Self-Reported Fatigue Among Women With Post-Breast Cancer Lymphedema

Corresponding author: Jane M. Armer, RN,C,PhD; Co-author: Davina Porock, PhD

This preliminary study aimed to examine the experience of fatigue among a group of community-dwelling (i.e. living independently, not in a hospital or nursing home) women experiencing both breast cancer and lymphedema. Amount of and disruption due to fatigue, as well as perceptions of causation and self-management, were examined by self-report.

Fatigue is defined as a complex multi-causal multidimensional sensation frequently associated with: 1. decline in behavior or work/performance; 2. a physical/physiologic or biochemical dimension; and 3. a subjective or symptom/sensory dimension.

This multidimensional phenomenon affects physical, cognitive, and affective sensa-tions and is found to vary among individuals in relationship to time and severity. Among persons with cancer, it is evident that symptoms (and often-times treatments) interrelate and compound one another. Similarly, fatigue contributes to the disability that often accompanies the chronic condition of breast cancer.

Decreased activity due to fatigue (or other reasons) contributes to reduced capacity to carry out activity and, cyclically, greater fatigue (see Winningham, 1992). Increased understanding of this multi-dimensional phenomenon in breast cancer survivors living with chronic illness (both cancer and lymphedema) is needed to develop and test appropriate interventions.

Lymphedema occurs as both an acute and chronic condition in which significant persistent swelling associated with an abnormal accumulation of protein-rich fluid is experienced in the affected area. The impact of unmanaged and unresolved lymphedema on quality of life among women living with lymphedema is extensive, encompassing interpersonal and family relationships; functional abilities; occupational roles; self-image; and self-esteem. Among the two million breast cancer survivors in this country, it is conservatively estimated that 20-40% will develop chronic lymphedema within their lifetimes.

There is a paucity of research on lymphedema in women with breast cancer and no published papers were located specifically investigating the relationship between lymphedema and fatigue. This is an interesting gap in the literature given that the preponderance of fatigue research has been focused on the breast cancer population.

In studies investigating quality of life and fatigue in cancer survivors there is an emphasis on correlating the same symptoms as described by those on active anti-cancer treatment. This is particularly true in the case of breast cancer survivors where no mention is made of any symptoms relating to chronic lymphedema despite the prevalence of the problem. An oversight of this nature suggests that many clinicians and researchers appear to be blind to lymphedema and its effect on breast cancer survivors. Two recent studies were located that investigated correlates of fatigue in breast cancer survivors. Neither study mentions lymphedema among the symptoms correlated with fatigue.

Lymphedema is likely to be accompanied by other related problems such as pain, sensation changes and increased range of motion. The impact of chronic pain on well-being is well recognized, specifically, its relationship to depression. Moreover, pain intensity is known to increase when fatigue is present. Lymphedema is known to have a negative effect on psychosocial well-being in terms of body image, depression, poorer adjustment to illness, less social support and lower self-esteem. Passik and colleagues tested predictors of psychological, social, and sexual distress, finding pain, decreased social support, and use of avoidance as a coping strategy to be important predictors of distress.

Combining the research on fatigue in breast cancer survivors with the physical problems and poor adjustment associated with lymphedema, it seems logical to hypothesize that women with lymphedema from breast cancer would be at greater risk for severe, chronic fatigue with the consequential negative effect on quality of life.

While clinically it is recognized that cancer survivors often experience chronic debilitating fatigue, as do persons with lymphedema, little published research addresses fatigue in women with post-breast cancer treatment lymphedema. Therefore, the purpose of this research was to contribute to building that body of evidence.

Research Aims

The aims of this research study were to: determine current level of fatigue among women treated for lymphedema; identify factors reported to cause fatigue; and identify self-care behaviors used by women with lymphedema to manage fatigue.

Research Methods

The study design was a descriptive cross-sectional survey. A convenience sample was drawn from community-dwelling women diagnosed with lymphedema who were previously treated for breast cancer (N=29). Instrumentation included a demographic/historical data collection.
guide and the Piper Fatigue Scale. Descriptive and thematic analyses are complete; further comparative analyses are planned.

**SAMPLE CHARACTERISTICS**

All participants met the inclusion criteria of reporting a diagnosis of arm lymphedema following breast cancer treatment. Eleven reported they were within 5 years of their initial treatment for breast cancer. The majority (80%) of participants were employed, 70% of these full-time. Mean age was 49.6 years (range = 29-80); mean years of education were 13.9 (range = 8-19); and the mean score for self-reported health was 2.0 (good) on a scale of 1 to 4. Most participants (15 of 25) were taking prescribed medications (mode = 3 medications, range = 1-6).

**PIPER FATIGUE SCALE (PFS)**

The first part of the PFS determines the frequency and severity of fatigue experienced and its interference on physical, psychosocial, and sexual activities. Overall, participants reported moderate levels of fatigue (mean=5.56, SD=2.08, mode=6, range=1-10). The majority (87.5%) of participants had been experiencing fatigue for at least “days,” with 37.5% reporting fatigue for “months or more.”

The second section of the PFS aims to describe the sensations that fatigue causes. Overall, for these sensations of fatigue, participants reported a moderate degree of the negative feelings. Memory (mean=3.32) and clarity of thought (mean=3.20) were the least experienced sensations reported by the women, whereas feeling tired (mean = 5.28) and feeling depressed (mean = 4.56) were the most experienced feelings.

T-tests and correlations were performed to test hypotheses regarding demographic variables and the degree and intensity of fatigue experienced. No significant differences were found for degree or intensity of fatigue by age; education; income; employment or student status. No significant differences were found for degree or intensity of fatigue with health rating, age, length of time fatigue was experienced, education, or income.

The final section of the PFS gives participants the opportunity to write about their own experience, what they find causes the fatigue and how they manage.

**PERCEIVED CAUSES OF FATIGUE**

Perceived causes of fatigue included: work; deconditioning and cancer treatment; sleep disturbances; heat; weight gain; lymphedema; fibromyalgia; thyroid disorder; diabetes; cancer; and age. Among work-related daily activities causing fatigue, respondents cited: normal day’s activities; stress of a normal work day; 14+ work hours/day everyday; “too many things to do”; and “self pressure to do and be everything to everybody.”

Regarding deconditioning/recovery from (breast) cancer and treatment (surgery, radiation, and/or chemotherapy), one respondent wrote, “I had radiation treatment in December ’78 because of cancer and have been fatigued most of the time since then.”

Another wrote, “I am not so energetic as I was before breast surgery.”

Some women identified sleep disturbances as causing fatigue, for example, “When (my affected) arm hurts, (I) don’t sleep well, causing distress.”

**SELF-MANAGEMENT TECHNIQUES**

Participants reported a variety of self-care behaviors to manage fatigue. Behaviors were clustered as physical and psychosocial. Physical behaviors reported to manage fatigue included positioning (sitting or lying down with legs or feet elevated), sleep rest/behaviors, exercise, massage, and nutrition and hydration. Psychosocial self-care behaviors for fatigue included reducing stress, prioritization, “acknowledging it and resting,” talking to someone about feelings, not “giving in” to fatigue and increasing self-awareness of increase in fatigue.

**VOICE OF LYMPHEDEMA AND FATIGUE**

One participant shared the increased insight into her fatigue experience gained in completing the research survey in this revealing statement: “I had this [survey] sealed and realized I hadn’t answered correctly...I had just had a nap, so my answers were less extreme than I usually feel. For instance, there is a fuller answer to the question [on social interaction]. I don’t socialize. When our kids call, often my husband talks longer than I do—I am too tired to hold a conversation. If I sit down, I go to sleep.”

**Summary & Recommendations**

This small study has shown that women with lymphedema following breast cancer report a moderate level of fatigue that can interfere with their physical, sexual and social activities. Fatigue was generally reported to be moderately severe and moderately disruptive. The results also show that the level of fatigue experienced could not be related to the women’s age, education, income, employment or student status, or their perceived health status. This finding leads us to hypothesize that the lymphedema itself is the major variable in the explanation of fatigue in these women. Further comparative research is needed to test this hypothesis.

Among the lessons learned in this preliminary exploration of the fatigue experience and self-management among women with breast-cancer related lymphedema are the following:

- Extent of fatigue among women with lymphedema;
- Severity of the disruption in the person’s life due to fatigue;
- The personal experience of fatigue in lymphedema;
- Individual fluctuation in fatigue levels;
- Perceived factors causing/increasing fatigue;
- Physical and psychological self-care behaviors; and
- Fatigue as a cue of health status change.

These preliminary findings suggest that fatigue is a particular problem for women with lymphedema, it is widespread and varied in nature. Further more comprehensive research in the area of fatigue in women with lymphedema is recommended in order to more fully evaluate the prevalence and severity of fatigue and the efficacy of reported self-care actions. Such work is preliminary to intervention research in this area. These findings will increase our understanding of similarities and differences in fatigue symptoms and self-management among women with lymphedema and others. They also will increase our understanding of fatigue as a major problem in chronic illness in general, as well as in lymphedema specifically.

References are available upon request. Please call 510-208-3200 or email nln@lymphnet.org to receive a copy via fax or email.

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Jane M. Armer, RN, C, PhD, is Associate Professor, Sinclair School of Nursing, University of Missouri-Columbia, and Director, Nursing Research, Ellis Fischel Cancer Center. She teaches in the areas of nursing research and health promotion, conducts research in chronic illness management, is certified as a manual lymph drainage therapist and is an active member of the NLN Medical Advisory Committee.

Davina Porock, PhD, is Associate Professor and Coordinator, Oncology Research Interest Group, Sinclair School of Nursing, University of Missouri-Columbia. She teaches in the field of oncology and palliative-care nursing, specifically radiation therapy and symptom management. Her current research program focuses on cancer-related fatigue.