The Role of Information Sources and Objective Risk Status on Lymphedema Risk-Minimization Behaviors in Women Recently Diagnosed With Breast Cancer

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Lymphedema, characterized by long-term arm swelling from disruption of the lymph nodes (Moffatt et al., 2003), is a physically debilitating condition that may develop following breast cancer surgery and treatment (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Loudon & Petrek, 2000). An estimated 20% of people treated for breast cancer will develop lymphedema (Hayes, Janda, Cornish, Battistutta, & Newman, 2008). Removal or irradiation of axillary lymph nodes (Bani et al., 2007; Goffman, Laronga, Wilson, & Elkins, 2004; van der Veen et al., 2004), infections, and obesity (Ridner & Dietrich, 2008; Swenson, Nissen, Leach, & Post-White, 2009) are known lymphedema risk factors. Compromised quality of life and psychological morbidity during short- and long-term survivorship have been associated with lymphedema (Armer, 2005; Greenslade & House, 2006; Mansel et al., 2006). Sentinel lymph node biopsy (SLNB), a less invasive surgical technique than axillary lymph node dissection (ALND), has reduced lymphedema incidence (Francis et al., 2006; Lucci et al., 2007) up to one year postsurgery (Langer, Guenther, Haigh, & Difronzo, 2004; Mansel et al., 2006; Purushotham et al., 2005). However, not all women are candidates for SLNB, and at least 35% of women who initially undergo SLNB return later for ALND following the detection of more extensive cancer (Husen, Paaschburg, & Flyger, 2006; Langer et al., 2007; Leidenius, Leivonen, Vironen, & von Smitten, 2005). Therefore, despite the availability of less invasive surgical techniques, a substantial number of women with breast cancer will undergo procedures that increase their objective lymphedema risk (Cheville, 2007).

Any means by which lymphedema risk can be minimized is beneficial. National breast cancer organizations publish guidelines that recommend lifetime adoption of strategies to minimize lymphedema risk and highlight the importance of early detection and treatment if

Purpose/Objectives: To assess the role of education sources and objective risk status on knowledge and practice of lymphedema risk-minimization behaviors among women recently diagnosed with breast cancer.

Research Approach: Prospective survey.

Setting: A hospital in Sydney, Australia.

Participants: 106 women recently diagnosed with breast cancer at increased risk for developing lymphedema following lymph node dissection.

Methodologic Approach: A questionnaire administered at the time of surgery and three months after surgery measured demographics, lymphedema knowledge, lymphedema information sources used, and adherence to risk-minimization recommendations.

Main Research Variables: Lymphedema knowledge, source of information used, objective lymphedema risk, and adherence to risk-minimization behaviors.

Findings: Knowledge was high and increased over time. Lymphedema information from the clinic (e.g., brochures, nursing staff) was the most cited source. Adherence to recommendations was moderate; nonadherence was mostly for behaviors requiring regular enactment. Regression analysis revealed that only receipt of information from nursing staff and lymphedema knowledge three months after surgery were significant predictors of risk-minimization behaviors.

Conclusions: Exposing women to lymphedema risk information at the time of breast cancer diagnosis facilitates increased awareness and enactment of risk-minimization behaviors. Nursing staff play a key role in disseminating this information and in convincing women to perform the recommendations.

Interpretation: Provision of lymphedema education by breast clinic staff is critical to ensure that women realize the importance of early detection and treatment. Reminder booster sessions by nursing staff may be beneficial particularly for longer-term knowledge retention and adherence to recommended behaviors.

symptoms develop (Bani et al., 2007; Erickson et al., 2001). Risk management information is a critical component of care for women with breast cancer who are at increased risk for developing lymphedema (Kirshbaum, 1996; Lee et al., 2009; Runowicz et al., 1998). The information is available from various sources including brochures, nursing and specialist staff in breast clinics, national breast cancer organizations, and the Internet. Breast care nurses are ideally placed to improve patient lymphedema education and provide general support (Halkett, Arbon, Scutter, & Borg, 2006; Liebert et al., 2003), but research suggests that the educational role of nurses is underused (Bosompra et al., 2002; Coward, 1999). Informal networks from family members or friends who have experienced breast cancer also may be a valuable source of information about lymphedema for women recently diagnosed with breast cancer (Bilodeau & Degner, 1996).

Despite the importance of lymphedema knowledge, limited cross-sectional data indicate that knowledge levels and exposure to lymphedema education are low, particularly among asymptomatic women (Bosompra et al., 2002; Coward, 1999). In addition, many women are unaware of lymphedema until they are diagnosed with the condition (Ridner, 2006; Thiadens & Armer, 2002; Thomas-MacLean, Miedema, & Tatemichi, 2005). Adherence to recommended risk-reduction behaviors generally is low but is higher for women experiencing symptoms (Bani et al., 2007; Bosompra et al., 2002; Coward, 1999), suggesting that once women understand the relevance of risk-reduction behaviors, they are willing to take appropriate action. The direct association of knowledge and adherence to recommendations has not been investigated, but asymptomatic women tend to have lower knowledge and lower adherence than women with lymphedema symptoms (Bosompra et al., 2002). High knowledge is matched by high adherence for some recommendations (e.g., blood pressure readings), but knowledge is not reflected in practice for others (e.g., avoiding trauma to the arm, wearing gloves for housework) (Bosompra et al., 2002). This may reflect the relative frequency of the recommendations—measuring blood pressure generally is sporadic, whereas the need to avoid trauma and wear protection for household duties requires consistent practice. Therefore, adherence to the latter two behaviors may require greater lifestyle change and vigilance, which is consistent with adherence for health-related lifestyle behaviors in general that are known to be difficult to initiate and maintain (Heisler, Cole, Weir, Kerr, & Hayward, 2007; Horne, 2006; Vermeire et al., 2005).

Caution is needed when interpreting the findings of prior research in this area. The cross-sectional, retrospective accounts are susceptible to recall bias and are limited in their ability to predict behaviors. Research also has been conducted among heterogeneous samples regarding time elapsed since breast surgery (up to five years) and lymphedema risk, with some studies including women with

Table 1. Sample Characteristics

Characteristic	X̄	SD
Age (years)	55.3	10.6

Characteristic	n	%
Region of origin		
Australia	72	68
New Zealand	3	3
United Kingdom or Ireland	10	9
Southeast Asia	10	9
Europe	6	6
Middle East	2	2
Pacific	1	1
Unknown	2	2
Education		
Less than 10 years	24	23
School certificate (10 years)	30	28
High school certificate (12 years)	5	5
Vocational or technical qualifications	15	14
Bachelor's degree	22	21
Postgraduate	9	8
Unknown	1	1
Marital status		
Married or partnered	74	71
Divorced or separated	17	16
Single	9	9
Widowed	5	5
Unknown	1	1
Type of lymph node surgery		
Sentinel lymph node biopsy	54	51
Axillary lymph node dissection	52	49
Clinical stage of breast cancer		
0	9	8
I	29	27
II	38	36
III	28	26
Unknown	2	2
Menopausal status		
Premenopausal	30	28
Postmenopausal	73	69
Unknown	3	3

N = 106
Note. Because of rounding, not all percentages total 100.

no lymph node surgery who were not at risk for lymphedema (Bani et al., 2007; Bosompra et al., 2002; Coward, 1999; Ridner, 2006). Low knowledge and adherence may be confounded by those methodologic shortcomings.

The current study addressed the methodologic shortcomings and extended previous research by undertaking a prospective, longitudinal assessment of lymphedema knowledge and adherence to risk-minimization behaviors among women recently diagnosed with breast cancer who were at increased risk for developing lymphedema following lymph node dissection. The sources of lymphedema information used were identified, as well as which sources were most influential in relation to risk-minimization behaviors. The authors compared knowledge and behaviors of individuals according to objective lymphedema risk. Assessments took place perioperatively and at three

months following surgery. The authors predicted that receipt of lymphedema information would be associated with greater knowledge and adherence to recommended behaviors. The authors further predicted that relatively low rates of adherence to recommendations requiring frequent practice would be evident, compared with less frequent activities. Women who had undergone ALND should demonstrate greater lymphedema knowledge and adherence to recommendations than women at lower objective risk who had undergone SLNB. Finally, the authors assessed the role of different lymphedema information sources, objective lymphedema risk, and knowledge to identify the strongest independent predictors of adopting risk-minimization behaviors.

Methods

Participants and Procedure

Participants were identified through the breast cancer clinic of a major hospital in Sydney, Australia. Inclusion criteria were women older than 18 years, diagnosed with breast cancer within the prior week, and scheduled for breast surgery including lymph node surgery (SLNB or ALND). Eligible women were invited into the study by the breast clinic's research and clinical trials coordinator on the day of breast cancer diagnosis. Willing participants contacted the researchers to receive a study package containing consent forms and the baseline questionnaire. Participants completed the self-report baseline questionnaire and returned it by mail to the researchers. A follow-up questionnaire was sent to participants for completion three months later. One hundred six of 160 eligible women participated (66% recruitment rate). Reasons given for declining the invitation included being overburdened with participation in other studies, not being interested in research participation, and insufficient time to participate in research. Four participants withdrew after baseline assessment, and four were unable to complete the follow-up because of ill health, leaving 98 participants in total. Analyses of variance and chi-square analyses were conducted to assess whether individuals who dropped out from the study differed from those who remained at three months. No differences were found between the two groups on demographic and medical history variables, baseline knowledge, and information sources used at baseline. Approval for the study was obtained through relevant institutional human ethics review committees.

Measures

Demographic and medical history variables: Age, country of birth, marital status, education level, and medical history including breast health and treatment history were collected.

Objective risk for developing lymphedema: Women undergoing ALND were classified as being at high risk for developing lymphedema (Lee, Kilbreath, Refshauge, Herbert, & Beith, 2008). Women with SLNB were classified as lower risk, reflecting the outcomes of short-term clinical trials data (Wilke et al., 2006).

Lymphedema-related knowledge: Twenty counter-balanced true-false items relating to lymphedema risk management were used to assess lymphedema knowledge, similar to items used in prior research (Bosompra et al., 2002; Coward, 1999). Correct answers were scored as 1 and incorrect answers were scored as 0. Scores were summed out of 20, with higher scores indicating higher knowledge ($\alpha = 0.72$, indicating acceptable item reliability).

Sources of lymphedema information: Participants indicated which lymphedema information sources they used from a checklist, including breast clinic sources (e.g., brochure, an allied health lymphedema information session, oncologist, breast care nurse) and external sources (e.g., Cancer Council New South Wales, local library, Internet), similar to previous research in this area (Lee et al., 2009). Breast cancer and lymphedema history in family and friends also was collected because those individuals are potential sources of information relating to lymphedema.

Adherence to risk-minimization behaviors: Twelve self-report items based on the national lymphedema guidelines were used to assess current adherence for each risk-management strategy. Recommendations practiced were scored as 1, with a total score summed out of 12. Cronbach alpha of 0.86 for this scale indicated high internal consistency.

Data Analysis Procedures

SPSS®, version 17, was used for all statistical analyses. Descriptive statistics were generated for all study variables. Bivariate analyses using Pearson correlation and chi-square explored the associations between outcome

Table 2. Adjuvant Treatments at Baseline and Follow-Up

	Baseline (N = 106)				Follow-Up (N = 98)			
	SLNB		ALND		SLNB		ALND	
Treatment	n	%	n	%	n	%	n	%
Chemotherapy	1	1	10	9[a]	12	12	21	21[b]
Radiation	3	3	–	–	12	12	14	14
Hormone therapy	–	–	2	2	9	9	9	9

[a] Significantly more women with ALND had chemotherapy at baseline (chi-square = 8.47, df = 1, p = 0.004).

[b] Significantly more women with ALND had chemotherapy at follow-up (chi-square = 4.04, df = 1, p = 0.044).

ALND—axillary lymph node dissection; SLNB—sentinel lymph node biopsy

Table 3. Awareness of Risk-Management Guidelines by Objective Risk Level

Guideline	Baseline SLNB (N = 54) n	Baseline SLNB (N = 54) %	Baseline ALND (N = 52) n	Baseline ALND (N = 52) %	OR	p	Follow-Up SLNB (N = 49) n	Follow-Up SLNB (N = 49) %	Follow-Up ALND (N = 49) n	Follow-Up ALND (N = 49) %	OR	p
Breast cancer treatment increases your chances of developing lymphedema.	41	82	42	84	1.15	0.79	43	92	37	77	0.35	0.08
Women who have ALND followed by radiation therapy have a higher risk for lymphedema.	39	78	43	86	1.73	0.3	45	96	38	91	0.21	0.03
Lymphedema can occur only within the first month following surgery for breast cancer.[a]	40	89	44	88	0.92	0.89	44	94	42	88	0.34	0.18
Lymphedema can occur at any time following breast cancer surgery.	42	84	46	90	1.75	0.35	45	94	45	94	1.1	0.91
Avoiding blood pressure readings and injections on the affected arm is advised.	43	88	47	92	1.64	0.46	47	98	43	90	0.2	0.1
Consult with the doctor or therapist immediately if you notice redness, warmth of the skin, pain in the arm, fever, any change in the size of arm, or heaviness or aching when doing activities.	49	96	51	100	0.98	1	48	98	47	98	1.1	0.96
When manicuring your nails, always cutting the cuticles is recommended. [a]	41	85	44	88	1.25	0.71	39	83	43	92	1.36	0.64
Keeping your affected arm very clean and well moisturized is recommended.	44	86	43	86	0.98	0.97	46	94	45	92	0.8	0.78
Consult with your therapist or doctor about precautionary measures that you should take if you are planning to travel long distances by air or road.	45	90	50	98	5.56	0.08	45	94	45	96	1.64	0.59
Always wear gloves when doing housework or gardening and treat cuts and scratches promptly.	46	90	43	84	0.58	0.37	47	98	47	96	0.55	0.62
Regularly exposing your affected arm to the sun is recommended. [a]	42	89	48	94	1.91	0.39	46	96	47	98	2.23	0.51
You should avoid carrying heavy shopping, luggage, or other objects with your affected arm.	48	94	46	90	0.58	0.46	49	96	48	90	0.4	0.27
Wearing tight jewelry around the affected fingers or arm is acceptable. [a]	48	94	44	88	0.46	0.28	48	96	48	92	0.52	0.46
Try to avoid extreme temperature changes when bathing, washing dishes, etc.	38	78	40	82	1.29	0.62	48	96	45	87	0.31	0.14
An inflammation or infection in the affected arm may be a sign of lymphedema.	23	50	29	59	1.45	0.37	28	62	26	59	0.98	0.96
Try to avoid trauma in the affected arm (e.g., bruising, cuts, burns, sports injuries, insect bites).	46	90	48	98	5.22	0.09	46	96	48	100	2.14	0.08
Wearing a well-fitted bra with wire support is advisable. [a]	32	67	38	76	1.58	0.31	38	81	39	85	1.47	0.49
Only using an electric razor to remove hair from under your arm is advisable.	34	72	34	68	0.81	0.64	40	85	40	83	0.97	0.96
If you cut or puncture your affected arm, wash the area immediately and cover with a gauze dressing.	47	92	48	98	4.09	0.17	45	96	46	94	0.75	0.75
Avoid strenuous, repetitive activity (e.g., scrubbing bathroom tiles).	39	78	43	86	1.73	0.3	41	87	42	84	0.6	0.44

[a] Reverse worded to avoid response bias and reverse coded when calculating awareness scores
ALND—axillary lymph node dissection; OR—odds ratio; SLNB—sentinel lymph node biopsy
Note. Because of missing data, sample sizes vary for each guideline across time points.

and all other variables and were used to identify variables that needed to be included as covariates in subsequent analyses. At follow-up, level of education was correlated with the number of information sources used (r = 0.213, p = 0.029). Therefore, education was treated as a covariate; adjusted means are reported. Analysis of covariance was conducted to assess differences in lymphedema knowledge and usage of information sources over time and by lymphedema risk. Chi-squared analyses with McNemar test were conducted to ascertain whether the frequency of participants using a source of lymphedema information differed from baseline to follow-up. Odds ratios were calculated for each knowledge and adherence item to determine differences in the likelihood of a participant answering the item correctly or adhering to the recommendation, respectively, according to her relative lymphedema risk. Finally, a linear regression model was applied to learn which variables were the strongest independent predictors of adherence to recommended behaviors. The variables of interest entered into the regression equation included objective lymphedema risk, information sources and knowledge, and the covariates education and chemotherapy status. Unless otherwise indicated, a critical p value of 0.05 was used.

Results

Table 1 and 2 show demographic and clinical characteristics for the sample, with about equal numbers of women receiving SLNB or ALND. At baseline and follow-up, the ALND group was more likely to be receiving chemotherapy, a variable controlled for in subsequent analyses.

Lymphedema Knowledge

Table 3 provides the percentage of participants correctly answering each knowledge item at baseline and

follow-up. No differences were found in knowledge according to lymph node surgery (a Bonferroni adjusted critical p value of 0.05 divided by 20 = 0.003 was used in these analyses).

The mean lymphedema knowledge score was 16.69 (SD = 2.71; range 8–20) at baseline and 17.78 (SD = 2.1; range 9–20) at follow-up. Knowledge increased from baseline to follow-up (F[1, 91] = 6.12, p = 0.015, η^2 = 0.063). Controlling for chemotherapy usage and education, no differences were found in knowledge by lymphedema risk at baseline (ALND: $\overline{X}$ = 16.92, SD = 2.44; SLNB: $\overline{X}$ = 16.3, SD = 3) or follow-up (ALND: $\overline{X}$ = 17.36, SD = 2.37; SLNB: $\overline{X}$ = 18.07, SD = 1.84).

Lymphedema Information Sources

Table 4 reports sources of lymphedema information used by participants. At baseline, the brochure was most cited as a source of information, followed by nursing staff, Cancer Council New South Wales materials, the oncologist, the Internet, allied health information sessions, and the library. At follow-up, nurses were cited most, followed by the brochure; otherwise, the order remained intact. The number of participants receiving information from nurses, oncologists, and the Cancer Council increased from baseline to follow-up; no changes were evident for usage of the other sources. At baseline, women informed by nursing staff were more likely to have received the brochure (r = 0.47, p = 0.0005), and women informed by the oncologist were more likely to have received information from the Cancer Council (r = 0.2, p = 0.042) and the Internet (r = 0.2, p = 0.04). At follow-up, women informed by nursing staff were more likely to cite the brochure (r = 0.3, p = 0.003) and the Cancer Council (r = 0.21, p = 0.044), whereas women informed by the oncologist were more likely to cite the Cancer Council (r = 0.02, p = 0.024). Women informed by the Cancer Council also were more likely to have used the Internet (r = 0.25, p = 0.013).

Table 4. Lymphedema Information Sources Used by Patients Recently Diagnosed With Breast Cancer

| | Baseline (N = 105) | | | | Three Months (N = 98) | | | | | |
| | Using Source | | Not Using Source | | Using Source | | Not Using Source | | | |
Information Source	n	%	n	%	n	%	n	%	χ^{2a}	p
Given brochure on lymphedema and risk minimization	63	60	42	40	68	69	30	31	1.35	0.65
Attended allied health lymphedema information session	4	4	101	96	8	8	90	92	1.16	0.15
Clinic surgeon or oncologist	31	30	74	70	50	51	48	49	10.99	0.001
Clinic breast care nursing staff	55	52	50	48	72	73	26	27	5.74	0.001
Cancer Council New South Wales	45	43	60	57	62	63	36	38	11.25	0.001
Internet searching	13	12	92	88	19	19	79	81	18.41	0.0118
Local library	2	2	103	98	3	3	95	97	0.067	0.8
Family history of breast cancer[b]	41	39	59	56	–	–	–	–	–	–
Family history of lymphedema[b]	29	28	64	61	–	–	–	–	–	–

[a] Using McNemar test

[b] Because of missing data, sample size varies.

In total, 41 (39%) participants indicated that they had received lymphedema information from a family member who had previously been diagnosed with breast cancer, and 29 (28%) received information from a family member or friend who had experienced breast cancer-related lymphedema. However, having a friend or family member with breast cancer or lymphedema was not related to usage of any other information sources.

Sixteen respondents at baseline (15%) did not receive any lymphedema information, compared with four respondents (4%) at follow-up. The mean number of baseline information sources used (2.61, SD = 1.5) was lower than at follow-up (3.22, SD = 1.63) (t = 3.77, df = 105, p = 0.0001), but no differences emerged by lymphedema risk at baseline (ALND: $\bar{X}$ = 2.81, SD = 1.72; SLNB: $\bar{X}$ = 2.47, SD = 1.3) or follow-up (ALND: $\bar{X}$ = 3.62, SD = 1.68; SLNB: $\bar{X}$ = 2.98, SD = 1.73). Lymphedema knowledge was associated with total number of information sources at baseline (r = 0.36, p = 0.0001) and follow-up (r = 0.28, p = 0.06).

Adherence to Risk-Management Guidelines

The mean total adherence was 9.53 (SD = 2.95; range 0–12), with 32 women performing every recommendation and 2 performing none (see Table 5). No differences in adherence were evident by lymphedema risk. Adherence was high for most recommendations. However, about 28% of participants were nonadherent to consulting a doctor if symptoms appeared, wearing gloves during housework and gardening, and using an electric razor to remove underarm hair. Odds ratios indicated that no differences were evident in adherence according to lymphedema risk. A nonsignificant trend (OR = 0.4, p = 0.056) suggested that women with SLNB were less likely to consult with a doctor once lymphedema symptoms arose. Adherence to guidelines was strongly correlated with lymphedema total knowledge (r = 0.5, p = 0.0001).

The impact of information sources on adherence to guidelines was first assessed by the mean adherence according to the information source cited (see Table 6). Adherence of women receiving information from the brochure and from clinic staff (e.g., nurses, oncologists, allied health session) was greater than adherence of women not receiving information from those sources. No difference in adherence to guidelines was evident for women receiving or not receiving information from the Cancer Council, library, the Internet, or family and friends. To ascertain the relative contribution of objective lymphedema risk, each information source, and overall knowledge to levels of adherence to behaviors, a linear regression model was tested controlling for education and chemotherapy status (see Table 7). The model was significant (F[13, 61] = 3.49, p = 0.0001). Only receipt of information from nursing staff and follow-up lymphedema knowledge were found to be significant independent predictors of the risk-minimization behaviors.

Discussion

The initial aim of the current research was to document lymphedema knowledge among women recently diagnosed with breast cancer who were at higher risk for developing lymphedema following lymph node dissection. Contrary to previous reports of low knowledge (Bosompra et al., 2002; Coward, 1999), participant knowledge was high at the time of surgery and had increased three months later. This discrepancy between findings may be related to the fact that the current sample only included women for whom lymphedema risk was salient, unlike the previous research that has used samples with varying risk. An unexpected finding was that objective risk did not distinguish between knowledge levels either in the perioperative period or at follow-up. This outcome

Table 5. Respondents Currently Performing Risk-Minimization Recommendations at Three Months

Recommendation	Total (N = 98)		SLNB (N = 49)		ALND (N = 49)		OR	p
	n	%	n	%	n	%		
Blood pressure readings should be taken on unaffected arm.	82	89	39	98	43	90	0.91	0.88
Consult with doctor if lymphedema symptoms are experienced.	63	72	25	63	38	81	0.4	0.06
Do not cut cuticles.	71	80	34	81	37	79	1.15	0.79
Well moisturize arm and hand.	79	88	41	93	38	83	2.88	0.13
Wear gloves when performing household cleaning and gardening.	61	66	29	64	32	67	0.91	0.82
Avoid sun exposure.	79	86	37	82	42	89	0.55	0.33
Avoid lifting heavy loads for long periods.	73	79	36	80	37	77	1.19	0.73
Avoid wearing tight jewelry.	81	87	40	89	41	85	1.37	0.62
Avoid temperature extremes.	78	84	37	82	41	85	0.79	0.68
Avoid trauma.	80	87	40	91	40	83	2	0.28
Wear loose clothing.	81	88	39	89	42	88	1.1	0.87
Use an electric razor for shaving underarms.	58	70	30	75	28	65	1.6	0.33

ALND—axillary lymph node dissection; OR—odds ratio; SLNB—sentinel lymph node biopsy

Note. Because of missing data, sample sizes vary for each recommendation across groups.

Table 6. Impact of Information Sources With Mean Use of Risk-Minimization Strategies

Information Source	Source Cited		Source Not Cited			
	X̄	SD	X̄	SD	t	p
Brochure	10.2	2.26	7.9	3.76	−2.98	0.005
Lymphedema information session	11.6	0.84	9.28	3.02	−5.46	0.0001
Clinic surgeon or oncologist	10.28	2.34	8.85	3.15	−2.41	0.019
Clinic breast care nursing staff	10.11	2.36	7.95	3.61	−2.53	0.018
Cancer Council New South Wales	9.97	2.47	9	3.31	−1.43	0.16
Internet searching	9.8	3.1	9.59	2.76	−2.48	0.81
Local library	9.67	2.31	9.64	2.84	−0.018	0.99
Family history of breast cancer	9.82	2.58	9.39	3.07	0.67	0.51
Family history of lymphedema	9.96	2.78	9.48	2.99	0.68	0.5

may be of concern, particularly for women deemed at higher risk of developing lymphedema. However, lymphedema knowledge was very high in both groups, suggesting a ceiling effect may have occurred. Curiously, when looking at responses to individual knowledge items, women in the higher risk group at follow-up were less knowledgeable about the link between lymphedema onset and breast cancer treatment, particularly axillary node surgery followed by radiation treatment. However, the same women demonstrated a complete awareness of the need to avoid trauma to the affected arm. The findings are perplexing and suggest some level of misunderstanding among high-risk women regarding the etiology of lymphedema.

The current study also documented the source and timing of lymphedema information accessed by women following breast cancer diagnosis. The brochure was the most used information source in the perioperative period, whereas information from breast care nurses was most used at follow-up. The strong association between receipt of the brochure and information from breast care nurses suggests that nurses are the primary source of distribution of the brochure. The receipt of information from nursing and specialist staff increased over time, suggesting that much of the information exchange occurs at follow-up consultations or during adjuvant treatment sessions. Family members and friends with experience in breast cancer and lymphedema were sources of information used by almost 40% of the current sample, consistent with prior research in the breast cancer context (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). However,

those particular sources of information were not related to adherence to risk-management behaviors.

A second aim was to document the level of adherence to risk management recommendations at the three-month assessment. Compared with prior research reporting low adherence (Bosompra et al., 2002; Coward, 1999), the current authors found moderate to high levels of adherence, suggesting that the message regarding risk management was being processed and accepted by most women in the study. Again, the difference in findings may be attributed to the use of a homogenous high-risk sample in the current research, compared with heterogeneous samples in earlier investigations (Bosompra et al., 2002). The current study also assessed knowledge and adherence in a relatively short timeframe, as opposed to prior studies that have assessed adherence up to 17 years postsurgery (Coward, 1999).

As predicted, and consistent with prior studies in this area (Bosompra et al., 2002; Coward, 1999), two of the risk management recommendations (wearing gloves when doing household duties and gardening and using an electric razor for underarm hair removal) had low adherence. Those actions require regular practice and a greater level of ongoing lifestyle change than other recommendations that involve more sporadic actions (e.g., which arm to use when taking blood pressure measurements) or activities that are similar to everyday behaviors. For example, the recommendation to keep skin moisturized is performed by many women as a matter of daily grooming and may not necessitate a large lifestyle change, whereas needing to wear protective gloves when undertaking

Table 7. Regression Model Predicting Practice of Risk-Minimization Behaviors

Variable	B	Standard Error	β	t	p
Education	0.08	0.17	0.06	0.49	0.63
On chemotherapy	0.46	0.62	0.08	0.74	0.46
Objective lymphedema risk	0.5	0.65	0.09	0.76	0.45
Brochure	0.6	0.75	0.09	0.8	0.43
Lymphedema information session	0.86	1.01	0.09	0.86	0.4
Oncologist	0.78	0.63	0.14	1.24	0.22
Nursing staff	2.07	0.79	0.31	2.63	0.01
Cancer Council New South Wales	0.03	0.75	0.01	0.04	0.97
Internet	−0.44	0.78	−0.06	−0.56	0.58
Local library	2.03	2.74	0.08	0.74	0.46
Family member with lymphedema	1.01	0.74	0.16	1.37	0.18
Family member with breast cancer	−0.43	0.72	−0.07	−0.61	0.55
Knowledge	0.56	0.15	0.42	3.74	< 0.001

Note. $R^2 = 0.4$

household duties may be perceived as inconvenient or uncomfortable. In addition, wearing protective gloves may be a constant reminder of breast cancer, which many women want to avoid to minimize distress (Costanzo et al., 2007).

Almost 33% of the sample reported nonadherence to the risk-management recommendation to seek medical advice if lymphedema symptoms emerge. The finding is concerning because early detection and treatment is key to managing lymphedema (Hayes et al., 2008). Although the current study identified a lack of adherence to that recommendation, the data do not identify the underlying factors. Lack of knowledge was not the reason because women in both groups showed a high level of awareness of that recommendation. Lack of belief in the efficacy of available lymphedema treatments may be a reason for reluctance to seek medical advice, but that is unlikely to be the result of the high overall levels of adherence in the current sample. More likely, women do not want to appear as if they are overreacting or burdening the medical system. They also may be in denial about their real risk for lymphedema and may not be prepared to face the reality of possible symptoms arising. This explanation is consistent with the finding that the ALND group was no more adherent to the recommendations than the SLNB group.

Limitations

The current study's approach had several limitations. A critical issue is the generalizability of the results. The study was conducted on a relatively small sample of women attending a breast clinic at one metropolitan location. Further investigations in this area should expand the scope of the research by encompassing a wider selection of clinic locations including metropolitan and regional or remote areas and by using larger sample sizes. However, the sample size of the current study was similar to that of other psychosocial studies reported in this area (e.g., Coward, 1999). Although the prospective data from the point of diagnosis add to the existing literature, the duration of follow-up was short, given that lymphedema risk is heightened for a lifetime. Those issues should be investigated prospectively for at least 12 months postsurgery as women enter the survivorship phase and focus on retaining good health. The current research identified that adherence to risk reduction guidelines was less than desired for some recommended actions; however, whether the concerned individuals had difficulty initiating those behaviors in the first instance or whether they had difficulty maintaining the behavior, possibly because of competing demands (e.g., coping with treatment regimens) or the need to avoid further reminders of breast cancer is unclear. In addition, the current study focused only on aspects of objective lymphedema risk, information sources, and knowledge in relation

to adherence to risk-management behaviors. Factors relating to individuals' social, psychological, and cultural context were not addressed. To further understand the factors underlying adherence behaviors, future research should be guided by current models of health behavior, particularly models adopting a broad social-cognitive-affective approach to understand the psychological and social factors that are associated with adherence. No published research has explored those aspects of lymphedema risk.

Conclusions

The current research demonstrated that educating women about lymphedema risk management raises awareness that is associated with increased adherence to the recommended actions. Information provided in brochure format and from clinic staff may be most beneficial to improving adherence because only those sources were found to be associated with performing recommendations in the current sample. In particular, breast care nurses appeared to play a lead role in the dissemination of lymphedema information and in convincing women to perform the risk-minimization behaviors. Nurses may have played a motivational role other than educating the women because research has identified a link between personal motivation and enactment of the recommended behaviors in lymphedema (Fu, Haber, Guth, & Axelrod, 2009). In addition, personal communications from nurses about risk-minimization strategies are likely to be more tailored to the actual needs of patients, considering individuals' objective lymphedema risk level as well their existing level of lymphedema awareness. Research in this area has suggested a need to tailor lymphedema risk-management information for patients with breast cancer (Lee et al., 2009). Information obtained from sources external to the breast center was not associated with adherence, suggesting that women were reluctant to accept advice from sources other than those immediately associated with the breast clinic, perhaps because they saw the clinic as a more trusted source. Breast care nurses appear to play an important role in disseminating lymphedema-related information; therefore, booster sessions, possibly by breast care nurses, may be useful to ensure ongoing adherence and vigilance to the recommended behaviors. Women undergoing extended adjuvant therapy who may forget information provided at the time of surgery may derive particular benefit from booster sessions conducted after adjuvant therapy completion.

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