercise	4 (5)
Radiation treatment	4 (5)
Airplane travel	3 (4)
Breast reconstruction	3 (4)
Other	9 (12)
<u>Interference with Daily Activities</u> ^a	
Yes	52 (69)
No	22 (29)
<u>Source of Interference</u> ^b (multiple responses permitted)	
Clothes	27 (52)

Characteristic	N (%)
Your appearance	24 (46)
Routine activities	12 (23)
Exercise	4 (8)
Other	11 (21)
<u>Current Swelling^a</u>	
Yes	57 (76)
No	17 (23)
<u>Sought Treatment for Swelling^a</u>	
Yes	28 (37)
No	45 (60)
<u>Type of Treatment for Swelling^c (multiple responses permitted)</u>	
Glove/sleeve compression	15 (54)
Machine compression therapy	11 (39)
Mechanical lymphatic drainage	8 (29)
Bandaging technique	8 (29)
Other	9 (32)
<u>Experienced Pain with Swelling^a</u>	
Yes	32 (43)
No	42 (56)
<u>Pain Severity^d (range 1-10)</u>	
Mean	5.34
<u>Pain Frequency^d</u>	
Occasional	22 (69)
Constant	6 (18)
Other	4 (13)
<u>Pain Interference with Daily Activities^d</u>	
Yes	15 (47)
No	16 (50)
<u>Spoke with a Physician about Pain^d</u>	
Yes	19 (59)
No	11 (34)
<u>Treatment Recommended for Pain^e</u>	
Yes	16 (84)
No	3 (16)

^a Note: Frequencies may not sum to sample size total due to missing data and skip patterns in questionnaire. Total possible sample sizes are: N = 75;

^b Note: Frequencies may not sum to sample size total due to missing data and skip patterns in questionnaire. Total possible sample sizes are: N = 52;

^c Note: Frequencies may not sum to sample size total due to missing data and skip patterns in questionnaire. Total possible sample sizes are: N = 28;

^d Note: Frequencies may not sum to sample size total due to missing data and skip patterns in questionnaire. Total possible sample sizes are: N = 32;

^e Note: Frequencies may not sum to sample size total due to missing data and skip patterns in questionnaire. Total possible sample sizes are: N = 19

Table IIIRelationship between arm/hand swelling, perceived physical functioning, and mental health^a

Outcome ^b	Swelling Since Surgery N=75	No Swelling Since Surgery N=170
Perceived Physical Functioning		
SF-36 physical component		
N	75	170
Mean	77.59	76.18
Median	85.00	90.00
Standard Deviation	26.00	29.76
Range	5 - 100	0 - 100
Mental Health		
Depression		
N	74	170
Mean	9.95	9.37
Median	7.00	7.00
Standard Deviation	8.92	8.41
Range	0 - 38.95	0 - 51
Breast cancer anxiety		
N	72	163
Mean	0.79	0.80
Median	0.67	0.69
Standard Deviation	0.46	0.45
Range	0.00 - 2.07	0.07 - 2.36
Body satisfaction		
N	75	167
Mean	25.09	26.06
Median	24.00	26.00
Standard Deviation	7.15	7.70
Range	12 - 40	8 - 40
SF-36 mental component		
N	75	169
Mean	76.11	77.04
Median	80.00	84.00
Standard Deviation	16.60	16.63
Range	28 - 100	20 - 100

^aNote: Frequencies may not sum to sample size due to missing data.^bThere were no significant differences between survivors who reported swelling and those who did not.

Relationship between arm/hand swelling characteristics, perceived physical functioning, and mental health among women reporting arm/hand swelling (N = 75)

Table IV

OUTCOMES															
Perceived Physical Functioning							Mental Health								
Swelling Characteristic	SF-36 Physical Component			Depression			Breast Cancer Anxiety			Body Satisfaction			SF-36 Mental Component		
	N	Mean (S.D)	p	N	Mean (S.D)	p	N	Mean (S.D)	p	N	Mean (S.D)	p	N	Mean (S.D)	p
Onset			NS			NS			NS			NS			NS
< 6 months	27	74.2 (26.5)		27	10.1 (9.9)		26	11.1 (5.7)		27	26.4 (8.2)		27	77.0 (17.8)	
6 mos. to < 2yrs	14	86.9 (15.4)		14	7.2 (7.3)		14	9.2 (4.5)		14	25.4 (8.3)		14	80.9 (9.4)	
2 years	19	68.6 (30.0)		18	8.4 (6.2)		17	12.6 (7.8)		19	24.2 (5.7)		19	78.5 (16.2)	
Frequency			NS			NS			0.006			NS			NS
Not Constant	31	74.7 (24.6)		31	11.3 (9.7)		31	13.7 (7.4)		31	23.4 (6.8)		31	76.1 (16.3)	
Constant	37	78.1 (26.7)		36	8.9 (8.1)		34	9.2 (4.6)		37	25.9 (6.8)		37	76.5 (17.1)	
Severity			0.008 ^a			0.16 ^a			NS			NS			0.08 ^a
Mild	38	84.3 (21.8)		38	8.7 (8.1)		37	10.5 (6.4)		38	25.3 (7.0)		38	80.1 (13.6)	
Moderate	28	75.9 (25.2)		27	9.5 (9.0)		27	11.9(6.7)		28	24.8 (7.5)		28	73.9 (17.0)	
Severe	7	48.6 (35.3)		7	16.7 (10.6)		6	10.8 (4.8)		7	25.0 (7.9)		7	66.9 (25.3)	
Activity Interference			0.01			NS			NS			NS			NS
No	22	88.1 (16.0)		22	8.6 (8.4)		21	9.7 (6.7)		22	25.5 (7.7)		22	78.7 (14.7)	
Yes	53	73.2 (28.2)		52	10.5 (9.2)		51	11.8(6.3)		53	24.9 (7.0)		53	75.0 (17.3)	
Interference Source			NS			NS			NS			NS			NS
Single	34	77.8 (25.2)		33	10.0 (9.4)		34	11.8(6.3)		34	24.5 (6.4)		34	75.3 (16.4)	
Multiple	19	65.1 (31.9)		19	11.4 (8.8)		17	11.5 (6.3)		19	25.7 (8.0)		19	74.5 (19.4)	
Treatment Seeking			0.06 ^a			NS			NS			NS			NS
No	45	73.1 (30.2)		44	11.3 (9.9)		44	11.5 (6.2)		45	24.9 (7.7)		45	74.4 (18.5)	
Yes	28	83.7 (16.7)		28	8.1 (7.0)		26	10.5 (7.0)		28	25.3 (6.5)		28	79.7 (12.8)	

^a p-value resulting from Jonckheere-Terpstra test (two-sided).