QUALITY OF LIFE AND LYMPHEDEMA FOLLOWING BREAST CANCER

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ABSTRACT

The aim of the study was to compare Quality of Life (QOL) of breast cancer patients with and without secondary lymphedema (SLE) using a cross-sectional design with a convenience sample. Research packets were mailed to 2088 breast cancer patients (BrCaPt). The QOL component of the study used the Quality of Life Instrument - Breast Cancer Patient Version for data collection. The sample (n = 537) was 12.9%African-American/Hispanic/Other (AA) and 87.1% European-American (EA). One hundred and twenty-two women (22.7%) reported SLE. Overall and subscale means were computed and ANOVA was determined for seven variables: age, marital status, educational level, race, type of surgery, time since diagnosis, and SLE. Women without SLE had a higher overall mean OOL score compared to women with SLE (p=0.02). Women with a greater than high school education had a higher mean QOL score compared to women with high school or less education (p=0.05). SLE patients had poorer QOL in the physical (p<0.001), and social (p=0.004) subscales. Older women had a

higher overall QOL compared to younger women (p<0.001). These results provide insight into the impact of SLE on women's QOL and pinpoint that physical and social well being are negatively influenced by SLE.

Keywords: secondary lymphedema, breast cancer, mastectomy, quality of life, social well being

Advances in screening, surgical procedures and treatments have significantly increased survival for breast cancer patients. Challenges remain to improve QOL when side effects such as secondary lymphedema (SLE) occur (1-3). SLE is a collection of excessive tissue proteins, edema and chronic inflammation within a limb or other body parts (4-5). It has been reported that up to 50% of BrCaPt treated by axillary lymph node dissection may develop SLE (4) with estimates of prevalence of SLE for all breast cancer treatments ranging from 28-38% (6-7). Although sentinel node biopsy is expected to significantly decrease the occurrence of SLE, currently over 2 million women are still at risk for developing this debilitating condition (8).

To date, few studies have compared QOL in women with and without SLE (9). Further, the relationships of QOL and its dimensions to age, social support, and other factors have not been identified. The overall aim of the After Breast Cancer (ABC) study was to examine women's knowledge of and experiences with and without SLE. A secondary aim of the study and the focus of this paper were to compare QOL of breast cancer patients with and without SLE.

Sequelae from breast cancer treatment can lead to functional impairment and worsened QOL (1,10-15). An important and sometimes overlooked sequela is SLE (16). QOL refers to a general sense of well being and encompasses multiple domains of a woman's life. We utilized Ferrell's framework in which QOL is composed of four dimensions of well being: physical, psychological, social, and spiritual (17). Overall QOL results from a combination of these dimensions (17-23).

Previous studies of SLE reveal continued impacts on physical, psychological and social well being years after diagnosis and treatment (13,20-33). Spiritual well being in patients with SLE has not been described. Living with SLE is more distressing to some patients than the initial diagnosis and treatment of breast cancer (24).

Physical effects (25,26) of SLE include sensory disturbances (27), pain (26), orthopedic problems (28), and susceptibility to infection (29). Women with SLE experience greater physical challenges than women with breast cancer of similar age and length of survival (30). Women with pain have more difficulty in physical functioning and perceive significantly less interpersonal support than those without pain (31-33).

Frustration is the most common reported emotion in dealing with SLE (24,34). Patients are angry about a loss of independence and perceive loss of control (34). Conversely, other women experience significant depression and anxiety (24,34-35). Patients frequently associate the swelling with a recurrence of

the original disease and anxiety persists despite reassurance (36).

Activities that involve heavy lifting, gripping, holding, and fine motor dexterity are impeded by SLE and interfere with certain job requirements (24,31-33). Patients find it difficult to complete household chores, give up hobbies, have less energy, and feel more disabled (28,34,37). Many women experience difficulties related to their work, social, and intimate relationships (24). Thus, SLE can also have a significant impact on a woman's body image and self esteem (38,39). Loss of interest in social activities, higher level of sexual dysfunction, and changes in occupational aspirations contribute to feelings of depression (31,36,40). The look of SLE and of the compression garment cause social anxieties. Feelings of isolation often heighten avoidance and social withdrawal, increasing social morbidity (31,41).

MATERIAL AND METHODS

The protocol was approved by an institutional review board for protection of human subjects in research and a privacy review. Women were recruited for this study from four sources: the institution's psychosocial oncology database, lymphedema treatment center, cancer data registry and a large oncology private practice. These women comprised a convenience sample of breast cancer survivors.

We developed a data collection booklet that included the following: demographic/personal data form, medical form, a SLE knowledge survey and the Quality of Life Instrument - Breast Cancer Patient Version (QOL - BCV) (19). These tools were designed to increase ease of use by the patient and to decrease likelihood of lost pages of data due to self administration. Two versions of this booklet were created, one for women who self reported SLE and one for those who denied having SLE. To draw attention to the two versions of the booklet, the covers were different colors. The instructions directed the

patient to choose a certain color if she had SLE which was defined as swelling of the arm on the side treated for breast cancer.

Packets containing the data collection booklets, the consent, information about the survey, and a self-addressed stamped envelope were mailed to 2088 women between May 2003 and August 2004. Of the 584 (28%) surveys returned between May 2003 and December 2004, 4 did not have proper consent; 4 respondents did not complete the QOL section of the data collection instrument; and 39 had no data in the local cancer registry. Therefore, 537 surveys were included in this analysis. We have reported elsewhere on decliners (42). After returning the data collection instrument and the signed consent form, each woman received a thank you gift of note cards featuring art by cancer patients.

The 28 item demographic and personal data form consisted of forced choice and open ended questions. Information obtained included date of birth (DOB), race, marital status, education, patient and family health history, activities, life situation and comorbidities. For the purposes of this paper, we used only data from 4 items: DOB, race, marital status and education. The sample included very few women who were either Hispanic or of other races. We chose to group these few women with the African American women as they are all minorities. Due to inconsistency in patient self report, we obtained the following data from the institution's cancer tumor registry: stage of cancer, number of lymph nodes removed, type of surgery, and if patient received radiation therapy. Access to this information was permitted using the patient's signed research consent form.

The 46 item scale measures four dimensions of QOL: physical, psychological, social, and spiritual well being (17). With permission of the developers, some wording was changed to improve readability. The overall QOL test re-test reliability was 0.89; Cronbach's alpha coefficient was reported as r = 0.93. In the current sample, Cronbach's

alpha reliability coefficients were 0.93 for the overall scale, 0.76 for physical, 0.92 for psychological, 0.80 for social and 0.68 for spiritual. The overall QOL correlation with the Functional Assessment of Cancer Therapy-G was 0.78.

Differences in proportions for categorical demographic variables were determined using Fisher's exact test. Means and standard deviations were calculated for all normally distributed continuous demographic variables (age and months since diagnosis) and differences were tested using a t-test. A nonparametric median test was used for those variables which were not normally distributed (total number of nodes removed and time since diagnosis). Analysis of variance (ANOVA) was used to calculate least squares means of QOL scores and to test for significant effects on QOL due to age, marital status, race, education level, type of surgery, time since diagnosis, and SLE. A linear model was used to describe each QOL subscale and the overall QOL scale for women with and without SLE. This model adjusted for six variables: age (divided into three groups, 30-49, 50-62, and 63+), marital status (married, not married), educational level (high school or less, greater than high school), race (European American, African American/other), type of surgery (mastectomy, breast conserving), and time since diagnosis (≤ 1 year, > 1 year).

RESULTS

Of the 537 women in the sample, 122 (22.7%) women reported SLE. *Table 1* details the overall description of the study population as well as the breakdown comparing SLE vs. no SLE. The mean age for all women was 60.5 years (SD 11.2) with a range of 32 to 90 years. Women who reported SLE were younger (p=0.04). Race, marital status, education and medical information are reported in *Table 1*. In this sample, women with SLE had more lymph nodes removed, were more likely to have had a mastectomy, were

Demogra		ΓABLE 1 Variables for Sa	mple and by S	SIAB
Variable	Overall (n=537)	LE (n=122)	No LE (n=415)	p-value* († statistically significant)
Age (mean ± SD)	60.5 ± 11.1	58.7 ± 11.2	61.0 ± 11.1	0.04†
Range	(32-90)	(32-90)	(33-88)	
Race (n=2 missing)		n (%)	n (%)	
European American	466 (87.1)	99 (82.5)	367 (88.4)	NS
African American/other	69 (12.9)	21 (17.5)	48 (11.6)	
Marital status (n=2 missing)				
Living with a partner	365 (68.2)	78 (65.0)	287 (69.2)	NS
Not living with a partner	170 (31.8)	42 (35.0)	128 (30.8)	
Education (n=1 missing)				
High school or lower	153 (28.5)	33 (27.3)	120 (28.9)	NS
More than high school diploma	383 (71.5)	88 (72.3)	295 (71.1)	
Stage at diagnosis				
DCIS	64 (12.0)	5 (4.1)	59 (14.2)	<0.001†
I-IIIA	451 (84.0)	108 (88.5)	343 (82.6)	
IIIB-IV	11 (2.1)	3 (2.5)	8 (1.9)	
Unknown	11 (2.1)	6 (4.9)	5 (1.2)	
Surgery type** (see comments)				
Mastectomy	310 (57.7)	85 (69.7)	225 (54.2)	<0.001†
Non-mastectomy	224 (41.7)	35 (28.7)	189 (45.4)	
None	3 (0.6)	2 (1.6)	1 (0.2)	
Received radiation treatment				
Yes	279 (52.0)	66 (54.1)	213 (51.3)	NS
No	238 (44.3)	53 (43.4)	185 (44.6)	
Unknown	20 (3.7)	3 (2.5)	17 (4.1)	
Total lymph nodes removed				
(median, range)	11 (0-45)	15 (0-45)	9 (0-41)	<0.001†
Months since diagnosis				
(median, range)	37.8 (1.5-183.7)	48.3 (7.6-167.5)	35.1 (1.5-183.7	7) <0.001†

^{*} The reported p value is testing the difference in the proportion of patients reporting LE versus those who did not.

diagnosed at a higher stage and had been diagnosed longer than women without SLE.

There was a positive linear relationship between age and mean QOL score as evidenced by the trends shown in *Table 2*. With each succeeding age group, there is

generally an increase in the mean score for each of the subscales as well as the overall QOL score. This holds true for both those patients with SLE as well as those patients without SLE.

^{**} Mastectomy = modified radical, total simple, and radical mastectomies; Breast conserving includes lumpectomy, partial mastectomy, segmental mastectomy, and re-excision.

		òò)L Scores* b	${\bf TABLE~2} \\ {\bf QOL~Scores*~by~Age~Group~for~Patients~with~and~without~SLE} \\$	TABLE 2 p for Patients	s with and w	ithout SLE			
	Overal	П	Physical	ıal	Psychological	ogical	Social	al	Spiritual	ual
Age group **	No LE	LE	No LE	LE	No LE	LE	No LE	LE	No LE	LE
30-39 (n=18)	5.0 ± 1.98	4.9±1.97	5.2±2.46	5.1 ± 1.90	4.5±2.39	4.8±2.51	4.5±2.38	3.8±2.70	6.7±1.85	6.6±1.41
40-49 (n=72)	6.7±1.57	6.6±1.44	6.3 ± 1.82	5.7±2.31	6.8±1.87	7.2 ± 1.75	6.4 ± 1.90	5.8±1.65	7.0 ± 1.91	7.4±1.66
50-59 (n=174)	6.9±1.53	6.4±1.56	6.5 ± 1.85	5.5±1.78	7.0±1.96	6.6 ± 2.10	6.7±1.93	6.2 ± 1.91	7.3±1.65	7.1±1.90
60-69 (n=155)	7.4±1.38	7.0±1.44	6.9 ± 1.82	6.8±1.67	7.6±1.82	7.0±1.84	7.4±1.64	6.6±1.81	7.4±1.85	7.3±1.62
70-79 (n=95)	7.4±1.28	6.6±1.85	7.3 ± 1.71	5.7±1.77	7.6±1.72	6.7±2.49	7.5±1.57	6.2±2.43	6.9 ± 1.74	7.7±1.90
80-99 (n=22)	8.0 ± 1.17	7.9±0.86	7.9±1.66	7.6±1.77	8.4±1.47	8.6±0.73	7.9±1.48	7.8±1.21	7.1±1.48	6.8±1.00
*Mean ± Standard Deviation.	urd Deviation.		**One patient did not report age.	report age.						

The ANOVA results comparing QOL for respondents with and without SLE are shown in Table 3. The advantage of using ANOVA is that the model controls for all variables. Overall OOL scores as well as social well being and physical scores were significantly lower for patients who reported SLE compared to women without SLE. Women with less education reported significantly lower psychological and social QOL as well as lower overall QOL. Younger women (age 30-40) reported lower overall QOL and lower physical, psychological, and social well being compared to older women (63+). AA women reported significantly higher spiritual well being, but had significantly lower social well being when compared to their EA counterparts. Living with a partner only influenced spiritual well being. Women who had a mastectomy reported lower overall QOL and less psychological and social well being compared to women who did not have a mastectomy. Time since diagnosis was significantly different only for the social well being score.

DISCUSSION

Our understanding of the relationship between SLE and QOL is masked by the patient's life situation and treatment. Patients most vulnerable to negative impact on QOL are younger women who are more likely to be working and caring for children while having fewer life experiences for coping. Their social well being which includes work and family is most affected.

Results lend credence to the assertion that African American and other minority women find strength in their faith. In contrast, breast cancer in AA women may be a stressor that challenges social well being. Taboos, stigma and myths about cancer may contribute to the lower social well being in these women (43). Therefore, AA women may experience social disconnection when diagnosed with cancer.

Several factors negatively impact social

		TABLE 3 Analysis of Variance for Quality of Life	3 or Quality of Life			
Variables	Overall QOL Scale†	Physical Subscale† Psychological Subscale† Social Subscale†	chological Subscale†	Social Subscale†	Spiritual Subscale†	
Lymphedema						
LE	6.3 ± 0.21 *	5.9 ± 0.26 **	6.5 ± 0.27	$5.5 \pm 0.25 **$	7.4 ± 0.24	
No LE	6.7 ± 0.17	6.5 ± 0.22	6.8 ± 0.22	6.1 ± 0.21	7.4 ± 0.20	
Highest education level						
High school or less	6.4 ± 0.20 *	6.1 ± 0.25	6.5 ± 0.26	5.6 ± 0.24 *	7.3 ± 0.24	
Greater than high school	6.7 ± 0.17	6.3 ± 0.21	6.8 ± 0.22	6.0 ± 0.21	7.4 ± 0.20	
Patient age						
Age 30-49	$6.0 \pm 0.22 **$	5.7 ± 0.28 **	$6.1 \pm 0.29 **$	5.1 ± 0.27 **	7.2 ± 0.26	
Age 50-62	6.5 ± 0.18	6.1 ± 0.22	6.7 ± 0.23	5.9 ± 0.22	7.5 ± 0.21	
Age 63+	7.0 ± 0.20	6.8 ± 0.25	7.2 ± 0.26	6.4 ± 0.24	7.5 ± 0.23	
Race						
European American	6.5 ± 0.16	6.3 ± 0.20	6.7 ± 0.21	6.2 ± 0.20 **	$6.8 \pm 0.19**$	
African American/other	6.5 ± 0.23	6.1 ± 0.28	6.7 ± 0.30	5.4 ± 0.28	8.0 ± 0.27	
Marital status						
Living with a partner	6.5 ± 0.19	6.1 ± 0.23	6.7 ± 0.24	5.7 ± 0.23	7.6 ± 0.22 *	
Not living with a partner	6.5 ± 0.19	6.3 ± 0.24	6.6 ± 0.25	5.8 ± 0.23	7.2 ± 0.22	
Surgery						
Mastectomy***	6.4 ± 0.18 *	6.1 ± 0.22	$6.4 \pm 0.23 **$	$5.5 \pm 0.22 **$	7.4 ± 0.21	
Non mastectomy	6.6 ± 0.19	6.3 ± 0.24	6.9 ± 0.25	6.0 ± 0.24	7.4 ± 0.23	
Time since diagnosis						
Less than 1 year	6.3 ± 0.30	6.2 ± 0.37	6.4 ± 0.39	5.3 ± 0.36 **	7.3 ± 0.35	
More than 1 year	6.8 ± 0.12	6.2 ± 0.14	7.0 ± 0.15	6.3 ± 0.14	7.5 ± 0.14	
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†Mean score ± Standard Error; *p<0.05; **p<0.01
*** Mastectomy includes modified radical, total simple, and radical mastectomies; Breast conserving includes lumpectomy, partial mastectomy, segmental mastectomy, and re-excision of biopsy site. The three patients who did not undergo surgery were removed for this analysis.

well being. These include level of education, race, age and type of surgery. Having a partner does not seem to mediate the impact on QOL which is contrary to research on social networks and stress (44-45). These factors could be a proxy for level of stress in these women.

Clinicians should consider age, education, surgery type and time since diagnosis as predictors of social and psychological distress in patients with breast cancer and SLE. Also, mental health staff should focus on social well being which includes family, job and partner relations as this area of life is at greatest risk for being disrupted by a breast cancer diagnosis. Having a mastectomy negatively impacts all dimensions of QOL except spiritual well being. Patients who have had a mastectomy and have been diagnosed less than a year may need more support.

Our research suggests several paths of future inquiry into QOL in women with breast cancer. Clearly, interventions are needed to address problems associated with social well being. A larger sample is needed for an in-depth study of stress and QOL in younger women. Investigators should explore support strategies for poorly educated women. Many challenges exist for clinicians and researchers in assuring better QOL for women with breast cancer and especially those with SLE.

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