

Psychologic and Social Sequelae of Secondary Lymphedema

A Review

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BACKGROUND. The psychological and social sequelae of secondary lymphedema (SLE) have been an underrecognized and little-researched complication of treatment for breast carcinoma. The reported incidence and prevalence of SLE varied widely (0–48%). Reported reasons for the differences are related to the lack of standard diagnostic and universal assessment criteria.

METHODS. A comprehensive, computerized search was performed. All combinations of the following keywords were used: arm lymphedema, arm swelling, breast cancer, psychological and social, and quality of life (QOL). Eighteen studies were identified.

RESULTS. The literature supported the view that SLE leads to psychological and social sequelae. Psychological sequelae included frustration, distress, depression and anxiety. Social sequelae comprised changes in role function, lack of social support and pain and disability. Pain was a significant predictor of psychological and social morbidity. These experiences resulted in diminution of QOL, particularly psychological and social health. This was particularly worrisome because women must attend daily to the precautions and treatments for SLE.

CONCLUSIONS. Researchers should use psychological and social measures along with physiologic parameters when evaluating the impacts of SLE. Clinicians should work to develop standardized primary prevention programs and limb circumference should be measured at the time of breast carcinoma diagnosis. Gaps in knowledge related to intra/interethnic diversity, poverty, and comorbidities of women with breast carcinoma-related SLE need to be explored. The combined efforts of researchers and clinicians would reinforce awareness and knowledge for women at risk and provide important baseline data for research and practice.

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Breast carcinoma survival rates have increased in recent decades as a result of increased screening rates, earlier diagnosis, and improved treatment regimens. Longer survival time makes it more likely that treatment side effects will emerge,¹ and one of these side effects is secondary lymphedema (SLE). Current use of sentinel lymph node biopsy (SLNB) is expected to greatly reduce SLE. However, patients still present with advanced-stage breast carcinoma, are lymph node positive, or lack access to SNLB, thus necessitating axillary lymph node dissection (ALND). In addition, women treated before receipt of SLNB are at risk for developing SLE their entire lives due to the long latency period.^{2–4} Therefore, the 2 million women⁵ who were treated before the advent of SNLB are at risk for developing SLE. For these

reasons, the psychological and social sequelae of SLE must be examined.

There is currently no cure for SLE, which is one of the most distressing and unpleasant sequelae after breast carcinoma.⁶ The disfiguring, disabling, and chronic nature of SLE places women at risk for psychological and social sequelae. Although diagnosis and treatment are important considerations in SLE research, the purposes of this review are to 1) identify the psychological and social sequelae that affect the quality of life (QOL) of women with breast carcinoma-related SLE, 2) to suggest areas where additional research is needed, and 3) to discuss clinical implications and recommendations. We briefly discuss the diagnosis, incidence, and risk/contributing factors to this disorder to aid in understanding.

SLE manifests as intermittent swelling resulting from an imbalance in capillary filtration and lymph drainage, which leads to a collection of fluid and protein in the extravascular and interstitial spaces of the affected limb.⁷ Researchers and clinicians disagree about diagnosis, incidence, and risk/contributing factors. The problems arise from the unpredictable onset of SLE. The onset of SLE can develop rapidly after treatment or years later. Onset has been reported in patients 30 years after treatment.²⁻⁴ In addition, there is a lack of consensus about clinical criteria for diagnosis and standard methods of assessment. The diagnostic methods used in the studies reviewed are detailed in Table 1.

The incidence of SLE is difficult to establish because the length of follow-up in research studies varies from 1 year to 20 years and surgical technique has changed over time. Reports of incidence vary from 10% to 48% with ALND.^{5,8-12} Petrek et al.¹³ conducted interviews with women 20 years after treatment. Forty-nine percent of the patients (128 of 263) were judged to have SLE. In a 20 year follow-up by Kornblith et al.⁹ 39% of the participants had been diagnosed with SLE. Deo et al.⁸ followed patients from 1 to 11.5 years and found that 33.5% of patients had clinically significant SLE and that 17.2% had severe SLE. Hinrichs et al.¹⁴ found an incidence of 27% for SLE in patients treated with mastectomy followed by radiotherapy. In these four studies, SLE was determined using patient self-report and self-circumferential measurement,¹³ patient self-report,⁹ serial circumferential measurement method,⁸ and chart review.¹⁴ In contrast to this research, current reports of incidence with SNLB has been 0-23%.^{5,10,12}

ALND^{5,15,18,21,22,23-26} and radiotherapy^{8,14,25,27,28} are thought to be contributing factors for SLE. However, lack of consensus occurs regarding which risk factors contribute consistently to SLE.^{8,14,24} Other factors that may increase the risk for developing SLE are

body mass index (BMI),^{14,29,30} dominant arm,^{31,32} age,³³ weight gain/obesity,^{5,11,13,29,33} staging,^{10,34} number of lymph nodes removed,²⁹ medical therapies,^{35,36} and infection.^{10,13}

MATERIALS AND METHODS

The following databases were searched: MEDLINE (National Library of Medicine, Bethesda, MD), CANCERLIT (National Cancer Institute, Bethesda), Cumulative Index to Nursing and Allied Health Literature (CINAHL; CINAHL Information Systems, Glendale, CA), and PsycINFO (American Psychological Association, Washington, DC). All combinations of the following keywords were used: arm lymphedema, arm swelling, breast cancer, psychological and social, and quality of life.

Publications included in the current review met the following inclusion criteria: an emphasis on social and psychological sequelae, and articles had to be published in English. To supplement this search, reference lists of identified articles were reviewed. Because of the selective search strategy, some relevant publications may have been inadvertently excluded. Eighteen studies were identified of which 14 were quantitative and 4 were qualitative. Table 1 presents detailed information about the individual publications that were identified.

Participants

A total of 2612 women participated in the 18 studies. Four hundred eighty-one (18%) of the participants had been diagnosed with breast carcinoma-related SLE by the researchers. The remaining 1472 (57%) participants had self-reported arm swelling, or had documented arm problems through medical chart review, and 659 (25%) were controls. The reported age range for the participants was 26-88 years, the range of time since breast carcinoma treatment was 3 months to 28 years, and the time since self-reported swelling began was a few days to 13 years. There was substantial variation in breast carcinoma and SLE treatments and staging for these women.

Only Passik et al.³⁸ and Beaulac et al.³⁷ reported nonwhite participants in their demographics. The Beaulac et al.³⁷ study included 14% nonwhite participants, and their findings provided evidence of the importance of using race as a covariate when investigating SLE. Passik et al.³⁸ reported that 18% of their sample was nonwhite. However, they did not investigate the association of race to the other factors in their study.

Study Methodology

Our review included 14 quantitative and 4 qualitative studies. Five^{28,37,39-41} of the quantitative studies were

TABLE 1
Studies Evaluating Psychosocial Issues for Women with SLE

References	No. of patients	Sample description	SLE defined and diagnosed/LVM	Type study/instruments
Maunsell et al., 1993 (Canada) ²⁸	201	Age NR Race NR T since diagnosis "recent" T since treatment NR T since swelling NR	NR LVM -none-self-report of arm problems	Descriptive The Psychiatric Symptom Index ^{56,57}
Tobin et al., 1993 (England) ⁴³	100	Age (M = 56.7) Race NR T since diagnosis NR T since treatment > 1 yr T since swelling (M = 49.8 mos)	> 200 mL in limb volume, as measured 15 cm above the lateral epicondyle, present for \geq 12 mo. Diagnosed (50) LVM - cases and controls measured at beginning of study	Quasi-Experimental case-control study Clinical Interview Schedule ⁶⁸ Hospital Anxiety and Depression Scale ⁶⁹ Karnofsky's performance scale ⁷⁰ Psychosocial Adjustment to Illness Scale (PAIS) ⁷¹ Social Stress and Support Inventory ⁷²
Woods, 1993 (England) ⁴³	37	Age NR Race NR T since diagnosis NR T since treatment (M = 32 mos.) T since swelling (a few days to 13 yrs)	Percentage increases in the size of the normal limb. Used to assess progress and evaluate treatments. Diagnosed (37) LVM - measured at baseline and during each follow-up assessment	Descriptive and correlational study Semi-structured interview (SSI) \times 2 PAIS ⁷¹
Woods, et al., 1995 (England) ⁴⁴		Comparison of the 2 previous studies comparing the results of the PAIS (see sample information above)	See above	Correlational secondary analyses (comparison of PAIS results reported above) PAIS ⁷¹
Mirolo et al., 1995 (Australia) ⁴⁶	25	Age (M = 58.1) Race NR T since diagnosis NR T since treatment (M = 8.3 yrs) T since swelling > 5 yrs for majority	Volume = π (circumference/ π) ² h, where the circumference = the mean of the adjacent circumferences, and h = 100 mm - Diagnosed (25) LVM - measurements were taken before the beginning of the intervention treatment phase, post-intervention, and at 1, 6, and 12 mo *	Quasi experimental design Scale development Functional Living Index scale specific to Cancer ⁷³ Wesley Clinic Lymphedema Scale ⁴⁶
Passik et al., 1995 (USA) ³⁸	69	Age (M = 57.42) Race 82%; EA, 12%; AA, 6%; H T since diagnosis (M = 6.33 yrs) T since treatment NR T since swelling (> 3 yrs for majority)	Percent difference total circumference of the affected and normal limbs, quantified by 5 measurements of arm during physical examination Diagnosed (69) LVM - measured	Correlational study The Brief Symptom Inventory ⁷⁴ Impact of Events Scale ⁷⁵ Derogatis Sexual Functioning Inventory ⁷⁶ Functional Interference Questionnaire ⁷⁷ Social Support Questionnaire—short form ^{78,79} Interpersonal Support Evaluation List ⁸⁰ Dealing with Illness Coping Inventory ^{81,82}
Carter, 1997 (USA) ⁴⁸	10	Age (range, 36–75) Race 100%; EA T since diagnosis NR T since treatment (M = 7.3 years) T since swelling (M = 4 yrs)	NR	Phenomenologic, qualitative, descriptive study SSI \times 2 (per participant 1 wk apart)
Hack et al., 1999 (Canada and USA) ⁴⁰	222	Age (M = 57.1) Race NR T since diagnosis NR T since treatment NR T since swelling NR	NR	Descriptive study Modified Post-operative Pain Questionnaire ⁸³ Pain Disability Index ⁸⁴ Short-form McGill Pain Questionnaire ⁸⁵ European Organization for Research and Treatment of Cancer Quality of life Questionnaire (EORTC-QLQ) ⁸⁶ Mental Health Inventory ⁸⁷
Velanovich and Szymanski, 1999 (USA) ²³	101	Age - ALND (n = 45) (M = 55.2) -SLE (n = 45) (M = 62.8) +SLE (n = 11) (M = 59.1) Race NR T since diagnosis NR T since treatment (range, 0.5–4 yrs) T since swelling NR	SLE confirmed if either the mid-humorous or mid-radius circumference of the operated side was > 1 cm > on the unaffected arm Diagnosed (11) LVM - measured	Quasi-experimental study Medical Outcomes Trust (SF-36) ⁸⁸

(continued)

TABLE 1
(Continued)

References	No. of patients	Sample description	SLE defined and diagnosed/LVM	Type study/instruments
Hare, 2000 (England) ⁴⁹	20	Age (M = 59.7) Race EA T since diagnosis NR T since treatment NR T since swelling (M = 4.5 yrs)	NR	Qualitative grounded theory approach focus groups
Coster et al., 2001 (England) ³⁹	308	Age Controls (M = 56.6) Cases (M = 61.6) Race NR T since diagnosis (range, 1–10 yrs) T since treatment NR T since swelling NR	NR	Descriptive study Scale validation Functional Assessment of Cancer Therapy: Breast Cancer (FACT-B +4, version 3) ⁵⁶
Radina and Armer, 2001 (USA) ⁵⁰	NR	Age (M = 45) (estimated) Race NR T since diagnosis NR T since treatment NR T since swelling NR	NR	Qualitative ethnographic approach Interviews Observation
Beaulac et al., 2002 (USA) ³⁷	151	Age (M = 62.4) Race 87%; EA, 14%; non-EA T since diagnosis "Newly"	SLE positive when the volume of the ipsilateral arm was ≥ 200 cm ³ that of the contralateral arm Diagnosed (42) LVM - Arm volume was measured using a modification of the volume displacement technique	Descriptive retrospective cohort study
Engel, 2003 (Germany) ⁴²	990	T since treatment (M = 4.8 yrs) T since swelling NR Age < 50 (226 [22.8%]) 50–69 (565 [57.1%]) $\geq 70+$ (199 [20.1%]) Race NR T since diagnosis w/in 1 yr T since treatment w/in 1 yr T since swelling NA	NR	FACT-B, (version 3) ⁵⁶ Correlational prospective cohort study EORTC QLQ-30 ⁸⁶
Johansson et al., 2003 (Sweden) ³⁰	12	Age (Range 44–59) Race NR T since diagnosis NR T since treatment NR T since swelling (< 2 years to approximately 7 yrs)	Arm lymphedema < 40% Diagnosed (12) LVM - NR	Qualitative, exploratory, phenomenological approach
Voogd et al., 2003 (Netherlands) ⁴¹	332	Age (M = 59; range = 26–88) Race NR T since diagnosis NR T since treatment (M = 4.2) (Range = 0.3–28 yrs) T since swelling NR	Difference in arm circumference of ≥ 2 cm Diagnosed (201) LVM = measured	Descriptive survey
McKenzie and Kalda, 2003 (Canada) ⁴⁵	14	Age (M = 56.6) Race NR T since diagnosis NR T since treatment (> 6 mo) T since swelling NR	Unilateral SLE > 2 cm and < 8 cm on ≥ 1 measurement point Diagnosed (14) LVM - measured every 2 wks for 8 wks	Experimental Medical Outcomes Trust (SF-36) ⁸⁸
Mondry et al., 2004 (USA) ⁴	20	Age (M = 64; range = 38–81) Race NR T since diagnosis NR T since treatment NR T since swelling 2–156 mo	Girth of both arms were measured at 9 specific points, a ≥ 2 cm difference was considered sufficient for SLE Diagnosed (20) LVM - measured at baseline, 3 and 6 mo, and at 1-yr	Evaluation study FACT-B, (version 3) ⁵⁶ Visual Analogue Scale (VAS) ⁸⁹

SLE: secondary lymphedema; ALND: axillary lymph node dissection; T: time; NR: not reported; NA: not applicable; AA: African American; EA: European American; H: Hispanic; LVM: lymph volume measurement; m: mean; mos: months; yrs: years; wks: weeks.

descriptive and provided point prevalence estimates of the magnitude of psychological and social outcomes. Other designs represented included four correlational,^{38,42–44} one experimental,⁴⁵ three quasiexperimental,^{23,46,47} and one evaluation study.⁴ Five studies measured participants at more than one time point.^{4,43–46} Five studies^{23,39,42,44,47} investigated differences in psychological and social sequelae experienced by survivors of breast carcinoma with and without SLE.

Two^{30,48} of the four qualitative studies used a phenomenologic approach to analyze data after a semi-

structured interview. Carter⁴⁸ interviewed participants a second time, 1 week after the first interview. Hare⁴⁹ used data from four tape-recorded focus groups and analyzed the data using a grounded theory approach. Radina and Armer⁵⁰ chose an ethnographic approach using a variety of sources i.e., interviews, follow-up interviews with six participants, interviews with health care professionals who had experience with patients with breast carcinoma and SLE, and observation of newly formed SLE support groups. Some common findings among the qualitative studies were themes related to the lack of information about SLE before

diagnosis; problems with dress and body image; difficulty making the adjustment to living with an incurable chronic condition; permanent role change; and loss of independence, purpose, and sense of self.

Methodologic Problems

Descriptive and correlational studies were predominant among the quantitative studies.^{28,37-44} One prospective study concerned the QOL experienced by survivors of breast carcinoma after breast carcinoma treatment.⁴² The other studies were retrospective. A critical problem with using retrospective designs to measure psychological and social sequelae is that the development of SLE has major overall impacts on women. Their perceptions of the time before developing SLE have been changed. In addition, the latency time between breast carcinoma treatment and the development of SLE could make self-report data less reliable.

The sample sizes of the studies were generally small. Seven researchers had only one contact with the patients.^{23,28,37-39,41,47} In some cases, this one contact for the purpose of data collection was not conducted at the same time point in the course of the condition, which limits the usefulness of the findings and makes comparison of the studies less effective.

Of the four qualitative studies, two^{30,48} utilized a phenomenologic approach, semistructured interviews, and directed questions to elicit specific concerns and to promote understanding of women with SLE. Hare⁴⁹ used data gathered from audio recordings of four focus groups, and analyzed the data using a grounded theory approach. Radina and Armer⁵⁰ claimed an ethnographic approach to capture lived experience. The authors used the Family Adjustment and Adaptation Model to interpret findings.

Qualitative studies are difficult to critique because of the lack of generally accepted criteria.⁵¹ Morse and Field⁵² proposed three standards to critique qualitative studies: a) significance of the research, b) theoretic evaluation, and c) methodologic assessment. Carter's study⁴⁸ met all three criteria. In particular, her methodology was powerful, providing rich description of the women's experiences. Similarly, Hare's study⁴⁹ demonstrated high quality especially in her reporting of analysis and results. Likewise, Johansson et al.³⁰ adequately achieved the criteria. Radina and Armer⁵⁰ strongly established the significance of their study question. However, these authors mixed their methodology, thus making it difficult to evaluate their method. In summary, three of the four studies met qualitative research criteria, thus substantiating their findings.

RESULTS

Findings from Review

Even though the studies reviewed had methodologic problems, the results documented considerable psychological and social sequelae. Significant numbers of women with SLE experience negative impacts on their everyday lives, particularly because they must attend daily to the precautions and treatments for SLE. The findings will be discussed in the following categories: first a brief description of the associated QOL findings, and then a description of psychological sequelae including subcategories of frustration, distress, depression and anxiety. Finally, social sequelae are described and include the subcategories of changes in role function, lack of social support, and pain and disability.

Quality of Life

QOL has been used often as the outcome variable in the study of cancer and its associated problems. QOL was mentioned in the articles even when it was not an outcome variable. Velanovich and Szymanski,²³ Passik et al.,³⁸ and Hack et al.⁴⁰ found that pain duration and intensity impacted participants' emotions and QOL. Coster et al.³⁹ and Engel⁴² found that participants with SLE scored significantly lower on subscales of QOL measures. Mondry et al.⁴ reported that while patients were undergoing complete decongestive therapy, decreasing girth correlated significantly with decreasing visual analog scale scores for pain, but not with increasing QOL. Beaulac et al.³⁷ found lower self-reported QOL scores. McKenzie and Kalda⁴⁵ found that three of the QOL domains showed trends toward improvement when participants were engaged in an exercise program. These findings provide ample argument for the use of QOL as an outcome variable.

Psychological Sequelae

Women with SLE exhibited an overabundance of psychological sequelae, such as, frustration, distress, and depression and anxiety. These sequelae contributed to impaired QOL for many participants.

Frustration

The women were challenged to manage their time while incorporating the treatment regimens for SLE into their usual routines. Women were aggravated by the difficulties with simple tasks such as zipping a zipper. Their disappointment in their changed shape and body image added to their mental suffering. Participants became angry about their loss of independence and perceived loss of control. For example, some participants had to give up their hobbies, driving, and paid employment.^{41,48}

Distress

Maunsell et al.²⁸ reported that arm problems increased the likelihood of psychological distress. Passik et al.³⁸ found a high level of psychological distress among participants with SLE. Physician's insensitivity and limited knowledge about SLE, the lack of access to treatment centers, and inconsistent treatment recommendations were conveyed as sources of distress.⁴⁸ Women with a BMI ≥ 25 were more distressed than those with BMIs < 25 .^{37,46}

Depression and anxiety

Hack et al.⁴⁰ and Tobin et al.⁴⁷ reported exclusion for current psychiatric diagnosis, and Maunsell et al.²⁸ adjusted the results for history of depression. Tobin et al.⁴⁷ and Carter⁴⁸ reported greater psychiatric morbidity for anxiety and depression. Lack of adequate information about SLE and poorer illness adjustment were found to be predictors of higher anxiety and depression. Finding information about SLE was difficult for some women. Participants disclosed that having information about SLE helped to ease their sense of loss and anxiety.⁴⁹ Depression and maladaptive coping were exacerbated by participant's difficulty with adjusting to a chronic disease and this impacted both problem and emotion-focused coping.³⁰

Social Sequelae

SLE intruded on many social aspects of the participants' lives — role function, lack of social support, and pain and disability. Many participants self-reported impaired QOL and/or lower scores on QOL measures.

Family, friends, work and play

SLE required special daily care and concern and caused women loss of independence and sense of purpose and self. Families who were more flexible in modifying daily tasks and who had preexisting resources for coping with stressors had more positive outcomes than did those families who were rigid and coped with stressors poorly.⁵⁰ Women reported diverse reactions from their sexual partners ranging from accepting to apathetic.⁴⁸

Some women attempted to avoid friends and hid their arm by not wearing bathing suits and short or tight sleeves. Socializing and dressing in summer months presented special challenges.^{44,48} Women reported avoiding social activities, and were surprised by the insensitive comments from others about their disfigured arm and this led to increased social isolation for some women.

Job responsibilities that involved regular use of the affected arm, such as lifting, gripping, holding, and other fine and some gross motor tasks were difficult to

perform, and some women lost or gave up their jobs because they could no longer perform their duties. Families that depended on income and/or benefits from women's paid employment were especially disrupted.⁴⁸

Playtime was minimized and decreased in quantity and intensity. Many had to give up or cut down on activities such as crocheting, gardening, tennis, golf, and walking, partly, because of the social discomfort of the lymphedemous arm.

Lack of social support

Lack of social support was significantly associated with increased morbidity and deteriorating sexual relationships.³⁸ Adequate social support was correlated with increased social functioning, and a lower incidence of feelings of abandonment and isolation.

Pain and disability

Pain had a disabling impact on self-care and sexual activities. Pain of any intensity resulted in more functional interference as well as a greater number of social and psychological problems.^{4,38,40} Pain was a significant predictor of psychological and social morbidity.

DISCUSSION

Although these studies provide a starting point, the research on psychological and social sequelae of SLE is far too limited. Existing studies have not recognized intra/interethnic diversity, poverty, and comorbidities of women with breast carcinoma-related SLE, thus excluding many women who, because of their circumstances, may have additional difficulties dealing with SLE. At this point, the little that is known about the psychological and social sequelae of SLE is applicable only to a homogeneous segment of our society.

Research Recommendations

Previous investigations have largely ignored the presence of factors that may moderate the psychological and social symptoms associated with SLE. For example, obesity, the extent to which women have followed recommended exercises, and whether the affected limb is on the dominant side may impact the number of symptoms reported. Covariates were not included in the studies reviewed. Covariates such as race/ethnicity, and other social factors, such as social class and socioeconomic status are, in contrast to other psychological and social variables, basically well defined, and it is possible to conduct comparative studies using established epidemiologic methods.²³

The importance attached to symptoms resulting from surgery can vary among physicians, and the use of project-specific symptom checklists has also con-

tributed to wide variations in self-reported psychological and social sequelae and symptoms between studies. As an example, physicians may view numbness as normal after breast carcinoma surgery, yet patients have consistently reported that numbness is unexpected and worrisome.⁵³

The significance of research findings to date is contingent on the accuracy with which psychological and social dimensions have been measured. Research conducted with patients with SLE and breast carcinoma has indicated that general psychiatric and QOL tools may not be sensitive enough to detect arm problems among women after breast surgery.^{40,43,46,47,54} Research results have also suggested that generic^{23,43,55} and cancer-specific QOL tools^{39,46,56} may not include a sufficient range of items to comprehensively assess the psychological and social sequelae of arm morbidity. Although generic measures allow for cross-disease comparisons, disease-specific measures are more sensitive to individual change. There is an obvious need for the development and use of disease-specific measures for SLE, such as, the Wesley Clinic Lymphedema Scale⁴⁶ and the Functional Assessment of Cancer Therapy-Breast.³⁷

The lack of systematic research continues to be problematic. Sequelae may differ among demographic groups and also by patient age and preoperative health. The importance of assessing not only the incidence of arm problems but also the impact of these symptoms on patients' physical and psychological and social health seems clear. It is likely that accounting for factors such as age, treatment, race, socioeconomic factors, social support, and services available in the community would reduce the variations in the findings and allow investigators to tailor interventions in a meaningful manner to specific groups of women with SLE. The lack of clarity in understanding the association among age, pain, and psychological and social and mental health calls for a prospective, longitudinal analysis of these variables.⁴⁰

Additional gaps in the existing literature include the underrepresentation of minority women in breast carcinoma-related SLE research. Beaulac et al.³⁷ provided evidence that nonwhite populations may suffer disproportionately with SLE. Further, although the research demonstrates the importance of the spousal relationship during the cancer experience, there is a lack of controlled research concerning couples or family interventions. Radina and Armer⁵⁰ conveyed important insights into issues that should be incorporated into the mainstream of SLE research. To better understand the context of surviving cancer, research inquiry using the family as the unit of analysis should be encouraged.⁴⁸

Spirituality may buffer against the negative effects of life stressors.⁵⁷ Spirituality may be an important

variable to assess among women with SLE. Surprisingly, in this review, only Hare⁴⁹ discussed spirituality, and found "counting blessings" was one of the themes that emerged from the grounded theory process. Women with SLE face multiple and complex stressors and it may be advantageous for researchers to study participants' spiritual health.

Future research, compatible with comparable statistical testing, is needed to determine precisely which psychological and social variables are effective in promoting better health for survivors of breast carcinoma with SLE. From such analyses, more effective interventions for psychological and social sequelae as outcome variables can be developed. Translating these findings to meaningful interventions and practice is a necessary shift toward providing physical, psychological, and social care to long-term, chronically ill patients and their families.

Clinical Implications and Recommendations

Sadly, SLE remains a "forgotten complication"⁵⁸ and women are not adequately educated about primary prevention measures.³⁸ The physical side effects of full ALND are common and well documented. However, women should also be fully informed of the risks and consequences of SLE at the time of obtaining consent for the breast carcinoma surgical procedure.⁵⁹

Prevention has historically been problematic because the efficacies of commonly suggested preventive measures and cautions have not been tested. There are few comprehensive treatment programs and they generally do not enroll patients for the purpose of primary prevention, but only after the arm problems have developed. Standardized primary prevention programs (PPP) should be developed, and limb circumference should be measured at the time of breast carcinoma diagnosis.^{60, 61}

Accurate baseline records would serve as a cue to awareness for women about the risk for SLE. Raising patients' awareness and using arm measurement as a teachable moment would involve patients in the primary prevention protocol. Such early involvement would protect psychological and social health through the possible reduction of feelings of despair and self-blame that women report when their awareness is fully realized, after the fact, when a diagnosis of SLE is made.

PPPs should be developed and implemented systematically for women at risk of SLE. A holistic approach including psychological and social considerations is recommended. Systematic evaluation of the programs using outcome and efficacy measures would produce evidenced-based research needed for continued use of PPPs for women at risk for SLE.

The psychological and social aspects of SLE need

to be taken more seriously by the medical community. Generally, QOL outcomes are underestimated by physicians.⁴² There are anecdotal reports of women being told by their health care providers that they "should be happy to be alive," that "lymphedema is a chronic problem," and that they should "learn to live with it."⁴⁸ Physicians may view morbidity after treatment for breast carcinoma as less important than the removal of cancer and detection of tumor recurrence.^{42,62}

It is important that health care practitioners have the knowledge and tools to facilitate better QOL for all survivors of cancer, including those with SLE. Importantly, the results of the current review suggest that psychological sequelae may not be directly related to the degree of the arm swelling, but rather to how successfully patients manage and adjust to their illness complications. In particular, it must be noted that a change in excess limb volume appeared to have no bearing on changes in psychological and social scoring on self-report quantitative measure scores.^{38,43,46,47,63} SLE increases psychological and social sequelae and this is in addition to the fear of cancer recurrence and metastasis. Women face multiple sequelae, which equate to exponential risk for distress and other psychological and social sequelae and the nonspecific instruments may not describe, adequately interpret, or add meaningful knowledge to research findings. SLE is chronic and is lifelong and requires daily vigilance to prevent and to keep the condition from exacerbating once it has developed.

In summary, we recommend moving beyond use of descriptive studies that confirm an association between SLE and psychological and social sequelae. Of greater need and importance is the exploration of factors (e.g., the extent to which women have followed recommended exercises, predictors of adherence to treatment, whether the affected limb is on the dominant side) that may moderate the severity of SLE-associated psychological and social sequelae. Outcomes research is needed to identify the rates of congruence between symptoms identified by clinicians as most troublesome and those identified by patients with SLE. Further, follow-up intervention and support should be a component of SLE research studies.

There are important methodologic issues to be addressed in future research. Prospective and longitudinal studies are critical to inform the research community and clinicians regarding the epidemiology of SLE. There is also a need for the development and use of standardized, well validated measures to begin to build theoretic constructs for the prevention of SLE. Failure to use and validate measures may be contributing to the inconsistencies in study results. There

should be more theory-driven studies of women that would represent broader segments of the population.

Neglect of psychological and social sequelae in SLE prevention and treatment results in inadequate and more expensive medical care. Leszcz and Goodwin⁶⁴ reported that although the addition of psychological and social interventions may increase costs in the short run, there is current evidence and promise of long-term cost-effectiveness and cost efficiency. Patient and provider resistance to addressing psychological and social factors must also be addressed through education, preparation, and effective collaboration.⁶⁴

Clearly, more data about aspects of psychological and social sequelae are needed to provide a more comprehensive and complete perspective on the needs of survivors of breast carcinoma survivors and patients with SLE. More women are surviving breast carcinoma and for longer periods of time, thus, women's needs assume increased priority in health care. The visibility and political participation of The National Lymphedema Network and the National Coalition for Cancer Survivorship have raised the profile of survivors of breast carcinoma survivors and the need for their well-being, as have activities of the National Cancer Institute, which has established an Office of Cancer Survivorship.^{60,65} These efforts raise the confidence that researchers will devote considerable attention to research for women with breast carcinoma-related SLE to improve their psychological and social health.

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