

The Psycho-Social Impact of Lymphedema

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Abstract

Patients with lymphedema experience multiple psycho-social problems. Healthcare professionals who deal with patients who have venous disease, lymphatic malformations, or secondary lymphedema are uniquely positioned to help address psycho-social issues in these patients. To address these concerns in practice settings, it is necessary to become familiar with the lymphatic system and to approach patients with compassion based upon an understanding of the difficulties and frustrations they may be experiencing. Caregivers must learn to recognize that these problems exist, assess patients for these problems, and assist them in obtaining needed services.

Introduction

THE PURPOSE OF THIS SEGMENT OF THE SYMPOSIUM is to provide an overview of the psycho-social impact of lymphedema on the lives of individuals who suffer from this condition. The information presented here was generated by multiple studies conducted from 2003 through 2009 in breast cancer survivors with and without treatment-related lymphedema. My research to date has been in breast cancer-related lymphedema; however, my research team and I receive a large number of phone calls and e-mails from individuals with primary lymphedema or secondary lymphedema related to other types of cancer treatment or traumatic injuries. It is important, as a contextual point of reference, that the thematic content of these communications be presented, as there are recurrent concerns voiced. These themes include: the lack of treatment resources, the lack of lymphedema research, pleas for research to be undertaken to study their conditions, a willingness to participate in research, deep anger that healthcare professionals seemingly either do not care or fail to understand the seriousness of their problems, reports regarding the lack of insurance coverage for treatment and supplies, and parental despair when dealing with a child who has lymphedema or lymphatic disease. Financial difficulties, work problems, and Quality of Life (QOL) concerns are also voiced. These recurring themes provide three important insights related to the psycho-social impact of lymphedema. First, all individuals with lymphedema or lymphatic disease, regardless of the cause, appear to experience psycho-social problems. Second, psycho-social issues may be more severe in families

that have children with lymphedema and/or lymphatic disease. Third, the psycho-social findings in breast cancer survivors which are outlined in this paper may generalize well to other lymphedema populations.

Research Findings

Foundational work for the data presented here commenced in 2003. Throughout all studies, valid and reliable psychological instruments have been used for data collection. Information about medication use and co-morbid medical conditions has also been collected from cancer survivor participants, with and without lymphedema.

The foundational, cross-sectional study compared symptoms and QOL between 64 breast cancer survivors with lymphedema and 64 breast cancer survivors without lymphedema.¹ All participants underwent an arm examination to stage lymphedema, had skin condition evaluated, and height and weight measured to calculate Body Mass Index (BMI). Bioelectrical impedance was used to measure extracellular fluid. All participants were asked to rate the perceived difference, if any, between the arm size on the side where they had undergone breast cancer treatment and the nontreatment side. Self-report instruments were used to measure symptoms and QOL. Participants with lymphedema were also asked to write briefly about any other problems they had experienced because of their lymphedema in the 2 weeks prior to study participation, after they had completed all other aspects of the study.

Findings from this study were enlightening. Group differences were not found in income, employment status,

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Supported by American Cancer Society Grants MRSG-07-012-01-CPPB and RSGTK-05-093-01-CPHPS; National Center for Research Resources-1UL1RR024975; Vanderbilt University Post-Doctoral Research Fund; National Institute of Nursing Research-1-F31-NR07854-01.

insurance coverage, and level of education. Lymphedema occurred across all stages of cancer diagnosis. BMI positively correlated with all outcome variables and was controlled for in the statistical analysis.

Extracellular fluid volume, as measured by bioelectrical impedance, correlated with symptom intensity ($r = 0.23$, $p < 0.01$), but not with the total number of symptoms or with symptom-related distress. However, perceived difference in arm size correlated with mean symptom intensity ($r = 0.28$, $p < 0.01$), mean symptom distress ($r = 0.23$, $p < 0.01$), and total symptoms ($r = 0.24$, $p < 0.01$). Many women in the nonlymphedema group, interestingly enough, reported perceived arm size differences, that, if accurate, would have led to a diagnosis of lymphedema. These data suggest that while extracellular fluid influences the intensity of symptoms experienced, an individual's perceived difference in limb size may more greatly influence the total number of symptoms experienced and symptom-related distress. This study also revealed that only 48% of the lymphedema participants were following therapist-recommended Phase II self-care.

Logistic regression revealed that women with lymphedema had symptoms that were different from those without lymphedema. Specifically, loss of confidence in body, decreased physical activity, fatigue, and psychological distress were present; as was altered limb sensation; a composite of sensations significantly different in the lymphedema arms. Symptoms were present in participants who had previously undergone volume reduction treatment, suggestive of a potential lymphedema symptom cluster. When measured by three different QOL tools, individuals with lymphedema reported a poorer QOL. The presence of this troublesome symptom cluster in individuals who had undergone limb reduction treatment offers a possible explanation for the poorer QOL. To summarize, the quantitative segment of this study revealed individuals with lymphedema: 1) reported a larger number of symptoms than those without lymphedema; 2) were more distressed than their nonlymphedema counterparts; and 3) had a poorer QOL.

Participants' written comments revealed multiple QOL, physical health, and psychological issues indicative of an interrupted life. They wrote about time management and exhaustion and described how difficult it was to complete self-care activities in Phase II of the decongestive therapy model. They had altered wardrobe, clothing, and jewelry to accommodate the swelling. They were fearful of everything from getting infections in their limbs to exercising too much, thereby making the arm bigger and more painful. They wrote about experiencing anger towards what they perceived as uninformed and/or uncaring healthcare professionals. They had atypical sleep disturbances. For example, they put pillows in the bed to elevate their arms or attempted to sleep only on the side that was not swollen. Their partners at times left the bed and slept somewhere else because there wasn't room in the bed due to the pillows, or they could not tolerate the participant tossing or turning. This had a significant impact on their quality of sleep and on their relationship with their partners. Socially, they had given up hobbies and activities with friends and family members that they had done for years. They had become more isolated.

Final coded categories for qualitative comments supported the quantitatively driven symptom cluster and included:

secondary impact on body; time management and exhaustion; altered hand and arm sensations; psychological distress; sleep disturbance; fear; abandonment by healthcare professionals; infection; and lifestyle changes.

Due to the issues related to self-care identified in this first study, a second descriptive study was conducted to examine the self-care management practices of breast cancer survivors with lymphedema. We hoped to identify burdens, barriers, and benefits to at home self-care, and to compare reported symptoms to self-care practices. Fifty-one breast cancer survivors with lymphedema enrolled in the study, and preliminary data analyses is in progress.

Thus far, in terms of burdens of self-care, a loss of self-confidence is reported. There is also a perception of lack of control when managing the lymphedema in their arm. Treatment burdens include "It's too expensive." and "My insurance doesn't pay." It is also hard to do "everything" that they were told to do to care for the arm and still live the rest of their lives. There appears to be a perceived lack of positive results from self-care. Barriers to completing self-care mirror the burdens, with one exception: the self-care they were taught to do was actually uncomfortable or hurt. The major benefit of self-care appears to be in maintaining some degree of control over perceived arm size.

Symptoms present in this group of participants include fatigue, sleeping problems, and concerns about body image. Decreased levels of physical activity and concerns that the body doesn't perform right anymore are also present. Sexual issues are apparent (e.g., decreased sexual activity, feeling less sexually attractive, and a lack of interest in sex). QOL scores were similar to those in the first study (low), with the psychosocial dimension reflecting the most impairment.

An on-going study is also providing insight into the psychosocial issues related to lymphedema. To address the identified psychosocial issues, a randomized clinical trial looking at the effects of dose-controlled expressive writing in breast cancer survivors with lymphedema is underway. Participants write for 20 minutes, four times, over 2 weeks. Participants receive start and stop calls for each session. The experimental group writes about deepest thoughts and feelings related to lymphedema, and the control group writes about aspects of daily living. Analysis of baseline (study entry) data has begun and qualitative analysis of the writings of each group is underway. For the first 95 participants, the Center for Epidemiological Studies Depression Scale mean at baseline is slightly over 16, indicative of depressive symptoms.² QOL is also low, with psychological and social dimensions showing the most impairment.

Qualitative analysis of the expressive writings analyzed thus far is suggestive of: psychological distress; abandonment concerns; anger; poor body image; difficulty coping with a chronic illness; guilt and punishment; and being embarrassed by their appearance when in social settings. For example, people may feel guilty for not having followed risk reduction guidelines to the letter, or they may feel that they are being punished for doing something wrong after treatment. Several participants complained about not being able to camouflage the swollen arm. Writings analyzed to date reveal difficulties coping with a chronic disease, "cancer is something you can get over; lymphedema is with you for the rest of your life." There is perceived lack of support from healthcare professionals about lymphedema management. This likely leads to

the feelings of abandonment and anger that are also being expressed in this study. The group writing about daily activities is painting a picture of overeating, physical inactivity, sleep problems, and the symptoms in the arm controlling what they do and do not do.

Another study has addressed the incidence, treatment costs, and complications of lymphedema 2 years after breast cancer treatment.³ It is important to note that the incidence of lymphedema is most likely understated in the study because only those with lymphedema and insurance were captured. Claims data for 1877 patients were examined. Ten percent of the 1877 survivors had claims indicative of lymphedema within the first 2 years after treatment. There were some slight geographical differences. People in the West were more likely to have claims from lymphedema than those in the Northeast. Matched control women, without diagnostic codes for lymphedema, were used to compare medical costs and infections. This comparison yielded information relative to psycho-social concerns. The lymphedema group had significantly higher medical costs. The lower bound estimate was approximately \$15,000 and the high end was a little over \$23,000. A major contributing factor to this cost difference was outpatient mental health services, as were more moderate and high complexity office visits. Lymphedema patients also experienced more interrupted days for hospitalization or office visits with a mean of 58.7 days compared to a mean of 46.5 in the nonlymphedema group. This was not only a statistically significant difference, but in terms of impact of QOL, losing a month every year for medical care is likely clinically significant.

Summary of Psycho-social Findings

Based on this brief review of studies, what can we conclude about the psycho-social impact of lymphedema?

First, significant psycho-social issues are associated with breast cancer treatment-related lymphedema. These include:

- Loss of confidence in the body:
 - “Doesn’t work like it used to”
 - “What else will go wrong”
 - “I am cancer-free, but have a chronic disability”.
- Performance and function concerns.
- Physical inactivity.
- Psychological distress (anger, sadness, depressive symptoms, feeling unheard, undesirable lifestyle changes). Sleep difficulties may contribute to this.
- Poor body image. They may feel “unattractive,” change the wardrobes to “fit” the limb, and perceive arms to be larger than they are.
- Lack of self-confidence in social activities, recreational activities, and in performing self-care.
- Sexuality concerns for both the person with lymphedema, but also for the partner who may either be uncomfortable with the appearance of the limb or fear hurting the person during sexual activity.
- Social anxiety and avoidance.
- Economic concerns exist as treatment is costly, they may have to change jobs, income may go down, and they spend more on healthcare overall.
- Mental health services are accessed more frequently by breast cancer survivors with lymphedema than those without the condition.

- Time management is an issue, patients must make time for burdensome self-care activities.

Second, it is likely that co-morbid conditions may contribute to the psycho-social concerns. Data collected about co-morbid conditions and medications reveal that individuals with lymphedema frequently experience fibromyalgia, arthritis, carpal tunnel syndrome, and neck and shoulder dysfunction.⁴ Many of these patients are also on antidepressants and cardiac medications.

Implications for Patient Management: What helps?

Self-Care

We conducted a study of home-based lymphedema treatment in cancer patients and in noncancer patients using the Flexitouch® System.⁵ In this study, lymphedema patients with cancer were compared to those without cancer because we thought there might be differences in protocol adherence between these patient groups. Questions asked included, did home self-care impact physical or emotional well-being? How satisfied were patients with the treatment modality, and how well did participants adhere to the treatment protocols for the device?

A valid and reliable tool, the SF-12, was used to evaluate patient physical and emotional health pretreatment, and then at 1 month post treatment.⁶ Post-treatment, every dimension on the SF-12 showed statistically significant improvement. Participants reported improvements in daily activities. They were doing more and felt more energetic. They were happy with their treatment and 95% of the people actually thought that their volume was either reduced or maintained. We did not measure the arm volume. As mentioned earlier, in another study we had asked about perceived arm size, and found that it was related to the patient’s symptoms. Therefore, we think these improved health scores post-treatment suggest that if people perceive they are doing something that is helping to reduce or maintain arm size, they feel more in control of their life. We also found that the cancer patients were more likely to use the Flexitouch® System more than the protocol calls for, and that the noncancer group tended to under use the device.

These findings suggest it is likely that people who perceive their self-care treatment is helping may show improved physical and emotional health. It is possible that they would likely achieve more improvement if, along with actual volume reduction treatment, caregivers address some of the psycho-social issues.

Clinical Practice Implications

There are several implications for clinical practice. First, it is important to recognize that the patients with lymphedema or lymphatic disease have underlying psycho-social issues. As a result, healthcare providers may need to allow for longer patient visits when seeing them in clinical practice settings. Second, patients with lymphedema or lymphatic diseases require routine assessment for psycho-social problems. Referrals to social workers, family therapists, vocational counselors, psychiatric professionals, nutritionists, and personal exercise coaches or trainers may be needed. Third, healthcare providers will encounter patients that believe the healthcare system and healthcare providers do not understand

lymphedema, are not knowledgeable enough to offer appropriate treatment, and do not care about them or their well-being. In order to respond to this perception, it is necessary to understand that it may be a valid concern driven by the patient's personal experience with the healthcare system and providers. Why might they have experiences that foster development of that perception? In regards to the healthcare system, lymphedema is a chronic condition that requires daily self-care. There are also exacerbations of swelling that require acute treatment and episodes of infection that must be medically managed. This type of disease trajectory is similar to chronic disease such as diabetes, but current reimbursement does not approach treatment from this frame of reference. Third party payers typically view lymphedema as a condition that requires rehabilitation, similar to a stroke. For example, a stroke patient undergoes initial treatment to regain as much function as possible. This is covered by insurance. Lifelong daily care, requiring bandages, massage, etc. generally is not required after initial rehabilitation treatment. Successful long-term management of lymphedema requires daily management, and healthcare coverage more along the lines of what is done with diabetes would be appropriate. This is a system where on-going management methods (medication, needles, syringes, checking blood glucose levels, etc.) are needed to maintain good glycemic control and are therefore covered by insurance, as are acute exacerbations (hyperglycemic and hypoglycemic episodes). Lymphedema patients consistently report not being able to obtain insurance coverage for supplies such as garments, or for maintenance lymphedema treatment or early treatment when swelling is beginning to worsen.

In the area of uninformed healthcare providers, the lymphatic system is not heavily stressed in most healthcare provider training programs. Thus, many healthcare professionals are truly uninformed about the lymphatic system, lymphatic diseases, and lymphedema. By becoming more knowledgeable about the lymphatic system and its diseases and disorders, caregivers can caringly respond to patients about their disease state and associated problems, including their psychosocial needs.

Conclusions

Healthcare professionals who deal with patients who have venous disease, lymphatic malformations, or secondary lymphedema, are uniquely positioned to help address psycho-

social issues in these patients. This can be accomplished by becoming familiar with the lymphatic system and by approaching patients with compassion, based upon an understanding of the difficulties and frustrations they may be experiencing. Caregivers need to recognize that these problems exist, assess patients for these problems, and assist them in obtaining needed support and services.

Disclosures

Dr. Ridner has no conflicts of interest or financial ties to report.

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