Survivorship care: preventing and managing cancer-related lymphedema a program development plan of education

Mary R. Pollock
The University of Toledo

Follow this and additional works at: http://utdr.utoledo.edu/graduate-projects
Survivorship Care: Preventing and Managing Cancer-Related Lymphedema

A Program Development Plan of Education and Advocacy

Mary R. Pollock
Faculty Mentor: Beth Ann Hatkevich, PhD, OTR/L
Site Mentor: Penny McCloskey, M.Ed.
Content Mentor: Kelly Farley, BS, OTR/L, MLDT/C
Content Mentor: Amy Huntsman, BS, OTR/L, CLT
Department of Rehabilitation Sciences
Occupational Therapy Doctorate Program
The University of Toledo
May 2012

Note: This document describes a Capstone Dissemination project reflecting an individually planned experience conducted under faculty and site mentorship. The goal of the Capstone experience is to provide the occupational therapy doctoral student with a unique experience whereby he/she can demonstrate leadership and autonomous decision-making in preparation for enhanced future practice as an occupational therapist. As such, the Capstone Dissemination is not formal research.
Table of Contents

Executive Summary.................................................................5

Introduction.................................................................6
  Program Goal.............................................................6
  Sponsoring Agency..........................................................7
  Organizational Structure..................................................9
  Investigation of Need......................................................9
  Review of Literature......................................................16
  Federal Initiatives and National Trends.............................22
  Significance of the Program Goal......................................25
  Occupational Therapy-Based Programming..........................26
  Models of Practice.......................................................27

Objectives.................................................................30
  Program Goal.............................................................30
  Objectives...............................................................30

Marketing and Recruitment of Participants..........................43
  Marketing.................................................................43
  Potential Participants...................................................45
  Inclusion Criteria for Potential Participants.......................45
  Expected Number of Participants.....................................46
  Plan for Describing Participants......................................47

Programming...............................................................48
  Direct and Indirect Services..........................................48
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordination of Care</td>
<td>48</td>
</tr>
<tr>
<td>Group Format</td>
<td>49</td>
</tr>
<tr>
<td>Assessments</td>
<td>49</td>
</tr>
<tr>
<td>Documentation</td>
<td>49</td>
</tr>
<tr>
<td>Occupational Forms</td>
<td>50</td>
</tr>
<tr>
<td>Weekly Programming Plan</td>
<td>50</td>
</tr>
<tr>
<td>Budgeting and Staffing</td>
<td>76</td>
</tr>
<tr>
<td>Budget Overview</td>
<td>76</td>
</tr>
<tr>
<td>Budget Justification</td>
<td>78</td>
</tr>
<tr>
<td>Staffing</td>
<td>80</td>
</tr>
<tr>
<td>Funding</td>
<td>82</td>
</tr>
<tr>
<td>Self-Sufficiency Plan</td>
<td>85</td>
</tr>
<tr>
<td>Program Evaluation</td>
<td>85</td>
</tr>
<tr>
<td>Process Evaluation Procedures</td>
<td>85</td>
</tr>
<tr>
<td>Formative and Summative Evaluators</td>
<td>86</td>
</tr>
<tr>
<td>Outcome Evaluation for Objectives</td>
<td>88</td>
</tr>
<tr>
<td>Timeline</td>
<td>97</td>
</tr>
<tr>
<td>References</td>
<td>98</td>
</tr>
<tr>
<td>Appendix A: Organizational Structure</td>
<td>105</td>
</tr>
<tr>
<td>Appendix B: Interview Questions for Program Director at TVC</td>
<td>106</td>
</tr>
<tr>
<td>Appendix C: Interview Questions for Other Staff Members at TVC</td>
<td>107</td>
</tr>
<tr>
<td>Appendix D: Interview Questions for Breast Patient Navigator</td>
<td>108</td>
</tr>
<tr>
<td>Appendix E: Interview Questions for Clinical OTR/L who Treat BCRL</td>
<td>109</td>
</tr>
</tbody>
</table>
Appendix F: Interview Questions for Patients in Treatment for BCRL
Appendix G: Interview Questions for Patients not Currently in Treatment
Appendix H: Participant Survey 2/2012 With Summary of Responses
Appendix I: Participant Survey 2/2011 With Summary of Responses
Appendix J: Needs Assessment: Results of the Semi-Structured Interviews
Appendix K: Workshop I: BCRL Education and Prevention Evaluation
Appendix L: Workshop II: Cancer-Related Lymphedema Evaluation
Appendix M: Workshop III: Managing BCRL Evaluation
Appendix N: Workshop IV: Competency Check-off
Appendix O: Marketing Flyer
Appendix P: Lymphedema Breast Cancer Questionnaire © (LBCQ)
Appendix Q: Summary Evaluation
Appendix R: Resource List
Appendix S: UE Arm Measurement Record
Appendix T: LE Leg Measurement Record
Appendix U: Occupation and Lymphedema Algorithm
Appendix V: Advertisement for Occupational Therapist
Appendix W: Funding Application Information
Appendix X: Letter of Support
Appendix Y: Additional Resources for Letters of Support
Executive Summary

According to the US National Cancer Institute’s SEER database for 2008, 11,958,000 Americans have had a cancer diagnosis. According to the American Cancer Society, for 2012, 1,640,000 new diagnosis are expected. Men and women who have had treatment for cancer are at risk for developing cancer-related lymphedema. Between 5-40 % of women treated for breast cancer, and on average 15% of people treated for non-breast cancers will develop lymphedema. Thirty percent of participants surveyed at The Victory Center (TVC) have or have had signs of breast cancer-related lymphedema. Survivors who develop lymphedema report a lower quality of life and higher levels of anxiety and depression. Lymphedema results in an increased likelihood of chronic pain, fatigue, difficulty with social functioning, and impaired functional abilities. Because there is no cure for lymphedema, prevention and precautions are necessary.

The goal of TVC’s Survivorship Care: Preventing and Managing Cancer-Related Lymphedema for the greater Toledo area is to increase participants’ knowledge about and self-efficacy for managing their risk for cancer related lymphedema. Programming will include four; stand-alone, two-hour workshops that are occupation based and focus on cancer-related lymphedema education and prevention.

The inclusion criterion includes any person who has ever had a cancer diagnosis. The total expected N for the first year is 90. The site for this program development plan is The Victory Center in Toledo, Ohio. TVC is a non-profit, community-based organization established in 1996 with the mission supporting cancer patients. The marketing will occur through direct emails from TVC as well as promoting the program through area doctors’ offices. Outcome measures include gains for increased knowledge and self-efficacy as measured with the program evaluations.
Introduction

Program Goal

The goal of The Victory Center’s *Survivorship Care: Preventing and Managing Cancer-Related Lymphedema* for the greater Toledo area is to increase participants’ knowledge about and self-efficacy for managing their risk for cancer related lymphedema.

The goal of this program ultimately addresses quality of life for cancer survivors with the aim of preventing the onset or exacerbation of cancer-related lymphedema – a chronic condition that necessitates life-long management. Health-related quality of life (HRQoL) as defined by Healthy People 2020 is:

A multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact health status has on quality of life. A related concept of HRQoL is well-being, which assesses the positive aspects of a person’s life, such as positive emotions and life satisfaction (U.S. Department of Health and Human Services, 2010).

According to St. Charles Surgical Hospital’s Center of Excellence for Lymphedema Treatment, “Lymphedema is a chronic medical condition where interstitial fluid inappropriately accumulates in the arms, legs or trunk of the affected individual resulting in a functional disability and risk for repeat infection requiring hospitalization...In its most profound state, lymphedema can result in repeated bacterial infections, limb dysfunction/immobility, elephantiasis and death” (St. Charles Surgical Hospital Center, 2010). According to the National Cancer Institute, lymphedema is one of the most poorly understood, relatively underestimated, and least researched complications of cancer or its treatment (U. S. National Institute of Health,
Sponsoring Agency

The site for this program development plan is The Victory Center in Toledo, Ohio. The Victory Center is a not-for-profit, community-based organization established in 1996 with the mission to “support and educate cancer patients and those closest to them by providing individual and group services in northeast Ohio and Southeast Michigan” (The Victory Center, 2007). The Victory Center originally began as a Cancer Wellness Center, which is a nationwide program of The Wellness Community. (In 2009, The Wellness Community joined with Gilda’s Club Worldwide to become what is now known worldwide as the Cancer Support Community.) In 1996, the decision was made in Toledo to break off from The Wellness Community and become what is known as The Victory Center. The decision was made in part to focus the programming on providing individual services (massage, reiki, healing touch, reflexology) to help the body deal with the symptoms of cancer and treatment and to provide a mental break for participants. According to Penny McCloskey, M.Ed., the Program Director, to her knowledge, no other program in the country offers this level of individual services free of charge to cancer patients.

In 2011, 400 people received support services from The Victory Center. During that time, TVC completed 6,387 units of service through individual non-medical based treatments, such as massage and reflexology, and also group programs that focus on emotional support, fitness, and social engagement. A unit of service is the provision of service to an individual. In other words attending a massage is considered one unit of service. Likewise, if 10 people attend a cancer support group that is considered 10 units of service. Individual services are available during cancer treatment and up to six months after treatment has ended. Individual services are
available once per week, with up to three individual services per month and last 30-60 minutes each. Group services are open to anyone who has had a cancer diagnosis. Group services, such as cancer support groups, are available one or two times a month and last 1.5 hours. Special groups meet weekly or monthly for 1-2 hours and include a knitting group, book clubs, and fitness classes. Anyone who uses The Victory Center whether currently in treatment or years past the completion of treatment is referred to as a “participant.”

The Victory Center serves an average of 80 participants per week. An average of 18 new participants come to The Victory Center each month. The Victory Center serves about 500 participants per year, half of which have a diagnosis of breast cancer. The Victory Center is supported through grants, foundations, donations, fundraising, and a very limited United Way funds.

The philosophy of The Victory Center includes the belief that programs should be participant driven and that it is the responsibility of The Victory Center to collaborate with other community services to best meet participants’ needs. In addition, The Victory Center’s website explains, “Our sole purpose is to nourish and comfort the body, mind and spirit during the fight against cancer. Programs are held in a comfortable homelike setting and are presented by licensed professionals with credentials appropriate to their specialty” (The Victory Center, 2007).

The typical population that receives services at The Victory Center is adults and adolescents with minimal pediatric involvement. Participants include both men and women from the point of cancer diagnosis and beyond. There are services aimed specifically at those in treatment and services for survivors as well as family members. While a half of the clients have a breast cancer diagnosis, other forms of cancer are well represented including rare cancers.
Recently, The Victory Center has been serving more men with typical diagnosis being, prostate, colorectal, blood, and lung cancers.

**Organizational Structure**

A Board of Directors and Medical Advisory Council support the Victory Center. Staff includes: Dianne Cherry, Executive Director; Penny McCloskey, MEd., Program Director; Michelle Keeling, Events/Volunteer Coordinator; Lora Johnson, Office Manager; and Lynn Chandler, Administrative Assistant. Currently, all staff members, therapists and support group facilitators report directly to the executive director. Exceptions include the administrative assistant who reports to the office manager. Also, volunteers report to the events/volunteer coordinator. Based on the current organizational set-up, it would be most appropriate for the occupational therapist to report directly to the executive director (see Appendix A for organizational structure).

**Investigation of Need**

A needs assessment was performed in order to determine the need for and interest in cancer-related lymphedema programming at The Victory Center. The needs assessment included semi-structured interviews with key informants from the community and from The Victory Center. For each interview administration, the informant was met in a quiet location, was introduced to the purpose of the needs assessment, was assured of confidentiality, and was given an explanation of the role of occupational. Interviews were conducted with: staff of The Victory Center; a nurse who has experience as a cancer navigator at a Toledo area hospital; occupational therapists who treat lymphedema; women in treatment for breast cancer-related lymphedema (BCRL); and women with BCRL who are not currently in treatment (see Appendices B - G for a copy of the interview questions). In addition to interviews, a survey was distributed to
participants during three groups at The Victory Center including the Healthy Steps exercise class, the Knit Wits activity group, and also the breast cancer support group (see Appendix H for a copy of the 2012 participant survey). In addition, a survey was distributed in February 2011 at the Healthy Steps exercise class and the breast cancer support group (see Appendix I for a copy of the 2011 participant survey). In 2011, 11 women completed the needs assessment participant survey. In 2012, 12 women completed the needs assessment participant survey. Based on the needs assessment, the results show strong support for lymphedema programming at The Victory Center by both the staff and participants.

**Participant survey results.** Overall, thirty percent of the women encountered at The Victory Center in 2011 and 2012 currently have, or had in the past, symptoms of breast cancer-related lymphedema. Two factors that put women at an increased risk for BCRL include removal of lymph nodes and radiation. For 2011 and 2012 100% of respondents had lymph nodes removed. For 2011, 75% of the respondents had radiation while 45% of the respondents in 2012 had radiation. Based on survey results and the reported rate of lymph node removal and radiation treatment, women attending The Victory Center with a diagnosis of breast cancer are at risk for cancer-related lymphedema.

In the 2011 needs assessment, while seven of the women (58%) reported being referred to an occupational therapist for lymphedema education and prevention, only four actually sought out services. In 2012, only two of the 11 women (18%) had been referred to an occupational therapist for lymphedema education and prevention. Both of these women followed through and went to see an occupational therapist. The 2012 survey shows a decrease in the number of women being referred to occupational therapy services for education and prevention of BCRL.

Based on the needs assessment, a program at TVC is supported by the fact that women
are not routinely referred to occupational therapy after cancer treatment for the prevention of and education about lymphedema. The physician/surgeon is the gatekeeper that provides a prescription for occupational therapy services. Because, most women do not have access to occupational therapy for the purpose of prevention, it makes sense to provide participants with the information and skills they need to reduce their risk for cancer-related lymphedema through a free, community-based program at The Victory Center.

Finally, all participants surveyed were interested in learning more about BCRL. In 2011, 100% of the women expressed interest in learning more about lymphedema. In 2012, 80% were interested in learning more about lymphedema while the other 20% noted that they were not interested because they felt it was, “Not relevant – no lymphedema” and also said they would be interested, “If I exhibit symptoms.” The 20% who were not interested in the lymphedema programming are notably at a lower risk of developing BCRL, as they did not have axillary nodes removed or radiation. Of the women surveyed, 83% of respondents in 2011 and 75% of the respondents in 2012 replied that they would be interested in attending a workshop to learn more information about preventing cancer-related lymphedema. If available, 66% of the 2011 respondents and 75% of the 2012 respondents also expressed interest in meeting with an occupational therapist one-on-one at The Victory Center to learn more about preventing BCRL. An additional 18% of the women in 2011 would be interested in meeting with an occupational therapist if they developed symptoms.

Other questions on the participant survey addressed the relationship of lymphedema and engagement in daily life. In 2102, 86% of respondents reported taking steps in their daily life to prevent lymphedema. For example, 83% avoided needles and blood pressure in the affected arm, 50% wear a compression sleeve, and 50% take other extra precautions such as, “When
doing heavy work or lifting, wear a warning bracelet, and engage in lymphatic exercises.” Fifty-seven percent of respondents limit activities and also avoid using the arm on the side where lymph nodes were removed to avoid lymphedema. Finally, 28% of respondents have given up hobbies or activities due to symptoms of lymphedema and 14% of respondents reported lymphedema affecting their ability to complete basic occupations of daily living.

When administering the surveys, it became clear that women have received inconsistent information related to their risk for lymphedema. One woman expressed, “My doctor really downplayed the risk for lymphedema so I have never really worried about it.” Another woman expressed, “I am so sorry I can’t help you with your survey, I don’t have lymphedema.” The more we talked the more she remembered the precautions she was told about and took during the first year after treatment. She expressed surprise at what she had forgotten and was very appreciative of being reminded about simple precautions. In short, when speaking with women at risk for cancer-related lymphedema they fall into one of three groups: women with BCRL who simply live with it; women who are aware of and worried about the risk and take proactive steps to avoid BCRL; women who are not aware that they are at risk (never informed, doctor downplayed, forgot/denial).

Finally, as the surveys were administered to determine the interest in BCRL programming, it became clear that people with other types of cancer diagnosis were interested in being a part of the data collection and felt left out. One woman shared that her friend was having a terrible time with lower extremity lymphedema after treatment for ovarian cancer. These comments as well and observations made at an out-patient lymphedema clinic and information gained by interviewing other staff at The Victory Center became the impetus for creating a cancer related lymphedema program that is not limited to only BCRL.
Semi-structured interviews with patients. Two women were interviewed who currently have BCRL. One woman developed lymphedema within a few months of treatment, while the other woman developed lymphedema within a few years after treatment. Both women tolerate their lymphedema. Both have had minimal treatment and poor follow through with management. The impetus for returning to treatment for one woman occurred when her clothes no longer fit. The other woman manages her lymphedema only when it interferes with her functional abilities. Despite the lymphedema, one woman continues with all her occupations. It is likely that her current career occupations and IODLs are aggravating her lymphedema; however, she is unwilling to make any changes to her habits and roles to accommodate her lymphedema. Both women expressed that their lymphedema becomes worse in summer and aggravated by lifting and pulling. Walking around a lot also leads to increased swelling.

Both women voiced problems with obtaining properly fitted compression garments, providing further evidence of a commonly voiced concern expressed by Toledo area women who rely on compression garments to manage lymphedema. The needs assessment identified a major need for qualified compression garment fitters in the Toledo area. One woman was measured for a compression sleeve with the fitter measuring her non-affected arm for a sleeve that was to fit her affected arm. It did not fit. The patient tried to advocate for herself and questioned if measuring this way made sense? The other woman interviewed also received a poor fitting glove that turned her fingers blue – it never fit and she never wore it.

Semi-structured interviews with clinical OTRs that treat lymphedema. The occupational therapists interviewed voiced concern about the financial burden faced by patients who are in active lymphedema treatment. Medicare and most other medical insurance do not cover bandages used for treatment. Most clinics charge the patient for bandages, which cost
about $100.00 to begin treatment. Visits can be from 2 times a week to 5 days a week for an intensive period of time with the goal of getting the lymphedema under control. Patients have a limited number of visits to occupational therapy and the number of visits is determined by the individual’s insurance. The co-pays for the therapy intense treatment can be an additional financial burden especially for those on a fixed income. All therapists interviewed thought there is a need for free lymphedema screenings.

The second concern identified by the occupational therapists is that poor-fitting compression garments is a huge problem for treatment and management compliance. According to a Toledo area occupational therapist, “Sleeves that are comfortable to wear and good fitting is critical.” Medicare does not cover compression garments except for breast cancer. Barton Carey, a local manufacturer of custom compression garments, makes a reasonable priced sleeve. Other local suppliers are very expensive. Likewise, there is a need for more qualified and competent fitters in the Toledo area. In short, according to one therapist, “Coverage of garments by insurance and good fit leads to compliance.”

Finally, the occupational therapists interviewed, expressed that when considering program development to consider that patients follow doctors’ advice. Therefore, it is important to develop relationships with the doctors. Some surgeons routinely refer their patients to occupational therapy for a preventative educational appointment. For example, at one site, 75-80% of patients seen for BCRL are for patient education, educating about signs of BCRL, and to establish a baseline. However, in talking with another therapist and her patient, the patient voiced that when she was referred to occupational therapy her surgeon told her, “Don’t let them talk you into one of those sleeves.” A compression sleeve is a central component of prevention and management of cancer-related lymphedema. That a surgeon would tell a patient not to use
the available resources for managing lymphedema shows a need for lymphedema therapists to advocate for an increased awareness of the role occupational therapy plays in treating lymphedema. In addition, inconsistent information provided to patients regarding cancer-related lymphedema leaves room for an increased level of patient education that could be provided at The Victory Center.

**Interview with program director and staff at The Victory Center.** According to the program director, the role of The Victory Center is to, “Give people the opportunity to get the support they need for the body, mind, and spirit during their cancer journey.” Also it was emphasized by both the executive director and program director that programming at The Victory Center is non-medical; however, it is intended to complement participants’ medical treatment. The executive director expressed, “The mission of The Victory Center is educational and non-medical.” Another staff member expressed, “The Victory Center provides support service. We do not provide treatment of any kind – support services only.” However, there is a medical advisory board that approves programming and services.

Over time the needs of participants becomes less; however, programs are still well attended over time by survivors. About 30% of people who come to The Victory Center during active cancer treatment continue to participate in programming after active cancer treatment has ended. However, according to the program director, “The main purpose of The Victory Center is to support participants during cancer treatment and care for them when things are most crisis-oriented.” She also noted, “The survivors’ needs become less over time.”

In summary, The Victory Center provides services for free to participants. Without insurance, people at risk for cancer-related lymphedema do not have access to an occupational therapist. Also, insurance limits the number of yearly visits to an occupational therapy. It makes
sense to educate cancer survivors on the prevention and management of cancer–related lymphedema through a program at The Victory Center. The program would educate participants about the role of occupational therapy in treating lymphedema and ensuring maximal occupational engagement by participants who are at risk for cancer-related lymphedema (see Appendix J for the full needs assessment results of the semi-structured interviews).

**Literature Review**

According to the US National Cancer Institute’s SEER database for 2008, 11,958,000 Americans have had a cancer diagnosis. According to the American Cancer Society, for 2012, 1,640,000 new diagnosis are expected. Cancer survival is up with an increased 5 year survival of 67% for the years 2001-07, up from 49% for the years 1975-77. Increased survivorship has led to a growing demand (by survivors, funding sources, the medical establishments and the national government) to develop programming that advocates for and addresses the unmet needs of cancer survivors. Those making a call to action include: Healthy People 2020, the Institute of Medicine, organizations such as LiveStrong, and funding sources like Susan G Komen for the Cure.

According to The National Cancer Institute’s patient information about lymphedema, (2011) “Lymphedema often occurs in breast cancer patients who had all or part of their breast removed and axillary (underarm) lymph nodes removed. Lymphedema in the legs may occur after surgery for uterine cancer, prostate cancer, lymphoma, or melanoma. It may also occur with vulvar cancer or ovarian cancer” (National Institute of Health National Cancer Institute, 2011). Lymphedema resulting from breast cancer is the most common form of cancer-related lymphedema. However, lymphedema also can result from treatment for other types of cancer.
Updated in 2011, the U.S. National Cancer Institute’s website explains the epidemiology of lymphedema.

Lymphedema can occur after any cancer or its treatment that affects lymph node drainage. It has been reported to occur within days and up to 30 years after treatment for breast cancer. Eighty percent of patients experience onset within 3 years of surgery; the remainder develop edema at a rate of 1% per year. Upper-extremity lymphedema most often occurs after breast cancer; lower-extremity lymphedema most often occurs with uterine cancer, prostate cancer, lymphoma, or melanoma. A large population-based study supports the evidence that lower-limb lymphedema is experienced by a significant proportion of women after treatment for gynecological cancer, with the highest prevalence (36%) among vulvar cancer survivors and the lowest prevalence (5%) among ovarian cancer survivors.

There is no consistency in the data on the incidence and prevalence of lymphedema after breast cancer, probably because of differences in diagnosis, the different characteristics of the patients studied, and inadequate follow-up to capture delayed development of the disorder. The overall incidence of arm lymphedema can range from 8% to 56% at 2 years post surgery (National Institute of Health National Cancer Institute, 2011).

In 2010, Lymphedema Beyond Breast Cancer: A Systematic Review and Meta-Analysis of Cancer-Related Secondary Lymphedema was published, in attempt to determine the rate of cancer-related lymphedema resulting from other cancers besides the breast cancer. When looking at the incidence of cancer related lymphedema excluding breast cancer, the authors found:
The overall incidence of lymphedema was 15.5% and varied by malignancy (P < .001): melanoma, 16% (upper extremity, 5%; lower extremity, 28%); gynecologic, 20%; genitourinary, 10%; head/neck, 4%; and sarcoma, 30%. Increased lymphedema risk was also noted for patients undergoing pelvic dissections (22%) and radiation therapy (31%). Objective measurement methods and longer follow-up were both associated with increased lymphedema incidence (Cormier, J.N., Askew, R.L., Mungovan, K.S., Xing, Y., Ross, M.I. & Armer, and J.M (2010).

The authors concluded that lymphedema has the possibility of affecting all cancer survivors and is dependent on the kind of cancer treatment.

What is important is to note that the risk for cancer-related lymphedema affects a percentage of all cancer survivors. Also significant is that cancer-related lymphedema can occur immediately or decades after active cancer treatment. An educational program about lymphedema would be relevant to all participants who attend The Victory Center.

When looking at breast-cancer related lymphedema, according to the American Cancer Society, “In 2009, an estimated 192,370 women in the United States were diagnosed with invasive breast cancer and about 40,610 women were expected to die from the disease” (American Cancer Society, 2010). According to Cathy Nelson, Board President for the American Cancer Society Lucas County, 8000 women will be diagnosed with breast cancer in Ohio in 2011. Fortunately, despite the rate of diagnosis, survival is increasing.

Lymphedema is the most common side effect of breast cancer surgery that survivors face. According to the non-profit organization Breastcancer.org, “Experts estimate that from 5% to 40% of women will experience some level of lymphedema after breast cancer surgery. The risk may be higher if you:
• Have a full axillary lymph node dissection (lymph nodes above, below, and underneath the pectoralis minor muscle -- known as levels I-III -- are removed);
• Have radiation to the lymph node areas after lymph node surgery;
• Have extensive cancer in the lymph nodes;
• Have chemotherapy;
• Choose mastectomy rather than lumpectomy;
• Are obese;
• Smoke heavily;
• Have diabetes;
• Have had surgery in the armpit area before now (Breastcancer.org, 2011).

The National Cancer Institute estimates that 500,000 US women suffer from lymphedema. Breast cancer survivors who have had axillary lymph node dissections and radiation make up the largest group of those seeking treatment for lymphedema.

"It's a terribly overlooked problem," says Robert Smith, Ph.D., director of cancer screening for the American Cancer Society (ACS). "Many of these women have significant out-of-pocket expenses, and prolonged and chronic health problems, as a result of it. It's not curable, and once women have lymphedema, unless it's properly managed and treated, it can become progressively worse. (Main Line Health, 2011).

A study reported in the Journal of Clinical Oncology found that breast cancer survivors who develop lymphedema report a lower quality of life and higher levels of anxiety and depression. In addition, they have an increased likelihood of chronic pain and fatigue and experience greater difficulty with social and sexual functioning (Main Line Health, 2011).
While rare today, it is possible that lymphedema can contribute to a secondary cancer diagnosis of soft tissue. According to the National Cancer Institute publication *New Malignancies Among Cancer Survivors: SEER Cancer Registries, 1973–2000*, Chapter 7 page 184 entitled “New Malignancies Following Breast Cancer” by Rochelle E. Curtis, Elaine Ron, Benjamin F. Hankey, and Robert N. Hoover, “Some soft tissue sarcomas of the upper limbs may be related to the lymphedema” which resulted after radical mastectomy (Stewart and Treves, 1948) (U. S. National Institute of Health, 2011). Chronic, untreated lymphedema can predispose a person to lymphangiosarcoma in the Stewart-Treves syndrome.

In 1998, a workshop sponsored by the American Cancer Society reviewed and evaluated the current state of knowledge about lymphedema. Recommendations and research initiatives proposed by the 60 international participants were presented in *CA-A Cancer Journal for Clinicians*. The work group had many recommendations related to lymphedema. Significant recommendations put forth include:

All patients treated for breast cancer should be assessed for signs and symptoms of lymphedema at an early interval following completion of healing from breast cancer therapy (within the first 12 weeks). Clinicians should pay attention to physical signs of lymphedema as well as to the patient’s subjective awareness of symptoms, as the latter may reveal early signs of an underlying pathology (Petrek, Pressman, & Smith, 2000, p. 304).

Lymphedema education is critical due to the high incidence and the resulting impact on functional abilities, mental health, and quality of life. Because there is no cure for lymphedema, prevention and precautions are necessary.

Finally, the National Cancer Institute advocates for prevention and management of
lymphedema through education and increased awareness amongst both patients and clinicians.

Lymphedema is an important consideration for clinicians who care for cancer patients because of its relatively high frequency and significant functional and quality of life implications for patients. Lymphedema is an independent predictor of decreased quality of life, even when other predictive factors such as socioeconomic status, decreased range of motion, age, and obesity are taken into account (National Cancer Institute, 2011).

Breast cancer survivors with arm lymphedema have been found to be more disabled, experience a poorer quality of life, and have more psychological distress than do survivors without lymphedema. In addition, women reporting swelling have reported significantly lower quality of life with multiple functional assessments. (National Cancer Institute, 2011).

It is important to diagnose and treat lymphedema when it is mild because those with mild lymphedema make up the cohort that gives rise to preventable severe, debilitating lymphedema. Women with mild lymphedema are more than three times as likely to develop severe lymphedema than are women with no lymphedema (National Cancer Institute, 2011).

With increased cancer survivorship, there is in increase in recent research related to the needs of survivors. There is an abundance of recent literature that provides a greater understanding of and interest in cancer-related lymphedema. Lymphedema is one area of survivorship care that can be addressed by programming at The Victory Center.

In summary, cancer survivors face a real risk of developing cancer-related lymphedema. The research shows that this chronic condition can have a negative impact on a person’s quality
of life. The literature emphasizes the need for patient education to increase patients’ understanding of lymphedema. Survivors need to become their own advocate by developing the skills that will allow them to prevent and or manage cancer-related lymphedema. Likewise, cancer survivors should have access to accurate, up-to-date information about preventing and managing cancer-related lymphedema. A program at The Victory Center could help fill the void that currently exists for many survivors in terms of accurate and timely education regarding cancer-related lymphedema.

Federal Initiatives and National Trends

According to Healthy People 2020, the overview for the topic of cancer notes, “In the coming decade, as the number of cancer survivors approaches 12 million, understanding survivors’ health status and behaviors will become increasingly important” (U. S. Department of Health and Human Services, 2012a.). The National Cancer Institute reports that women make up 54 percent of cancer survivors. In addition, breast cancer survivors are the largest group of cancer survivors at 22 percent.

Healthy People 2020 identify four overarching goals directed at achieving the goal of people living long and healthy lives. The four overarching goals of Healthy People 2020 include:

1. Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death.
2. Achieve health equity, eliminate disparities, and improve the health of all groups.
3. Create social and physical environments that promote good health for all.
4. Promote quality of life, healthy development, and healthy behaviors across all life stages.
(U. S. Department of Health and Human Services, 2012b). The proposed program at The Victory Center will meet goals one, two, and four of the Healthy People 2020 overarching goals. The program will serve to improve quality of life, prevent disability, and promote health equity.

Healthy People 2020 also identify a goal to “Reduce the number of new cancer cases, as well as the illness, disability, and death caused by cancer” (U. S. Department of Health and Human Services, 2012a). Under the topic of cancer, Healthy People 2020 also identifies objective C-14 (Developmental) to “Increase the mental and physical health-related quality of life of cancer survivors” (U. S. Department of Health and Human Services, 2012a). In short, Healthy People 2020 identifies the goal of reducing disability related to cancer and increasing health-related quality of life. The program for lymphedema education for participants at The Victory Center has the same goals. The purpose of creating this program at The Victory Center is to advocate for participants so that they are empowered with knowledge. Participants will be provided with knowledge and skills to reduce their potential for disability resulting from cancer-related lymphedema. Likewise, the program is aimed at increasing the quality of life of participants. The program will do this by helping survivors to assess how they can safely remain engaged in meaningful occupations. The program will help teach survivors to catch and treat lymphedema when it is mild and manageable. Finally, the program can help connect those with cancer-related lymphedema with the resources available for treatment and management.

Increased survival rates after a cancer diagnosis has led to a recent focus on considering the long-term needs of cancer survivors. The National Cancer Institute of the U.S. National Institutes of Health explains:

As the number of cancer survivors continues to increase, it is important for medical and public health professionals to be knowledgeable of issues survivors may
face, especially the long-term effects of treatment on their physical and psychosocial well-being,” said Arica White, Ph.D., M.P.H., an epidemic intelligence service officer in CDC’s Division of Cancer Prevention and Control. “This understanding is critical in promoting good health and coordinating comprehensive care for cancer survivors (National Cancer Institute, 2011).

The program aims to address one issue that survivors face by helping them to assess and manage their risk for cancer-related lymphedema. As noted earlier in the literature review, lymphedema can be an immediate side effect or occur as a long-term effect of treatment. The literature also shows how detrimental cancer-related lymphedema can be to a person’s physical and psychosocial well being. The hope is that lymphedema programming at The Victory Center will serve to increase awareness of this cancer side effect and by doing so promote the well being of the participants. Finally, educating survivors on the role of occupational therapy for treating and managing lymphedema can contribute to comprehensive care of survivors.

According to the website, The Institute of Medicine (IOM) “is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public. Established in 1970, the IOM is the health arm of the National Academy of Sciences.” In 2006, the IOM produced a report entitled, From Cancer Patient to Cancer Survivor: Lost in Transition to advocate for the unmet needs of the growing number of cancer survivors. One such recommendation is that every cancer patient receives a “survivorship care plan.” A survivorship care plan would outline for the patient important information related to the cancer diagnosis, treatment, and potential consequences such as late term effects of treatment. Other information to be included is, “the timing and content of follow-up visits; tips on maintaining a healthy lifestyle and preventing recurrent or new cancers; legal rights affecting
employment and insurance; and the availability of psychological and support services” (Hewitt, M., Ganz, P. A., eds., 2006). As a result of this report, many organizations have since promoted the use of a survivorship care plan. The report also points out the lack of education provided to patients about the late effects of treatment such as lymphedema. One aspect of a survivorship care plan for women with breast cancer would include information about lymphedema – a late effect, and the most common side effect, of treatment. The lymphedema program for The Victory Center is a component of survivorship care. The program will provide education to all survivors not just breast cancer survivors and provide them with basic skills for preventing and managing cancer-related lymphedema.

**Significance of the Program Goal**

According to National Cancer Institute, services that may be useful during follow-up care include occupational therapy. Based on the literature review it is clear that people who are post-treatment for cancer are at risk for cancer-related lymphedema. Lymphedema has been shown to have a negative effect on quality of life, function, and mental health. Research by Bani et al. (2007) found that the only positive predicative factor for women receiving lymph-drainage massage services (effective treatment for managing lymphedema) was education about the condition. In other words, women who were educated about lymphedema were more likely to receive treatment for lymphedema.

Based on the survey conducted in needs assessment in both 2011 and 2012, the women at The Victory Center expressed strong interest in learning more about breast cancer-related lymphedema. In both 2011 and 2012, thirty percent of the women encountered at The Victory Center had symptoms of breast cancer-related lymphedema. Furthermore, the needs assessment clarified the need for lymphedema education for all cancer survivors not just breast. The goal of
the program is in alignment with the mission of The Victory Center, which is to educate those affected by cancer and to connect them with area resources while not duplicating services. The goal of the program supports goals put forth by Healthy People 2020 by striving to reduce disability and increase quality of life. Finally, the goal of the program supports recommendations made by The American Cancer Society and the Institute of Medicine regarding survivorship care by addressing lymphedema which is a known side-effect of cancer treatment -- especially given the negative impact lymphedema can have on a person’s quality of life.

Lymphedema, once developed, is a chronic medical condition that requires a daily concerted effort on the part of the patient to manage. New occupations of daily self care result from managing lymphedema and include: meticulous skin care, self-massage, lymphatic exercises, and wrapping of the affected limb. Managing lymphedema is a time-consuming occupation of daily living. Lymphedema has a negative impact on engagement in self-care, leisure and employment. Likewise, lymphedema can disrupt roles. Because occupational therapy traditionally is a holistic practice that addresses the physical and psychosocial aspects of the person, the best person to manage this proposed program would be an occupational therapist who has training in anatomy, research, and the psychosocial aspects of engagement in all levels of occupation.

**Occupation Based Programming**

The program objectives will address three areas from the Model of Human Occupation including volition, habituation, and performance capacity to support the program goal to increase participants’ knowledge about and self-efficacy for managing cancer-related lymphedema. All programming will be educational and occupation based. Participants will learn about signs and symptoms of lymphedema. They will be taught and have the opportunity to practice monitoring
for symptoms. Participants will assess their own personal risk factors that could increase their risk for developing cancer related lymphedema. They will gain an understanding of the importance of skin care and avoiding skin infections. Survivors will also review treatments available and learn more about the available tools for managing lymphedema. Participants will practice lymphatic exercises that stimulate the lymphatic system. Programming will also provide the opportunity to learn and practice basic manual lymphatic drainage massage. Another possible component of the program may include the opportunity to be screened by an occupational therapist for signs of cancer-related lymphedema.

Many of the programs at The Victory Center are provided in a group format. Individual treatments are limited to people receiving active cancer treatment. Furthermore, programming at The Victory Center is non-medical. In order to develop new programming that is in alignment with current Victory Center programming, its mission, and to maximize access for participants given a modest program budget, this program will provide four, stand-alone, two-hour, group workshops each with a different theme that will each be offered three times a year. The benefit of meeting in a group is that is a cost-effective means for delivering services.

**Model of Practice**

Two models of practice will be used in this programming. The first model is Model of Human Occupation (Keilhofner, 2008). A second model that will support assessment is the biomechanical model of practice (Flinn et al., 2008).

The Model of Human Occupation (MOHO) “is concerned with individuals’ participation and adaptation in life occupations” (Keilhofner, 2009, p. 149). MOHO is a holistic model that “views a person as an open system, which has the capacity to reorganize itself or be reorganized” (Cole, 2005, p. 263). Cancer survivors who have received treatment for cancer are at risk for
developing cancer-related lymphedema. Recommendations for survivors are often related to what not to do so as to avoid cancer related lymphedema. The goal of this program is to ensure survivors’ full participation in their life through adaptation as guided by MOHO. MOHO “stresses that occupation results from an interaction of the inner characteristics of the person (volition, habituation, and performance capacity) with the environment” (Kielhofner, 2009, p. 152).

MOHO outlines three concepts related to the person including volition, habituation and performance capacity. Volition describes the process that motivates people to engage in occupation. Volition considers thoughts and feelings. For example, personal causation considers the thoughts and feelings a person has about their own capacities and effectiveness as they engage in occupation. Volition also considers values and interests. Kielhofner points out, “How people experience life and regard themselves and their world is largely a function of their volition. Importantly, when people experience impairments, their volition can be severely affected. People may experience themselves as losing capacities and being unable to perform as they feel is important” (Kielhofner, 2009, p. 150). Volition will be addressed in the program by providing the opportunity to reflect on how to how to safely engage in occupation. Furthermore, participants will be able to reflect upon any limitations they have adhered to (related to occupational engagement) as a means of avoiding or managing lymphedema. Participants will be provided with the opportunity to consider if those self-imposed limitations are supported by current lymphedema research. Ultimately, the goal is for people to regard themselves as empowered by being provided with the knowledge and skills needed to make educated choices about how they manage their risk for cancer-related lymphedema.
Habituation relates to how people organize their life into patterns and routines. Habits are learned and automatic. Roles guide actions people take and provide a sense of identity. Habits and roles guide how people interact with their environment. Impairments can have a negative impact on habits and roles. Redefining habits and roles are an important aspect of promoting engagement in occupation. One aspect of being a cancer survivor is the need to change certain habits and routines in order to reduce the risk of cancer-related lymphedema. The program will provide the opportunity to assess current habits and determine safer alternatives. The program will also encourage the development of new habits and routines including the practice of lymphatic exercises and manual lymphatic drainage massage that will support a healthy lymphatic system.

Performance capacity relates to the physical and mental abilities that are used for engaging in occupation. This aspect of MOHO would be addressed by another model of practice, in this case, the biomechanical model of practice. The biomechanical model of practice is concerned with musculoskeletal dysfunction and how this impairs normal occupational performance. Taking measurements of arm circumference would fall under the biomechanical model of practice and is a tool that will be practiced by program participants. Assessment related to manual muscle strength testing and range of motion may be appropriate during an individual screening session with an occupational therapist. Likewise the lymphatic exercises to be performed by the program participants will serve to addresses not only stimulating the lymphatic system but in addition provides the opportunity to improve range of motion. Finally, because lymphedema can be chronic in nature, it is possible that the therapist will have to offer participants compensatory techniques that allow them to perform and engage in occupation despite the lymphedema.
MOHO identifies three levels of occupational functioning including: exploration, competence, and achievement. There are also three levels of occupational dysfunction including inefficacy, incompetence, and helplessness. (Cole, 2005). Finally, MOHO is concerned with occupational adaptation, which is defined as, “Constructing a positive occupational identity and achieving occupational competence over time in the context of one’s environment” (Kielhofner, 2009, p. 169). Given the physical and emotional changes associated with a cancer diagnosis and the ensuing treatment, it is hoped that this programming that focuses on education and self-efficacy will serve to help participants have a positive occupational identity that will in turn improve their quality of life.

**Objectives**

The goal of The Victory Center’s Lymphedema Program for the greater Toledo area is to increase participants’ knowledge about and self-efficacy for managing their risk for cancer related lymphedema.

**Workshop I: Breast Cancer-related Lymphedema Education and Prevention**

**Objectives 1.** By the end of Workshop I, participants will demonstrate a significant increase in knowledge from baseline about the signs and symptoms of breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation (see Appendix K for the Workshop I: BCRL Education and Prevention Evaluation).

The rationale for this objective is based on the following research:

- Ridner, Dietrich & Kidd (2011) note that while most people received lymphedema education during treatment, a significant portion felt the information to be inadequate. The author suggests on-going lymphedema self-care education and risk reduction that
should be multi-disciplinary and provided by nurses, therapists, physicians, and social workers.

- Fu, Axelrod & Haber (2008) show that women who reported receiving information about lymphedema reported significantly fewer symptoms of lymphedema. “Accordingly, 41% of participants who did not receive information could be diagnosed with State I of lymphedema and 27% with latent stage, while only 19% of those who received information could be diagnosed with Stage I lymphedema and 10% with latent stage” (Fu, Alexrod & Haber, 2008).

- The National Lymphedema Network (2012) recommends everyone who is at risk for cancer related lymphedema be informed of signs (meaning changes that are apparent upon physical examination such as increased measurements on the at-risk arm or leg), symptoms (meaning changes that are experienced and reported by the participant such as feelings of heaviness in the at-risk arm or leg).

**Objectives 2.** By the end of Workshop I, participants will demonstrate a significant increase in knowledge from baseline about risk reduction behaviors that can reduce their incidence of breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

The rationale for this objective is based on the following research:

- Fu, Axelrod, & Haber (2008) found that that women who received education about lymphedema reported practicing significantly more risk-reduction behaviors.

- The National Lymphedema Network (2012) recommends everyone who is at risk for cancer related lymphedema be informed about risk reduction.
• Petrek, Pressman, & Smith (2000) advocate that since there is no cure for lymphedema, prevention and precautions are necessary.

**Objectives 3.** By the end of Workshop I, participants will demonstrate a significant increase in knowledge from baseline about *treatment options* for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

The rationale for this objective is based on the following research:

• Bani, et al. (2007) found, “The only independent positive predictive factor found to be associated with the use of lymph-drainage massage services was the provision of information about the condition.” In other words, educating people about treatment options such as manual lymphatic drainage massage resulted in increased use of lymphedema therapy.

• Armer (2008) found that patients use recommended techniques for managing lymphedema 47% of the time but patients are also using alternative methods that may not be recommended by health care professionals.

• Armer (2008) also found that the most common method of managing 12 out of 14 symptoms including swelling and heaviness was to do nothing 29 percent to 65 percent of the time.

• Finally, based on observation, alternative compression devices are used in some clinics but not others. Informing participants of all their choices may improve their willingness to use another form of compression when the compression stocking garments are not palatable to the participant.
Objective 4: By the end of Workshop I, participants will assess themselves for signs and symptoms of BCRL by measuring arm circumference, completing a visual exam, and completing the Lymphedema Breast Cancer Questionnaire (LBCQ)© (Armer, n.d.).

The rationale for this objective is based on:

- Early detection results in improved treatment outcomes.
- Teaching participants how to measure for signs of lymphedema empowers participants to manage their own risk.

Objectives 5. By the end of Workshop I, participants will demonstrate a significant increase in their level of self-efficacy from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

The rationale for this objective is based on the following research:

- Ridner (2006) explains that based on self-regulation theory, people’s ability to cope (in this case with cancer-related lymphedema) is dependent on being given information to understand their risk for and management of lymphedema. Knowledge and understanding of lymphedema provides people with the foundation from which to make informed decisions about their healthcare. This knowledge serves to improve coping, decrease levels of stress, and reduce the feelings of abandonment by healthcare professionals, which many women with BCRL report.

Objective 6. Twelve weeks after the conclusion of the Workshop I, 80% of participants will demonstrate an increase in their level of knowledge from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.
The rationale for this objective is based on:

- Determining the lasting effects of the program in relation to increased knowledge.

**Objective 7.** Twelve weeks after the conclusion of Workshop I, 80% of participants will demonstrate an increase in their level of *self-efficacy* from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

The rationale for this objective is based on:

- Determining the lasting effects of the program in relation to increased self-efficacy.

**Workshop II: Cancer-Related Lymphedema Education and Prevention (non-breast cancers)**

**Objectives 1.** By the end of Workshop II, participants will demonstrate a significant increase in knowledge from baseline about the *signs and symptoms* of cancer-related lymphedema as measured by a change in the Cancer-Related Lymphedema (CRL) Education and Prevention Evaluation (see Appendix L for the Workshop II: CRL Education and Prevention Evaluation).

The rationale for this objective is based on the following research:

- Ridner, Dietrich & Kidd (2011) that notes that while most people received lymphedema education during treatment, a significant portion felt the information to be inadequate. The author suggests on-going lymphedema self-care education and risk reduction that should be multi-disciplinary and provided by nurses, therapists, physicians, and social workers.

- Fu, Axelrod & Haber (2008) shows that women who reported receiving information about lymphedema reported significantly fewer symptoms of lymphedema.
“Accordingly, 41% of participants who did not receive information could be diagnosed with State I of lymphedema and 27% with latent stage, while only 19% of those who received information could be diagnosed with Stage I lymphedema and 10% with latent stage” (Fu, Alexrod & Haber, 2008).

- The National Lymphedema Network (2012) recommends everyone who is at risk for cancer related lymphedema be informed of signs (meaning changes that are apparent upon physical examination such as increased measurements on the at-risk arm or leg), symptoms (meaning changes that are experienced and reported by the participant such as feelings of heaviness in the at-risk arm or leg).

**Objectives 2.** By the end of Workshop II, participants will demonstrate a significant increase in knowledge from baseline about *risk reduction behaviors* that can reduce their incidence of cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

The rationale for this objective is based on the following research

- Fu, Axelrod, & Haber (2008) which found that that women who received education about lymphedema reported practicing significantly more risk-reduction behaviors.
- The National Lymphedema Network (2012) recommends everyone who is at risk for cancer related lymphedema be informed about risk reduction.
- Petrek, Pressman, & Smith (2000) advocate that since there is no cure for lymphedema, prevention and precautions are necessary.

**Objectives 3.** By the end of Workshop II, participants will demonstrate a significant increase in knowledge about *treatment options* for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.
The rationale for this objective is based on the following research:

- Bani, et al. (2007) who found, “The only independent positive predictive factor found to be associated with the use of lymph-drainage massage services (OR 5.74) was the provision of information about the condition.” In other words, educating people about treatment options such as manual lymphatic drainage massage resulted in increased use of lymphedema therapy.

- Armer (2008) found that patients’ use recommended techniques for managing lymphedema 47% of the time but patients are also using alternative methods that may not be recommended by health care professionals.

- Armer (2008) also found that the most common method of managing 12 out of 14 symptoms including swelling and heaviness was to do nothing 29 percent to 65 percent of the time.

- Finally, based on observation, alternative compression devices are used in some clinics but not others. Informing participants of all their choices may improve their willingness to use another form of compression when the compression stocking garments are not palatable to the participant.

**Objective 4.** By the end of Workshop II, participants will assess themselves for signs and symptoms of cancer related lymphedema by measuring leg circumference and completing a visual exam.

The rationale for this objective is based on the following research:

- Early detection results in improved treatment outcomes. In addition, teaching participants how to measure for signs of lymphedema empowers participants to manage their own risk.
Objectives 5. By the end of Workshop II, participants will demonstrate a significant increase in their level of self-efficacy from baseline for managing their risk for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

The rationale for this objective is based on the following research:

- Ridner (2006) who explains that based on self-regulation theory, people’s ability to cope (in this case with cancer-related lymphedema) is dependent on being given information to understand their risk for and management of lymphedema. Knowledge and understanding of lymphedema provides people with the foundation from which to make informed decisions about their healthcare. This knowledge serves to improve coping, decrease levels of stress, and reduce the feelings of abandonment by healthcare professionals, which many women with BCRL report.

Objective 6. Twelve weeks after the conclusion of Workshop II, 80% of participants will demonstrate an increase in their level of knowledge from baseline for managing their risk for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

The rationale for this objective is based on:

- Determining the lasting effects of the program in relation to increased knowledge.

Objective 7. Twelve weeks after the conclusion of Workshop II, 80% of participants will demonstrate an increase in their level of self-efficacy from baseline for managing their risk for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

The rationale for this objective is based on:

- Determining the lasting effects of the program in relation to increased knowledge.
Workshop III: Managing Breast Cancer Related Lymphedema

Objectives 1. By the end of Workshop III, participants will demonstrate a significant increase in knowledge from baseline about the chronic and progressive nature of breast cancer-related lymphedema (including the stages and the symptoms) as measured by a change in the Managing BCRL Evaluation (see Appendix M for the Workshop III: Managing BCRL Evaluation).

The rationale for this objective is based on the following research:

- Armer (2008) found that the most common method of managing 12 out of 14 symptoms including swelling and heaviness was to do nothing 29 percent to 65 percent of the time. Lymphedema is progressive in nature and left untreated will advance to more severe stages and be more difficult to treat with poorer treatment outcomes.

Objectives 2. By the end of Workshop III, participants will demonstrate a significant increase in knowledge from baseline about the treatment options for breast cancer-related lymphedema as measured by a change in the Managing BCRL Evaluation.

The rationale for this objective is based on the following research:

- Bani, et al. (2007) who found “The only independent positive predictive factor found to be associated with the use of lymph-drainage massage services was the provision of information about the condition.” In other words, educating people about treatment options such as manual lymphatic drainage massage resulted in increased use of lymphedema therapy.

- Armer (2008) found that patients use recommended techniques for managing lymphedema 47% of the time but patients are also using alternative methods that may not be recommended by health care professionals.
Radina et al. (2007) found that for all but two symptoms, participants took no action 29.4–65.2% of the time. Armer (2008) also found that the most common method of managing 12 out of 14 symptoms including swelling and heaviness was to do nothing 29 percent to 65 percent of the time.

Finally, based on observation, alternative compression devices are used in some clinics but not others. Informing participants of all their choices may improve their willingness to use another form of compression when the compression stocking garments are not palatable to the participant.

Objectives 3. By the end of Workshop III, participants will identify in writing three risk-reduction behaviors that they want to implement to reduce their risk for aggravating cancer-related lymphedema.

The rationale for this objective is based on the following research:

- Petrek, Pressman, & Smith (2000) expresses the fact that since there is no cure for lymphedema, prevention and precautions are necessary.
- Fu, Guth, & Axelrod (2011) “emphasizes the need for patients to have adequate information to gain understanding of lymphedema risk, make decisions about risk reduction, and implement risk reduction behaviors.” By understanding risk people can make decisions and implement behaviors that reduce the risk for cancer-related lymphedema.
- By providing support through this program to people at risk for cancer-related lymphedema, the program serves to promote competence and motivation or self-efficacy, which in turn will promote positive behavioral outcomes for managing lymphedema risk.
**Objective 4.** By the end of Workshop III, participants will identify in writing three *self-care behaviors* that they want to implement to reduce the effects of their lymphedema.

The rationale for this objective is based on the following research:

- Ridner, Dietrich & Kidd (2011) found that participants are not spending a lot of time on self-care related to their lymphedema. The study notes that while most people received lymphedema education during treatment a significant portion felt the information to be inadequate. The author suggests on-going lymphedema self-care education and risk reduction should be multi-disciplinary and provided by nurses, therapists, physicians, and social workers.

**Objective 5.** By the end of Workshop III, participants will review basic energy-conservation strategies and identify three strategies they could use to manage fatigue associated with BCRL.

The rationale for this objective is based on the following research:

- There was some research by Armer & Porock (2002) that suggests fatigue can be associated with lymphedema.

- Some patients’ report of fatigue that can be associated with lymphedema.

- Common recommendations for the affected arm are to limit the amount of pushing, pulling, and weight lifted.

**Objectives 6.** By the end of Workshop III, participants will demonstrate an increase in their level of *self-efficacy* from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

The rationale for this objective is based on the following research:
• Ridner (2006), explains that based on self-regulation theory, people’s ability to cope (in this case with cancer-related lymphedema) is dependent on being given information to understand their risk for and management of lymphedema. Knowledge and understanding of lymphedema provides people with the foundation from which to make informed decisions about their healthcare. This knowledge serves to improve coping, decrease levels of stress, and reduce the feelings of abandonment by healthcare professionals, which many women with BCRL report.

**Objective 7.** Twelve weeks after the conclusion of Workshop III, 80% of participants will demonstrate an increase in their level of knowledge from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the Managing BCRL Evaluation.

The rationale for this objective is based on:
• Determining the lasting effects of the program in relation to increased knowledge.

**Objective 8.** Twelve weeks after the conclusion of Workshop III, 80% of participants will demonstrate an increase in their level of self-efficacy from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the Managing BCRL Evaluation.

The rationale for this objective is based on:
• Determining the lasting effects of the program in relation to increased knowledge.

**Workshop IV: Objectives: The Basics of Lymphatic Exercise and Manual Lymphatic Drainage Massage**

**Objectives 1.** By the end of Workshop IV, participants will demonstrate basic competence in deep breathing exercises to stimulate the lymphatic system with 100% accuracy ¾
trials per observation by the occupational therapist using criteria found on Workshop IV Competency Check-off (see Appendix N for the Workshop IV: Competency Check-off).

The rationale for this objective is based on the following research:

- Deep breathing stimulates the lymphatic system by “enhancing the efficiency of fluid transported by the thoracic duct” (Kelly, 2002, p. 72)

**Objectives 2.** By the end of Workshop IV, participants will demonstrate basic competence in completing a lymphatic exercise routine with 80% accuracy per observation by the occupational therapist using criteria found on Workshop IV Competency Check-off.

The rationale for this objective is based on the following research:

- These exercises stimulate the lymph regions, which accompany the affected area of the body. Kelly (2002) notes that exercises promote the stimulation of the lymphatic system by:
  
  - Increasing lymph vessel contractions
  - Improving the circulation of lymph fluid through body movement
  - Enhancing the efficiency of fluid transport by the thoracic duct through deep breathing
  - Varying total tissue pressures via muscle contractions
  - Assisting in maintenance of normal tissue hydrostatic pressure
  - Preventing further accumulation of fluid. (Kelly, 2002, p. 72)

**Objectives 3.** By the end of the workshop IV, participants will demonstrate basic skill using manual lymphatic drainage massage to clear four major nodes with 80% accuracy per observation by the occupational therapist using criteria found on Workshop IV Competency Check-off.
The rationale for this objective is based on the following research:

- Schrauder, Beckmann, & Bani (2007) which found that “the only independent positive predictive factor found to be associated with the use of lymph-drainage massage services was the provision of information about the condition.”

- Self-MLD is a daily self-care occupation for people with lymphedema. It is a technique that is unlike regular massage and can be confusing and complicated to learn without practice and guidance from a lymphedema therapist.

**Objective 4.** By the end of Workshop IV, participants will identify precautions and considerations related to lymphatic exercise and MLD with 80% accuracy using the post-test section found on the Workshop IV Competency Check-off.

The rationale for this objective is based on the following research:

- MLD can be contraindicated based on medical conditions and the participants’ current health status.

**Marketing and Recruitment of Participants**

**Marketing**

The main stakeholder to be approached for the marketing campaign includes anyone with a cancer diagnosis, either current or in the past, who has had lymph nodes removed and or radiation therapy. The primary stakeholders to be approached include current and past participants of The Victory Center. The current and past participants have an established relationship with The Victory Center and have already either received services or currently attended support groups and activity groups at The Victory Center.

Other community stakeholders to approach include Toledo area breast surgeons and oncologists. Educating area doctors about the program, as well as educating them about other
services provided by The Victory Center, could result in more informal referrals. The Victory Center is already a known entity by most area physicians and nurses who work with cancer patients. Furthermore, The Victory Center has a positive reputation in the community for the services it provides to people who are currently managing a cancer diagnosis or who have completed treatment for cancer.

The final stakeholder to be approached is both the program director and the executive director of The Victory Center for approval on all materials and the budget.

Marketing will include a flyer that was created to promote the program (see Appendix O for a copy of the marketing flyer). The flyer will be posted at The Victory Center with a sign-up sheet for registration. All programs at TVC are advertised by posting the program flyer next to the program’s sign-up sheet. The primary marketing will happen through The Victory Center participant email. An email blast will be sent out to the 691 participants on the email list. In addition, information promoting the program will be included in The Victory Center’s monthly newsletter and monthly calendar. The monthly newsletter and calendar is emailed to 691 people and mailed to 360 people for a total of 1051 people.

Other marketing opportunities include leaving flyers with area infusion, oncology, and radiology waiting room offices. In addition to leaving the flyer, a nice tri-fold brochure could be created that surgeons and oncologists could pass on to their patients. Presentations and flyers may also be given at area breast cancer support groups to increase awareness about the program. Short lunchtime presentations could also be given at area physician’s offices to inform them about the programming. Detailed information should also be provided on The Victory Center’s website. This kind of targeted marketing is the most economical and effective for informing the potential audience for this program. While there will be no formal radio, television or news print
advertising, a general press release will be issued prior to the start the program to local Toledo area newspapers.

Marketing efforts will begin during the fifth month of program development including the development of marketing material and networking with area doctors. Once marketing materials are developed, active marketing will begin during the seventh month of program development. Marketing will be continuous and ongoing throughout the life of the program.

**Potential Participants**

The pool of potential participants includes anyone who has had a diagnosis of cancer. However, the program is most appropriate for people with a current or past cancer diagnosis who anticipate receiving or have received any of the following treatments: radiation, cancer related surgery, sentinel lymph node biopsy, and any lymph node removal.

The main pool of potential program participants that marketing will target includes current and past participants of The Victory Center who regularly receive updates and newsletters form The Victory Center. This pool is about 1050 in number. A secondary participant pool includes patients at area oncology and radiation offices. A third pool of participants includes men and women who attend area cancer support groups within a 45-mile radius of The Victory Center.

**Inclusion Criteria and Expected Number of Participants**

The inclusion criterion includes any person who has had a cancer diagnosis either currently or in the past and is interested in learning more about cancer-related lymphedema. People are encouraged to attend the sessions of interest within 12 weeks of surgery; however, participants are welcomed no matter how long it has been since surgery and cancer treatment. The expected N for each individual workshop is different based on each workshop topic. During
the first year of programming, four different individual and stand alone workshops will be offered including:

1. Breast Cancer-Related Lymphedema Education and Prevention
2. Cancer-Related Lymphedema Education and Prevention (non-breast cancers)
3. Managing Breast Cancer Related Lymphedema
4. The Basics of Lymphatic Exercise and Manual Lymphatic Drainage Massage

One workshop per month related to lymphedema will be offered on a rotating basis with the four workshops each being offered for a total of three times per year. A sample schedule follows.

<table>
<thead>
<tr>
<th>Month</th>
<th>Topic</th>
<th>Expected N</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>Breast Cancer-Related Lymphedema Education &amp; Prevention</td>
<td>10</td>
</tr>
<tr>
<td>February</td>
<td>Cancer-Related Lymphedema Education &amp; Prevention (non-breast cancers)</td>
<td>5</td>
</tr>
<tr>
<td>March</td>
<td>Managing Breast Cancer Related Lymphedema</td>
<td>5</td>
</tr>
<tr>
<td>April</td>
<td>The Basics of Lymphatic Exercise and Manual Lymphatic Drainage Massage</td>
<td>10</td>
</tr>
<tr>
<td>May</td>
<td>Breast Cancer-Related Lymphedema Education &amp; Prevention</td>
<td>10</td>
</tr>
<tr>
<td>June</td>
<td>Cancer-Related Lymphedema Education &amp; Prevention (non-breast cancers)</td>
<td>5</td>
</tr>
<tr>
<td>July</td>
<td>Managing Breast Cancer Related Lymphedema</td>
<td>5</td>
</tr>
<tr>
<td>August</td>
<td>The Basics of Lymphatic Exercise and Manual Lymphatic Drainage Massage</td>
<td>10</td>
</tr>
<tr>
<td>September</td>
<td>Breast Cancer-Related Lymphedema Education &amp; Prevention</td>
<td>5</td>
</tr>
<tr>
<td>October</td>
<td>Cancer-Related Lymphedema Education &amp; Prevention (non-breast cancers)</td>
<td>5</td>
</tr>
<tr>
<td>November</td>
<td>Managing Breast Cancer Related Lymphedema</td>
<td>10</td>
</tr>
</tbody>
</table>
It is expected that a total of 90 people will participate in this program during the first year. With a participant base of 1050 and at a rate of lymphedema being anywhere between 15-30%, it is likely that cancer-related lymphedema could be affecting up to 150-300 people within The Victory Center’s participant pool. In reality, we do not know which of the 1050 people will become the ones affected by cancer-related lymphedema. So, in that sense, the program is appropriate for most if not all of the current and past participants. It is anticipated that the program would continue being offered in the same format for the subsequent years.

**Plan for Describing the Participants**

The descriptive criteria will be based on actual enrolled participants to include:

- Age
- Cancer type diagnosed
- Length of time since diagnosis and treatment
- Do they have lymphedema?
  - What grade of lymphedema?
- Have they seen an OT for lymphedema?
- Cancer treatment received
  - Type of surgery
  - Radiation
  - Chemotherapy
  - Any lymph node dissection
  - Sentinel node biopsy
• Mean score on the program assessment related to knowledge as measured at the beginning and end of the session across participants.
• Mean score on the program assessment related to self-efficacy as measured at the beginning and end of the session across participants.

Programming

Direct and Indirect Services

Direct services include group sessions that are an occupationally based approach to lymphedema education and prevention. Services will not include active lymphedema treatment such as wrapping or manual lymph drainage massage, which is also known as complete decongestive therapy. If it is determined that a participant is in need of these services, they will be referred to an outpatient clinic. Offering a basic screening for lymphedema by an OT is being explored by The Victory Center.

Indirect services include other aspects of programming such as marketing the program, educating participants about the program by visiting local breast cancer groups. Writing articles about the program to include in TVC newsletter would be another indirect service. Developing relationships with area surgeons and oncologists would be another indirect service that would benefit enrollment in the program.

Coordination of Care

One of the problems with lymphedema is that often cancer survivors and patients are often unaware of the services available for managing and treating cancer-related lymphedema. The programming emphasis is to make participants aware of the services available in the Toledo area, which can help to manage any lymphedema needs that may arise. In this way, this program promotes coordination of care by helping participants gain access to care through increased
awareness. The occupational therapist that is leading the program will provide resources for treatment, for education, and for access to compression garments.

**Group Format**

The methods used to deliver the therapeutic occupations include didactic presentations, peer exchange, direct experience, and personal exploration. The anticipated changes that I expect are that participants will have an increased knowledge about cancer-related lymphedema and an increased level of self-efficacy for managing cancer-related lymphedema. Because the goal is to encourage engagement by the participants, a facilitative leadership style will be used – ultimately; however, the leadership style will be determined by the group members’ needs.

**Assessments**

Assessment will include workshop specific, pre-session/post-session evaluations. Participants in the breast cancer workshops will also complete the Lymphedema Breast Cancer Questionnaire© (LBCQ©), used with permission and created by Jane Armer PhD (n.d.) (see Appendix P for the LBCQ©).

**Documentation**

Documentation will include: the record of attendance at the workshop sessions using a sign-in sheet provided by The Victory Center and the recorded change on the pre-session and post session assessments. This documentation will be recorded on the summary evaluation form (see Appendix Q for the summary evaluation form). A non-identified summary of the LBCQ© (Armer, n.d.) will also be maintained. Documentation of attendance, the change on program assessments, and the LBCQ© will be compiled on an excel spreadsheet. This information will be used to track program effectiveness. All documentation will be secured on a password-protected computer and paper copies will be stored in a locked file cabinet.
**Occupational Forms**

Group sessions will take place in the large main programming room. The benefit of this room is that it is very versatile. The room is 32 feet by 26 feet. In a corner of the room is a sitting area that has a comfortable sitting area with couches and chairs and can accommodate up to 12 people. There is a large wooden table located in another part of the room that can accommodate up to 12 people. In addition, there is a large open space floor area that is available for larger groups with additional chairs stacked in the corner of the room. The room is lit with overhead lighting, floor lamps, and windows.

**Program Plan: “Workshop I BCRL” and “Workshop II CRL Non Breast”**

Workshop I: Breast Cancer-related Lymphedema Education and Prevention and Workshop II: Cancer-Related Lymphedema (Non-Breast) Education and Prevention share much of the same content. The content and information will be described together here and it will be noted when information is different for each workshop. Workshop I: Breast Cancer-Related Lymphedema Education and Prevention will be referred to as “Workshop I BCRL” and Workshop II: Cancer-Related Lymphedema (Non-Breast) Education and Prevention will be referred to as “Workshop II CRL Non-Breast”.

These workshops are designed for the occupational therapist to conduct as follows. As much as possible, reputable sources have been used, providing official documents for educating the participants including documents from the National Cancer Institute at the National Institutes of Health (NCI), the American Cancer Society (ACS), and National Lymphedema Network (NLN). The purpose for using documents from these organizations is that these documents are reviewed by medical advisory boards annually and provide the most current information on the topic of lymphedema. Materials and resources used to conduct programming are listed on the
resource list (see Appendix R for the resource list). Each participant will be provided with a notebook that includes information and resources, which will be reviewed during the workshops. The notebook will allow the participant to follow along with the programming. The notebook will be reused at each workshop. All the information will be sent to participants via email in order to reduce costs. In this way, participants can print out the information that they find interesting. Or, they may simply keep it as an electronic resource.

**Defining occupational therapy.** After welcoming participants, the first step is for the occupational therapist to introduce herself and define occupational therapy. According to the American Occupational Therapy Association:

Occupational therapy is a science-driven, evidence-based profession that enables people of all ages live life to its fullest by helping them promote health, prevent—or live better with—injury, illness, or disability. This is accomplished through designing strategies for everyday living and customizing environments to develop and maximize potential.

By taking the full picture into account—a person's psychological, physical, emotional, and social make-up—occupational therapy assists people in:

- Achieving their goals
- Functioning at the highest possible level
- Concentrating on what matters most to them
- Maintaining or rebuilding their independence
- Participating in the everyday activities that they need to do or that simply make life worth living
It helps individuals design their lives, develop skills, adjust home, school, or work environments, and build health-promoting habits and routines. Occupational therapy uses everyday activities as the means to enable people to thrive. Occupational therapy works to get beyond disability or limitations, creating ways for individuals to live life to its fullest no matter what. (AOTA, 2004-2008)

After defining occupational therapy, the therapist will point out the handout entitled “The Role of Occupational Therapy in Oncology (AOTA, 2011) (see Resource List item 1).

Pre-test assessment. The next step is to hand out the workshop evaluation, which serves as a pre-test. The participants will use a blue pen to complete the pretest. At the end of the session, a different colored marker or pen will be used on the same form to indicate any change from the beginning of the workshop. Blue is chosen as the initial color for the pre-test because blue starts with the letter “b” which represents before. In this way, whenever the program is conducted, the pretest color will always be blue.

Defining lymphedema. After the pretest is complete, the next step is to define the lymphatic system and lymphedema. Participants need to understand the lymphatic system in order to understand why lymphedema occurs and to understand the logic of preventative measure and treatment. In basic terms, lymphedema is the accumulation of unwanted fluid in an area of the body that can occur as a result of the removal of lymph nodes or damage to lymph nodes from chemotherapy and radiation. Lymphedema can develop slowly over time and can be mild or severe. Likewise, it can develop immediately after surgery or decades later. Lymphedema is a chronic condition that increases a person’s risk of infections such as cellulitis. Lymphedema is becoming more widely understood and researched in large part due to the efforts of the National Lymphedema Network, which is a solid resource for this program.
Workshop I BCRL. Defining lymphedema will be communicated by referring to the American Cancer Society handout *Lymphedema: What Every Woman With Breast Cancer Should Know* (2012) (see Resource List item 2).

Workshop II CRL Non Breast. Defining lymphedema will be communicated by referring to the National Cancer Institute’s *Lymphedema (PDQ) Patient Version* (2011) page three-four (see Resource List item 3) and American Cancer Society’s *Understanding Lymphedema – For Cancers Other Than Breast Cancer* page two (see Resource List item 4).

Anatomy of the lymphatic system. In order to understand the risk factors and precautions, it is important for participants to have an understanding of the basic anatomy of the lymphatic system. The following information is available on a DVD entitled *Lymphatic Drainage Massage* (2004). This information can be communicated via verbal explanation as described below with the support of visuals and or by playing the anatomy section of the DVD *Lymphatic Drainage Massage* (2004) (see Resource List item 5).

In basic terms, the lymphatic system and the circulatory system work together. The circulatory system circulates blood and fluid through the body using the heart as a pump. Arteries carrying oxygen rich blood meet veins at capillaries where the exchanges of nutrients, fluids, and wastes occur with the tissues. When plasma passes out of the capillary cell walls it is called interstitial fluid. Most of this interstitial fluid returns to the heart via the veins. However, 2-10% of the interstitial fluid is returned to the heart via the lymphatic system. When this fluid enters the lymph system it is known as lymph. The lymphatic system in the arms and legs is just below the surface of the skin. The lymphatic system opens up and collects the excess interstitial fluid and protein when there is a pressure increase or when the skin slightly stretched. The lymphatic system is
4-6 times bigger than capillaries. Therefore, the lymphatic system is able return proteins found in the interstitial fluid back to the heart. These proteins can be too big to reenter the capillaries. The purpose of the proteins is to draw fluids out of the capillaries, which allow for that exchange of fluid with the surrounding tissues. If an excess of proteins remain in the interstitial space, edema or swelling can result. Swelling occurs because proteins are hydrophilic meaning they attract water.

The lymphatic system removes: proteins, dead cells, waste products, bacteria, viruses, inorganic substances, water, and fats. The lymphatic system works with one-way valves so that it moves the lymph in only one direction. When the lymphatic system stretches and contracts it pushes fluid forward and also creates a vacuum effect behind it, resulting in a chain reaction of pull and push through the system. Stimulating the lymphatic system in one area of the body can help to stimulate the system in other areas of the body. The lymphatic system is stimulated by muscle contractions, deep breathing, changes in pressure, and manual lymphatic drainage massage. Lymph nodes filter and purify the lymph and produce lymphocyte, which destroy harmful substances in the body and is part of our immune system” (Real Bodywork, 2004).

The locations of the lymph nodes are as follows (see Resource List item 6). There are 400 - 700 lymph nodes in body with about 170-200 in neck and about 200-350 in abdomen. There are also nodes in the joints of the elbow, the back of the leg, and under the arms. The inguinal nodes at the top of the leg drains the legs and lower belly, the axillary nodes found in the arm pits drain the arms, back and breast area. The lower body drains in to the thoracic duct and then enters the blood stream. Deep breathing stimulates the thoracic duct and in-turn the
Understanding the anatomy of lymphedema is critical for participants. Living with the risk of lymphedema means participants should consider making changes to their habits and routines to reduce that risk. Understanding the why behind the risk reduction behaviors will help participants to understand the reasoning behind the recommendations and motivate them to change their habits and routines.

**Risk factors.** Risk factors that predispose people for developing cancer-related lymphedema include cancer-related surgery, radiation, removal of lymph nodes and chemotherapy. Contributing factors that can contribute to the onset of lymphedema include: skin infection, skin trauma, obesity, high intensity exercise practiced without a gradual build up, constricting clothing, air travel, exposure to extreme heat or cold, and prolonged standing or sitting (National Lymphedema Network, 2012).

**Diagnosing lymphedema.** The methods used to diagnose lymphedema are typically circumference measurements taken at standard points along both arms, legs or of the head. In general, when there is a difference between arms (or legs for lower extremity lymphedema) that exceeds 2 cm for the entire arm (or leg) then lymphedema is diagnosed. Water displacement may be used to determine a difference in arm volume; however, participants will be taught the measurement method for home self-monitoring. In addition, symptoms should be taken into account and can be assessed for Workshop I: BCRL using the Lymphedema Breast Cancer Questionnaire ©, which was created and copyrighted by and used with the permission of Jane Armer PhD (n. d.). Symptoms to consider for both workshops include, according to the National Lymphedema Network, “Perceived swelling, tightness, tingling, or heaviness in the arm, chest or
trunk” (National Lymphedema Network, p. 2, 2011). Other symptoms can include trouble moving a joint, tight clothing, jewelry or shoes. Because some of these symptoms can be signs of other conditions, it is important to encourage participants to contact their doctor for further assessment. Swelling could result from problems related to the heart, kidneys, lungs or liver, and could also result from a blood clot.

The symptoms of lymphedema can have a negative impact on engagement in occupation. The fear of worsening lymphedema can result in participants choosing to avoid occupations including those of self-care, leisure, home maintenance, and employment. In addition, active lymphedema can make it difficult to find clothes that fit properly. Jewelry such as wedding rings may no longer fit. The changes associated with the signs and symptoms of lymphedema can take a toll on a person’s identity especially if directly on the heels of cancer treatment. For example, during a treatment session, a patient broke down crying, “I’m not a wife!” All the caregiving that was a part of her identity as a mother, wife, and daughter was severely impacted by her arm lymphedema.

**Staging lymphedema.** The International Society of Lymphology classifies lymphedema by stages. What follows describes the physical changes and the stages associated with those changes. Stage 0 is a latent phase where despite impaired lymph transport there is no swelling evident. At this stage that patient’s sense of fullness or heaviness may be an important symptom to indicate continued self-monitoring. This stage can occur months or years before progressing to the next stage. Stage I is assessed when there is an accumulation of protein rich fluid. At this stage pitting edema may or may not be present. Edema is resolved with elevation. Stage II is evident when there is pitting edema and swelling does not subside with elevation. As swelling progresses the pitting may no longer occur due to the deposits of fat and fibrotic tissue. Stage III
is considered lymphostatic elephantiasis where there are physical changes to the skin. The International Society of Lymphology also notes using the volume differences to determine functional severity. Minimal severity is considered a change in volume that is less than 20%. Moderate severity is considered an increase of 20-40% and severe is any increase that is greater than 40% (International Society of Lymphology, n. d.).

Of note is that the current system for diagnosing cancer-related lymphedema is not perfect. A 2 cm difference is very different on someone who is thin versus someone who is overweight and on the arms versus the legs. In addition, the current system does not account for the negative effects lymphedema has on function. Finally, research is showing that there can be symptoms of lymphedema long before the outward measurement of 2 cm occurs.

Through direct observation in the clinic, it was apparent that men and women who were diagnosed with lymphedema within a year of cancer treatment had a much harder time emotionally managing the diagnosis of cancer-related lymphedema than those who developed it years after treatment.

**Visible signs of lymphedema and self-assessment.** This section will allow the participants to see images of lymphedema and the opportunity to assess themselves for signs and symptoms of cancer related lymphedema. Please note the differences for each workshop as noted below.

**Workshop I: BCRL.** Participants in Workshop I BCRL will review images of lymphedema by viewing the Visible Signs of Lymphedema – A Pictorial (Breastcancer.org, 2006) (see Resource List item 7). Next, participants will visually inspect their arms for signs of lymphedema based on the American Cancer Society recommendations found on page 7 of *Lymphedema: What Every Woman With Breast Cancer Should Know* (American Cancer Society,
2012). Signs to look for include: swelling in the breast, chest, shoulder, arm, or hand; skin changes (texture that feels tight or hard, or looks red); less movement or flexibility in nearby joints, such as the shoulder, hand, or wrist; swollen areas that are hot and red. Finally, both sides of the upper body will be compared by the participant themselves for changes in size, shape, or skin color on the breast cancer side of the body.

At this point in the program, participants will refer to handout Upper Extremity Measurement Record and will be taught how to measure their arms (see Appendix S for UE Arm measurement record). The participants will pair up with a partner and be directed step-by-step on accurately measuring the arm circumference. Starting at the base of the third finger (middle finger) the participant will use a washable marker to measure out seven locations along the arm including: palm of hand, wrist, low-forearm, upper-forearm, elbow, mid-upper arm, and upper arm. The participant needs to record in centimeters where each location is on their arm starting from the base of the second finger. By doing this, the participant can ensure that when comparing measurements in the future, they are comparing the exact same site. At each of these seven markings along the arms, circumferential measurements will be taken and recorded. The participant should be instructed to use centimeters for more accurate measurements. Also, they should pull the tape taught but not tight and digging into the skin. Consistent technique and measurements is key for monitoring any increase in size of the at-risk limb. After completing the measurements, the participant will then complete the Lymphedema Breast Cancer Questionnaire© (Armer n. d.).

When participants have completed measurements and the LBCQ© (Armer, n. d.) they will take a short break to last 10 minutes. During this time the occupational therapist can address any personal questions or concerns.
Participants are asked to continue to engage in this new occupation for managing risk by developing the habit of observation making sure to check the arms for signs of lymphedema on a regular basis. Likewise, participants are encouraged to continue monitoring themselves for lymphedema by regularly measuring their limb circumference.

**Workshop II CRL Non Breast.** Participants will review images of lymphedema by viewing Lymphedema Pictures from Lymphedema Therapy’s website (see Resource List item 8). Next, participants will visually inspect their legs from the knee down for signs of lymphedema based on the American Cancer Society recommendations found on page 4 of *Understanding Lymphedema – For Cancers Other Than Breast Cancer* (American Cancer Society, 2011). Signs to look for will include: swelling in the feet, legs, chest, shoulder, head or neck; skin changes (texture that feels tight or hard, or looks red); less movement or flexibility in joints, such as shoulder, neck, or legs; swollen areas that are hot and red. Finally both lower legs will be compared for changes in size, shape, or skin color on the at-risk side of the body.

At this point in the program, participants will refer to handout Lower Extremity Measurement Record and will be taught how to measure their lower legs (see Appendix T for LE leg measurement record). The participants will pair up with a partner and be directed step-by-step on accurately measuring the foot and leg circumference. Starting at the base of the second toe, the participant using a washable marker to measure out five locations along the leg including: middle of the foot, above the anklebone, low-calf, upper-calf, and the knee. The participant needs to record in centimeters where each location is on their leg. By doing this, the participant can ensure that when comparing measurements in the future, they are comparing the exact same site. At each of these five markings along the leg, circumferential measurements will be taken and recorded. The participant should be instructed to use centimeters for more accurate
measurements. Also, they should pull the tape taught but not tight and digging into the skin. Consistent technique and measurements is key for monitoring any increase in size of the at-risk limb.

When participants have completed measurements they will take a short break to last 10 minutes. During this time the occupational therapist can address any personal questions or concerns.

**Break and review of self-assessment by occupational therapist.** Any signs of lymphedema based on the self-evaluation and measurements, will be cause for the occupational therapist to suggest that the participant talk with their physician and consider an out-patient evaluation with a certified lymphedema therapist. Likewise, symptoms should also be considered. According to the National Lymphedema Network position statement *Screening and Measurement for Early Detection of Breast Cancer Related Lymphedema*, participants should contact their healthcare provider if they have symptoms such as feelings of heaviness or tightness in their affected side, or if they have signs noted by swelling in the arm, chest or trunk, and or if the same areas become red or hot. The NLN also recommends an increase of 1 cm in any of the arm measurements should be monitored by a healthcare professional. In addition, an increase of 2 cm in any measurements warrants assessment by a certified lymphedema therapist.

**Lymphedema risk reduction.** After the break, the second half of the workshop will address risk reduction behaviors and what is considered safe occupational engagements as well as occupations that are not recommended. The last component will be a review of treatment options. There are three documents that relate to prevention and precautions that should be reviewed by Workshop I: BCRL including The American Cancer Society’s *What Every Woman Should Know About Lymphedema* pages 4-6, the National Lymphedema Network’s position
Do's and Don'ts: Preventing Breast Cancer-Related Lymphedema

Dos

- Do moisturize your skin frequently and regularly. Use lotions such as Moisturel, Eucerin, Vaseline Intensive Care, or your own favorite brand to make your skin supple and prevent it from cracking.

- Do keep your hand and arm extra-clean, but don't use harsh soaps such as Ivory (despite Ivory's advertised image as a gentle soap) or Dial. Use Dove instead.

- Do use rubber gloves when you wash dishes or hand-wash clothes.

- Do wear protective gloves when you garden or do outside chores.

- Do take more frequent rest breaks when scrubbing, mopping, cleaning, or while doing other vigorous or repetitive activities, especially if your arm feels tired, heavy, or achy.

- Do wear oven mitts when handling hot foods.

- Do use an electric razor instead of a safety razor.

- Do use insect repellents that won't dry out the skin, such as Avon's Skin-So-Soft, which actually moisturizes the skin. Avoid brands that contain a significant amount of alcohol. (Any ingredient that ends in "ol" is a type of alcohol.)

- Do apply antibiotic ointment (like Bactroban) to any insect bites or torn cuticles (as long
as you are not allergic to its contents).

- Do protect your arm from sunburn with sunscreen. Use a product with a minimum SPF of 15, although SPF 30 is much better.
- Do use a thimble when you sew.
- Do REST your arm in an elevated position. But don't hold up your arm without support for a long time because your muscles will tire.
- Do control your blood sugars very carefully if you have diabetes, to minimize the danger of damage to the small blood vessels and infection.
- Do wear compression bandages or a compression sleeve and glove on the affected arm when flying in airplanes (if you already have arm swelling).

Don'ts

- Don't take unusually hot baths or showers.
- Don't go from extreme hot to cold-water temperatures when you bathe or wash dishes.
- Don't go into high-heat hot tubs, saunas, or steam baths.
- Don't apply heating pads or hot compresses to the arm, neck, shoulder, or back on the affected side. Also, be cautious of other heat-producing treatments provided by physical, occupational, or massage therapists, such as ultrasound, whirlpool, fluidotherapy, or deep tissue massage. Heat and vigorous massage encourage the body to send extra fluid into the compromised area.
- Don't carry heavy objects with your at-risk arm, especially with the arm hanging downward.
- Don't wear heavy shoulder bags on the affected side.
- Don't wear clothing that has tight sleeves or that restrains movement.
- Don't wear your watch or other jewelry on your affected hand or arm.
- Don't use a heavy breast prosthesis after mastectomy. It may put excessive pressure on
alternative routes of lymphatic drainage that are already doing double duty. Find a lightweight model or make one yourself.

- Don't drink much alcohol. Alcohol causes blood vessels to expand and leak extra fluid into the tissues.
- Don't smoke. Smoking narrows the small blood vessels, lessening the flow of fluids in the arm.
- Don't get manicures that cut or overstress the skin around the nails.
- Don't permit blood pressure testing on your at-risk arm. If you've had breast cancer in both breasts, ask that your blood pressure be tested on your thigh. If this is not possible, ask that the person measuring your blood pressure inflate the cuff only slightly above your normal systolic pressure (the first, higher number of your blood pressure).
- Don't permit the skin of your at-risk arm to be pierced for any reason: injections, drawing blood, or vaccinations. (Don't trust anyone, not even your personal physician, to remember which is your at-risk arm.) If you've had breast cancer in both breasts along with underarm lymph node dissections, blood should be drawn from another part of your body. If blood must be drawn from your arm, use your non-dominant arm (your left arm, if you are right-handed; your right arm, if you are left-handed). If one side had no lymph node dissection, use the arm on that side, regardless of whether it's your dominant arm.

http://www.breastcancer.org/tips/lymphedema/avoid.jsp

This second chart by NLN applies to both workshops.

<table>
<thead>
<tr>
<th>Lymphedema Risk Reduction Practices, NLN</th>
</tr>
</thead>
</table>

**I. Skin Care - Avoid trauma / injury to reduce infection risk**

- Keep extremity clean and dry
- Apply moisturizer daily to prevent chapping/chafing of skin
• Attention to nail care; do not cut cuticles

• Protect exposed skin with sunscreen and insect repellent

• Use care with razors to avoid nicks and skin irritation

• If possible, avoid punctures such as injections and blood draws

• Wear gloves while doing activities that may cause skin injury (i.e., washing dishes, gardening, working with tools, using chemicals such as detergent)

• If scratches/punctures to skin occur, wash with soap and water, apply antibiotic cream or ointment, and observe for signs of infection (i.e. redness)

• If a rash, itching, redness, pain, increased skin temperature, fever or flu-like symptoms occur, contact your physician immediately for early treatment of possible infection

II. Activity / Lifestyle

• Exercise regularly with a combination of activities including strength, flexibility and endurance exercises. Gradually build up the duration and intensity of any activity or exercise

• Take frequent rest periods during activity to allow for limb recovery

• Monitor the extremity during and after activity for any change in size, shape, tissue, texture, soreness, heaviness or firmness • Maintain optimal weight

III. Avoid Limb Constriction

• If possible, avoid having blood pressure taken on the at-risk extremity

• Wear clothing and jewelry that is not too tight and does not have a tourniquet effect on the at risk part

IV. Compression Garments

• Should be well fitting. Sleeves may need to be worn with a gauntlet to avoid constriction.
• May consider wearing a compression garment for strenuous activity

• Consider wearing a well-fitting compression garment for air travel

V. Extremes of Temperature

• Cover the at risk part with protective clothing when exposed to extreme cold, which can be associated with rebound swelling, or chapping of skin

• Avoid prolonged (greater than 15 minutes) exposure to extreme heat, particularly hot tubs and saunas. In very hot climates, use a spray bottle to cool off and drink water frequently.

• Avoid placing limb in water temperatures above 102°Fahrenheit (38.9°Celsius)

VI. Additional Practices Specific to Lower Extremity Lymphedema

• Avoid prolonged standing, sitting or crossing legs. Change position frequently. If sitting for extended periods, do ankle pumps.

• Wear proper, well-fitting footwear and hosiery. Clean inside of socks and slippers.

NOTE: Given that there is little evidence-based literature regarding many of these practices, the majority of the recommendations must at this time be based on the knowledge of pathophysiology and decades of clinical experience by experts in the field.

© 2011 National Lymphedema Network (NLN). Permission to duplicate this handout as-is, in its entirety, for educational purposes only, not for sale. All other rights reserved. For reprint permission, please contact the NLN office at 415-908-3681 or nln@lymphnet.org.

As noted by the NLN, many of the recommendations are based on clinical observation and pathophysiology rather than evidence-based literature; however, research is improving in this area. Most of the recommendations require participants to make changes to their daily routines. In this way, participants can work with the occupational therapist to rethink
occupational engagement and the therapist can help participants to problem solve ways to safely engage in occupation.

**Skin care.** Skin care and avoiding injury to the at-risk area of the body is important information that will be discussed using the National Lymphedema Network’s position statement on Lymphedema Risk Reduction Practices. Participants will now make a personal safety kit to include:

- Alcohol wipes
- Hand Sanitizer
- Antibiotic ointment
- Band-Aid
- Small Ziploc bag
- Directions for skin care from the ACS which will be printed out on a small piece of paper

```
“How to care for cuts, scratches, or burns

- Wash the area with soap and water.
- Put an over-the-counter antibiotic cream or ointment on the area. Check with your doctor, nurse, or pharmacist if you are not sure what to use.
- Cover with a clean, dry gauze or bandage. Keep the area clean and covered until it heals. Change the dressing each day and if it gets wet.
- For burns, apply a cold pack or cold water for 15 minutes, then wash with soap and water and put on a clean, dry dressing.
- Check every day for early signs of infection: pus, rash, red blotches, swelling, increased heat, tenderness, chills, or fever.
- Call your doctor right away if you think you may have an infection” (ACS, 2012, p. 6).
```
**Health and fitness.** The next component will address the importance of keeping a healthy weight, exercising, and drinking water. Participants will be informed of the Healthy Steps class, which is an evidence-based, exercise program that provides lymphatic exercises and also addresses strength, range of motion, and balance. Participants will be encouraged to attend the Healthy Steps classes held at TVC. It is very important to explain to participants that they must complete the lymphatic exercises correctly and they need to attend either TVC’ s Healthy Steps class or attend the lymphedema Workshop IV that addresses lymphatic exercises. A handout included in the notebook from Healthy Steps that is for lymphatic exercises that can be completed while in an airplane, car, or any other confined, seated location (see Resource List item 11). Finally, participants will be instructed in deep lymphatic breathing. A diagram can be used for a visual to help explain deep breathing (see Resource List item 12). Participants will also use bubbles to exhale for immediate feedback, to encourage deeper exhalations, and to make the deep breathing more fun. This technique is used in the Healthy Steps class and is effective for encouraging deep breathing that is occupation based.

Occupational therapists are trained to view people in a holistic manner. As described in the programming thus far, the changes participants should consider making, in order to reduce their risk, affects many area’s of the participants’ lives.

**Lymphedema treatment.** The workshop will finish with a review of treatment options. Participants will be told that the first step to treatment is to be obtain a referral from their physician to see a lymphedema therapist. The physician may want to rule out a blood clot, heart, lung, or kidney disorders that could be the cause of the swelling. Participants will be told that trained lymphedema therapist should provide treatment. Lymphedema therapists may be either
occupational therapists or physical therapists who have undergone specialized training for the treatment of lymphedema. Treatment includes the use of manual lymphatic drainage massage, the use of short stretch compression bandages, skin care, and patient education. Treatment is focused on improving the patient’s lymphatic function and in-turn their functional abilities. Treatment is also focused on teaching the patient the steps involved with on-going self-care such as self-MLD, lymphatic exercises, breathing, skin care, wrapping of compression bandages, and proper fit and care of compression garments.

Lymphedema therapy often uses an intensive approach whereby the patient may come to the clinic three times a week. This is necessary to gain control of the lymphedema and to educate the patient properly on the use of the short stretch bandages used for wrapping. MLD is a technique that is use to stimulate the lymphatic system and to reroute lymphatic fluid to areas of the body where lymph nodes have not been removed or damaged. This is not like regular massages. The goal of MLD is to use flat hands to make short stretching motions of the skin in order to stimulate and direct lymph flow. For the upper extremity, MLD will address areas around the neck, under the arms, across the front and back of the chest and at the top of the legs. For the lower extremity, MLD will address areas around the neck, under the arms, legs, trunk and abdomen. Learning self-MLD massage takes practice and guidance.

In addition to MLD, compression is used to reduce swelling and to encourage movement of lymph out of the affected area. The bandages are not ace bandages. They provide continuous, gradient compression whereby there is 100% compression distally and a gradual decrease as the bandages move proximally so that fluid moved in the desire direction along the pressure gradient. The bandages are not applied directly over the skin but over a layer of cotton fluff or foam. The compression wraps are worn per the recommendation of the therapist, typically 23
hours a day 7 days a week until the desired reduction in edema has been achieved. Once the compression has achieved desirable results, the patient can be fitted for a compression garment, which simply maintains the achieved level of reduction. Alternative devices exist and should be briefly reviewed. In short, bandaging reduces 100%, alternative devices can reduce up to 20%, and compression garments simply maintain reduction.

Finally, participants should be made aware of how to obtain a compression sleeve or garment that can be used as a preventative measure. They need a prescription from their doctor. To obtain a sleeve, two options include going to durable medical equipment company or going directly to a local manufacturer called Barton Carey. Barton Carey is a wholesale maker of compression garments. They also sell to the public and charge wholesale costs. Therefore, for some people, it may be most beneficial and cost effective to go directly to Barton Carey and obtain a custom fit sleeve or stockings. Participants will be given instructions on ordering a sleeve directly at Barton Carey.

Lymphedema treatment brings with it entirely new occupations of self-care which can be very demanding. In treatment, patients are expected to perform a series of self-massage, lymphatic exercises, and learn the foreign task of wrapping themselves with bandages. Managing lymphedema means committing to these new tasks of self-care daily.

**Post-test and summative evaluation.** After the session is complete, time will remain to complete the post-test evaluation.

**Program Plan Workshop III: Managing Breast Cancer Related Lymphedema**

Because each workshop is a stand-alone workshop, it is possible that women will attend this workshop without having attended Workshop I: Breast Cancer-related Lymphedema Education and Prevention. Therefore, the start of this workshop should review the sections listed
above from Workshop I including: defining occupational therapy, defining lymphedema, anatomy of the lymphatic system, risk factors, diagnosing lymphedema, staging lymphedema, visible signs of lymphedema and self-assessment, lymphedema risk reduction, skin care, health and fitness, and lymphedema treatment. What makes this workshop different is that it will cover some material more in-depth and provide the opportunity for the participants to problem solve on how to best manage their cancer-related lymphedema. Likewise, there should be opportunities for participants to ask questions throughout each section of the workshop.

**Introduction.** After the occupational therapist introduces herself and welcomes everyone, occupational therapy should be defined as noted above in Workshop I.

**Pre-test assessment.** Next the pre-test assessment should be given and conducted as above with Workshop I and II.

**Overview.** An overview will be provided of content covered in Workshop I: BCRL including: defining lymphedema, anatomy of the lymphatic system, risk factors, diagnosing lymphedema, staging lymphedema, visible signs of lymphedema and self-assessment, lymphedema risk reduction, skin care, health and fitness, and lymphedema treatment. See above Workshop I: BCRL for content details.

**Self-assessment and staging.** As was discovered in the needs assessment and the annotated bibliography, many women with BCRL simply ignore the signs and symptoms and take no action to treat their lymphedema. Because it is chronic and progressive in nature, the goal of the self-assessment is to help the participant determine the severity of his or her own lymphedema. This will be done as in Workshop I: BCRL by completing a visual inspection, measuring both arms, and completing the LBCQ© (Armer, n. d.).
After completing the self-assessment the therapist should review the staging of lymphedema. The therapist should note the difference between Stage I and II. In Stage I, the swelling will go down with elevation; however, if not addressed, it can progress to Stage II where elevation is no longer effective and swelling will not reduce without treatment. The goal in this discussion is to make the women aware that the swelling will not go away by ignoring the signs and symptoms. The occupational therapist can problem solve with participants on what may be contributing to their lymphedema and work to help participants become more open to seeking out treatment.

**Treatment options.** Treatment options will be reviewed as above in Workshop I: BCRL. However, alternative compression devices will also be reviewed for the upper arm and use of compression pumps will be reviewed. Other forms of alternative treatment will be reviewed including the use of kinesio tape, and those noted in NCI’s document *Lymphedema PDQ*. Likewise, National Lymphedema Network’s position statement *Topic: The Diagnosis and Treatment of Lymphedema* (NLN, 2011) (see Resource List item 13) will be used to review alternative techniques and to cover the evidence of research or lack thereof when choosing to use alternative treatments. As noted in the annotated bibliography, it was found that women are using alternative treatments for lymphedema; therefore, it is important to address the efficacy and safety of alternative treatments. Finally, the therapist will explain the types and levels of trainings to look for when choosing a lymphedema therapist based on the recommendations of the NLN.

Time should allow for participants to voice what has worked for them and what aspects of treatment are difficult for them in terms of compliance. By allowing a discussion format the
occupational therapist as well as other participants can help to problem solve with the goal of increasing the participants’ willingness to seek out and engage in treatment.

**Compression garments.** The use of compression garments should be addressed. This would be a good time to get participant feedback on their own experience with compression garments. Again, it was noted in the needs assessment that some women are averse to wearing a sleeve or have received a poor fitting garment. Discussion allows the opportunity for the therapist to try to problem solved with the participants on how to ensure a more open attitude to wearing a sleeve and ways to increase compliance. At this time, also review the pros and cons of going directly to Barton Carey for a custom fit garment.

**Risk-reduction behaviors.** At this time participants will have the opportunity to also review risk factors as well as ways to manage those risks by using the Occupation and Lymphedema Algorithm (see Appendix U for occupation and lymphedema algorithm). An algorithm will be reviewed as a tool for problem solving. The patient will use the algorithm to determine the safety and risk of engaging in occupations. Examples that the therapist will review while teaching the participants how to problem solve using the algorithm will include: washing dishes, gardening, manicures, shaving and shoveling. Participants will then, use the Occupation and Lymphedema Algorithm to problem solve their risks for lymphedema associated with three self-identified meaningful occupations. The predicted outcome is that participants will have competence in using the algorithm to problem solve on their own to determine the risks associated with certain occupations. The hope is that participants will take recommended steps to continue engaging in occupations while following safety precautions.

Participants will write on an index card three risk-reduction behaviors that they want to implement to reduce their risk for aggravating of cancer-related lymphedema.
Participants will also make an emergency safety kit as outlined above in Workshop I.

**Energy conservation.** Based on some patient report, fatigue can accompany lymphedema. Likewise, issues related to range of motion can accompany lymphedema, cancer surgery and radiation. Therefore, the therapist will review energy conservation techniques (see Resource List item 14).

**Self-care behaviors.** Self-care involves behaviors that are proactive for reducing one’s risk of lymphedema. Self-care can also involve seeking out professional treatment for lymphedema. Self-care is also a daily occupation of maintaining healthy skin, weight, and nutrition. Also, it can be the daily occupation of self-MLD, wrapping, and lymphatic exercises.

This time is for an open discussion and brainstorming of how participants can increase their level of commitment to and engagement with self-care behaviors and occupations that will reduce their lymphedema or reduce the incidence of it becoming a problem. The benefit of the group is that they have personal experience and knowledge they can share coupled with the perspective of the occupational therapist to help members see new possibilities for managing their lymphedema. Participants will write on an index card *self-care behaviors* that they could implement to reduce the effects of their lymphedema.

**Conclusion and post-assessment survey.** Participants will be thanked for their attendance. They will complete and return the evaluation that serves as a post assessment.

**Program Plan: Workshop IV: The Basics of Lymphatic Exercises and Manual Lymphatic Drainage Massage**

Hopefully participants that attend this workshop have attended one of the other workshops so that they have an understanding of the anatomy of lymphedema as well as risk factors and strategies for managing that risk. The focus of this workshop is to teach participants
basic ways to support their lymphatic system.

**Introduction and occupational therapy.** This program will begin by welcoming the participants, introducing the therapist and defining occupational therapy as noted Workshop I.

**The lymphatic system.** The instructor should review the basics of lymphatic system as outlined in Workshop I. It is important for the participants to understand why the deep breathing, exercises, and MLD are important and effective by being able to reference the location of the lymph nodes.

**Deep breathing.** Deep breathing known as belly breaths or diaphragmatic breathing will be reviewed and practiced. When practicing deep breathing participants should find a comfortable position and breath in deeply through their nose and exhale either through their nose or mouth. Another strategy is to have participants blow bubbles such as those used at weddings. This facilitates a good exhalation, which will in turn encourage deeper breathing. The therapist should explain the benefit of deep breathing and how it stimulates the lymphatic system.

**Lymphatic exercise.** Healthy Steps is a great evidence-based, exercise program that stimulates the lymphatic system. It is taught at TVC. The current instructor could be contacted to come and instruct this portion of the workshop. Otherwise, the DVD entitled *The Lebed Method Focus on Healing Through Therapeutic Exercise and Movement DVD* (2006) that begins with lymphatic exercises. The lymphatic opening exercises lasts about 20 minutes. The goal is for the participants to experience the routine so that they will choose to regularly engage in lymphatic exercise by coming to Healthy Steps, purchasing the instructional DVD, or following along with a certified instructor on U-Tube (see Resource List item 15).

**Manual lymphatic drainage massage.** The basic of MLD will be taught to the participants. A therapist trained in MLD should give instruction. According to the DVD
Lymphatic Drainage Massage (Real Bodywork, 2004) the goal is to use one to four ounces of pressure. That is enough pressure to deform the skin only. The goal is to stretch the skin and release. Likewise, MLD is to be performed on the skin – not on clothing over the skin. Although for the purposes of this workshop the groin lymph nodes at the top of the leg where the legs meet the trunk will be massaged over the clothing. The therapist should note that if participants press too hard that will damage the lymphatic system. Likewise, sliding over the skin will not achieve the desired results. Participants should know to push towards the correct nodes. If movement is in the wrong direction, it will not be effective. Participants should be informed that there is an order to the steps of self-MLD and that order should be followed. For this workshop, participants will be instructed on how to clear the major nodes including: deep breathing, the nodes above the collarbones, the nodes in the armpits, and the nodes at the groin. The participants will start with taking five deep breaths breathing in through the nose and out through the mouth. Next, participants will massage the nodes above the collarbones stretching the skin from the soft area above the collarbones down towards the collarbones ten times. Step three is massaging the nodes under the armpits in a scooping motion towards the collarbones ten times. Finally, participants will massage the nodes where the legs met the trunk by scooping up towards the belly button ten times.

Precautions for MLD. It is important for participants to know that swelling can have other causes and that perhaps it is not lymphedema. Problems with the heart, liver, kidneys, or a blood clot could cause swelling that is not cancer-related lymphedema. Participants should be made aware of any precautions that would indicate they should not engage in MLD. The NCI recommends avoiding MLD when a person has: open wounds, bruises, broken skin, tumors that are on the skin surface, a blood clot, area of sensitive skin due to radiation. Other
contraindications would be the presence of acute inflammation, major heart problems, kidney problems, asthma, thyroid problems, undergoing chemotherapy, in the first three months of pregnancy, menstruation and having a removed spleen.

**Conclusion.** After learning the basic steps of MLD, deep breathing, and lymphatic exercises, the therapist can answer any questions the participants may have about the content. The participants will now complete the evaluation that serves as a post-test and summative evaluation on the workshop.

In short, the risk and fear of cancer-related lymphedema is real and daunting. Active lymphedema brings with it new occupations of self-care that can be overwhelming. The workshops of this program provide the opportunity for participants to gain knowledge about lymphedema, gain skills needed to monitor their risk, and increase their ability to advocate for themselves. The role of the occupational therapist for this program is that of a clinician, an educator, and an advocate.

**Budgeting and Staffing**

**Budget Overview**

**Personnel**

<table>
<thead>
<tr>
<th>Position</th>
<th>Hours per Month</th>
<th>Salary from Grant</th>
<th>Fringe Benefits</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contracted Occupational Therapist</td>
<td>Up to 5 hours per month (As needed ranging between minimum of 2 hours up to 5)</td>
<td>$35.35/hour as independent contract worker</td>
<td>$0</td>
<td>Base of $848.40/year Up to $2,121.00</td>
</tr>
</tbody>
</table>

**Marketing**

| Marketing Budget | $200.00 |

**Program Supplies and Equipment**

<p>| Item | Source | Quantity | Cost per item | Total cost |
|------|--------|----------|---------------|------------|------------|</p>
<table>
<thead>
<tr>
<th>Item</th>
<th>Supplier</th>
<th>Quantity</th>
<th>Price</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lymphedema Breast Cancer Questionnaire © (Armer n. d.)</td>
<td>Armer</td>
<td>45</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Coffee</td>
<td>Staples</td>
<td>2</td>
<td>$8.99</td>
<td>$17.98</td>
</tr>
<tr>
<td>Snacks</td>
<td>Dollar Store</td>
<td>24</td>
<td>$1.00</td>
<td>$24.00</td>
</tr>
<tr>
<td>Towels</td>
<td>Wal-Mart</td>
<td>3</td>
<td>$14.98</td>
<td>$44.94</td>
</tr>
<tr>
<td>Wedding Bubbles</td>
<td>Dollar Store</td>
<td>2</td>
<td>$1.00</td>
<td>$2.00</td>
</tr>
<tr>
<td>Envelopes</td>
<td>Staples</td>
<td>1</td>
<td>$18.99</td>
<td>$18.99</td>
</tr>
<tr>
<td>Dry Erase Pens</td>
<td>Staples</td>
<td>1</td>
<td>$4.49</td>
<td>$4.49</td>
</tr>
<tr>
<td>Paper</td>
<td>Staples</td>
<td>1</td>
<td>$46.99</td>
<td>$46.99</td>
</tr>
<tr>
<td>Binder</td>
<td>Staples</td>
<td>15</td>
<td>$3.29</td>
<td>$49.35</td>
</tr>
<tr>
<td>Paper Size Page Protectors</td>
<td>Staples</td>
<td>10</td>
<td>$13.39</td>
<td>$133.90</td>
</tr>
<tr>
<td>File folders</td>
<td>Staples</td>
<td>1</td>
<td>$6.29</td>
<td>$6.29</td>
</tr>
<tr>
<td>Notebook tabs</td>
<td>Staples</td>
<td>60</td>
<td>$2.29</td>
<td>$137.40</td>
</tr>
<tr>
<td>Pens</td>
<td>Staples</td>
<td>2</td>
<td>$6.00</td>
<td>$12.00</td>
</tr>
<tr>
<td>Hanging files</td>
<td>Staples</td>
<td>1</td>
<td>$14.99</td>
<td>$14.99</td>
</tr>
<tr>
<td>Antibiotic ointment</td>
<td>Staples</td>
<td>10</td>
<td>$3.99</td>
<td>$39.90</td>
</tr>
<tr>
<td>Band-aids</td>
<td>Staples</td>
<td>2</td>
<td>$5.49</td>
<td>$10.98</td>
</tr>
<tr>
<td>One Zip Sandwich Bags</td>
<td>Dollar Store</td>
<td>8</td>
<td>$1.00</td>
<td>$8.00</td>
</tr>
<tr>
<td>Alcohol wipes</td>
<td>Staples</td>
<td>2</td>
<td>$6.79</td>
<td>$13.58</td>
</tr>
<tr>
<td>Kleenex</td>
<td>Staples</td>
<td>9 boxes</td>
<td>$5.99/3 boxes</td>
<td>$17.97</td>
</tr>
<tr>
<td>Stamps</td>
<td>US Post</td>
<td>1 roll</td>
<td>$42.00</td>
<td>$42.00</td>
</tr>
<tr>
<td>Miscellaneous office supplies (stapler, staples, tape, dispenser, tape, paper, clips)</td>
<td>Staples</td>
<td>--</td>
<td>--</td>
<td>$60.00</td>
</tr>
<tr>
<td>Desk</td>
<td>TVC</td>
<td>1</td>
<td>*In-kind</td>
<td></td>
</tr>
<tr>
<td>Locking File Cabinet</td>
<td>TVC</td>
<td>1</td>
<td>*In-kind</td>
<td></td>
</tr>
<tr>
<td>Computer</td>
<td>TVC</td>
<td>1</td>
<td>*In-kind</td>
<td></td>
</tr>
<tr>
<td>White Board</td>
<td>TVC</td>
<td>1</td>
<td>*In-kind</td>
<td></td>
</tr>
<tr>
<td>Printer</td>
<td>TVC</td>
<td>1</td>
<td>*In-kind</td>
<td></td>
</tr>
</tbody>
</table>
Budget Justification

In order to have an occupational therapy program a trained therapist will need to be hired for 2-5 hours per month. The schedule will fluctuate depending on the needs of the program.

Programming is two hours a month. The therapist will work a minimum of two hours a month with up to three hours potentially available for preparation, record keeping, and marketing/outreach. Based on The 2010 *Occupational Therapy Compensation and Workforce*
Study, the hourly rate for an occupational therapist working in a community-based setting is $35.35 an hour.

One of the main assessments used is Lymphedema Breast Cancer Questionnaire © (Armer n. d.). There is no cost to use this assessment other than the photocopying involved.

Each month coffee and snacks will be provided to the participants to make them feel comfortable and welcomed. The snacks will be purchased at The Dollar Store and will include pretzels, popcorn, or chips. Likewise, tissue will be on hand for participants to use.

Part of the programming includes taking off shoes and socks to assess the lower legs and feet for sighs and symptoms of lymphedema. To ensure a clean space on the floor for the participants to place their feet, they will be provided with a clean towel to use for the duration of the self-evaluation.

The program will focus on providing information to help participants make changes to their lives based on increased knowledge of lymphedema prevention and management. The participants will each use a binder with notebook tabs to organize the information during the presentation of the workshops. The binders will be reused at each workshop therefore the pages will be placed in sheet protectors. All documents will be sent to participants electronically in order to reduce the cost of photocopying documents. In the event that a person does not have a computer, copies of requested documents will be provided to that participant. There will be many opportunities for writing in the program such as completing assessments and taking notes. Pens will be provided to the participants for use during the group sessions.

Instruction will be provided to the participants in a variety of formats. When the group is participating in discussions it is possible we will use a white board to record the information
discussed. While TVC has a white board for our use, the program will need to provide dry erase pens.

The Victory Center will provide use of a locking file cabinet. In order to organize materials for the program, file folders and hanging files will be purchased. Envelopes and stamps will be purchased to use for mailings including promotional material. Miscellaneous office supplies for administration for the program will be needed including: stapler, staples, tape, dispenser, tape, and paperclips.

Paper will be a very important supply since the assessments and participant material that will make-up the resource binders will be photocopied. To save money it will be double sided when possible. Materials to be photocopied include: assessment forms, the publication Lymphedema: What Every Woman With Breast Cancer Should Know (American Cancer Society, 2010), documents from the National Cancer Institute at the National Institutes of Health (NCI), the American Cancer Society (ACS), and National Lymphedema Network (NLN), the algorithm for assessing safety and risk of occupations, the directions for skin care from the American Cancer Society, pre-test and post-test evaluations, and sign-in sheets.

One of the occupations during the program is to make a purse-size emergency safety kit. The reason for this occupation is that risk of infection is a contributing factor for the on-set of lymphedema. Each safety kit will include a single use package of antibiotic ointment, Band-Aids, alcohol wipes and a zip-lock sandwich bag container for the items.

**Staff Credentials**

A occupational therapist, licensed in the state of Ohio, will be hired for this part-time, contract position. The therapist must be registered by NBCOT. Experience with lymphedema and oncology patients is required. Lymphedema certification is not required but desired.
Experience working in community-based settings is desirable. Experience facilitating group sessions in a teaching and learning format would be helpful.

**Job Description**

Occupational therapist, licensed in the state of Ohio, NBCOT Registered, will be responsible for administering a cancer survivorship program that promotes increased self-efficacy for managing cancer related lymphedema and in turn quality of life through the use of occupation based therapy to educate participants about the prevention and management of cancer-related lymphedema. Services delivered to participants at a community-based setting through group therapy workshops.

**Responsibilities**

- Graduate from approved program in occupational therapy.
- Current license in the State of Ohio-renewed every two years.
- Must maintain CPR certification.
- Informally screens participants for cancer-related lymphedema and gathers data from the participants.
- Responsible for administering individual assessments as well as facilitating occupational therapy group sessions.
- Support participants and be responsive to participants’ needs during workshops.
- Document participants attendance and assessment results including level if change.
- Respects and adheres to the non-medical approach of TVC when working with participants.
- Maintain equipment and work area in a safe and clean condition.
- Make presentations to support marketing efforts at local breast cancer support group
meetings and other sites or events.

- Handle job responsibilities in accordance with the standards of The Victory Center’s Code of Conduct, AOTA’s Code of Ethics, and other appropriate professional standards and applicable state/federal laws.

- Demonstrates knowledge and skills necessary to treat and provide care appropriate to the population served.

- Annually reviews and updates documents used including those by the National Cancer Institute at the National Institutes of Health (NCI), the American Cancer Society (ACS), and National Lymphedema Network (NLN).

- Annually performs literature search for the most current research pertaining to cancer-related lymphedema.

- Re-evaluates and modifies the program and its goals when appropriate, and prepares written documentation as required by The Victory Center and granting agency.

**Sample Advertisement**

Advertisement for an occupational therapist would be sent to area practicing lymphedema therapists, The University of Toledo, University of Findlay, The Toledo Blade, OT Practice, and AOTA Job Connections (see Appendix V for the advertisement for occupational therapist).

**Funding**

**Funding Plan**

Three funding sources have been identified to support this program (see Appendix W for funding application information). The funding sources include: Susan G. Komen for the Cure Northwest Ohio Community and/or Small Grants, Savage & Associates Charitable Donation, and the Community Foundation Community Funds. Funding for the program will be split
between two or more funding sources. Two of the workshops are directly for breast cancer survivors and funding for this portion of programming will be sought through Komen for the Cure. The other half of the programming, which is open to all types of cancer, cannot be funded by Komen for the Cure, since the organization only supports breast cancer related programming. Therefore, other funding sources will be approached for the remaining two workshops.

The Susan G. Komen for the Cure Northwest Ohio Community Grants application is available once a year in June/July. The Susan G. Komen for the Cure Community Grants has a history of providing funding for similar lymphedema programs up to $50,000 in other states. Grants applications are obtained at the Susan G. Komen for the Cure Northwest Ohio website in June and are due October, 14th 2012. Applications are submitted to the Northwest Ohio Affiliate, Susan G. Komen for the Cure and awarded yearly to non-profit organizations. The grant would provide funds to cover salaries and fringe benefits, clinical services or patient care costs, educational materials, supplies, equipment for educational purpose, and other direct program expenses. Susan G. Komen for the Cure Northwest Ohio reviews community grants one time a year. Notification is made within 30 days and made in the form of a written letter.

The proposed lymphedema program at TVC meets funding priorities for Northwest Ohio that were identified by The Northwest Ohio Affiliate of Susan G. Komen for the Cure through a comprehensive community needs profile for 2009. One funding priority identified by the community profile is to support projects for breast cancer patients at the early or newly diagnosed stage and ongoing through treatment. The second funding priority is to support programming which encourages a collaborative relationship to effectively address community needs in the area of breast health including education. An expansion of the 2009 priorities was
made in 2011 to emphasize education including for survivors about life after treatment. The proposed lymphedema education program at TVC will address all of these priorities.

The actual 2011-2012 application for a Northwest Ohio Affiliate of Susan G. Komen for the Cure community grant specifies four priorities for funding. The lymphedema program at TVC meets priorities three and four. Priority three relates to access to breast cancer diagnosis and or treatment. The grant application specifically notes assistance for lymphedema treatment as an example of priority three. The fourth priority is breast cancer survivorship programs.

For 2010-2011, Komen for the Cure of Northwest Ohio funded 14 grants with awards ranging between $10,000 and $98,000. One grant was to The Victory Center ($12,500) for support for women with breast cancer. This money is to provide support groups and counseling, yoga, healthy steps, and oncology massage. Another grant of interest was awarded to Hickman Cancer Center at Flower hospital ($22,000) to assist 75 breast cancer survivors in developing a survivorship care plan. The Victory Center was also awarded $18,000 for 2011-2012. That grants have been awarded to The Victory Center in the past as well as local grants for survivorship care is a good indication that this program’s goals meets those of the granting agency.

The second funding source is Savage & Associates, a prominent Toledo financial services company. Applications for funding are reviewed by a committee and awarded once a month. Awards are given to non-profit organizations and are for a specific project. This grant would fall under health and human services program area. The type of support provided would be for general operating or project support.

Savage & Associates has demonstrated support for projects related to breast cancer. The company is a regular corporate sponsor of The American Cancer Society’s Making Strides
Against Breast Cancer and participates annually in the Toledo Komen Race for The Cure. In addition, The Victory Center has a history of receiving funds from previous Savage & Associates Golf Classic fundraisers. Kelly Savage has personally supported The Victory Center’s fund development events. Likewise, Ryan Dauterman is an investment advisor with Savage & Associates and he has been involved with TVC by providing workshops on legacy planning to participants at TVC. Based on the demonstrated commitment of Savage & Associates to support breast cancer and The Victory Center, this is a viable funding source.

The final funding source is the Toledo Community Foundation Community Funds, which was recommended by the executive director of TVC. She suggested this funding source because the Community Foundation gives priority to funding new programs. In particular, this lymphedema program would contribute to the Community Foundation’s second area of funding emphasis, which is to, “Enable families to develop skills/resources needed to support and nurture each member” (Toledo Community Foundation, n.d., para. 2). The application would meet six of the nine grant review criteria including: demonstrating a new approach in the solution of a community problem; focusing on prevention of problems rather than a cure; providing an unduplicated opportunity to meet a community need; providing specific programming; proposing to generate matching funds; and providing a reasonable plan for continuing financial support.

**Self-Sufficiency Plan**

The program as developed will cost approximately $3,000 to administer per year. Komen grants can be applied for every year. However, it is unlikely that the other funding sources would be renewable. One option is to meet with the director of The Victory Center and discuss the possibility of The Victory Center supporting the program directly. A new fund development event could be created specifically to support this program. Currently TVC has
begun an ambassador program where “ambassadors” commit to raising a minimum of $1000 per calendar year for TVC. An ambassador could raise funds that could be earmarked for the lymphedema program.

**Program Evaluation**

Program evaluation is an important component of determining the effectiveness of the programming. Program evaluation will be used to improve the programming and to ensure that the program goal is being achieved. The program evaluation will monitor and track program effectiveness and be an important record used to obtain future funding. The program will be evaluated by participants and by key stakeholders. In addition, participant satisfaction will be taken into account.

**Process Evaluation Procedures**

The program must be evaluated for implementation; in other words, was the program administered as described? This would include keeping a record of conducting the workshop and noting any deviations from material presented during the workshops. The therapist will provide a sign in sheet that will be circulated at the beginning of each workshop. The occupational therapist will keep a record of attendance at each workshop of the program for an annual record of attendance.

**Formative Evaluators and Summative Evaluators**

Formative evaluations occur at set intervals during the program and help to improve and refine the programming to more closely meet the needs of the participants. Summative evaluations occur at the end of the program cycle, which in this case would be every four months after the series of four workshops have been conducted. Participant satisfaction will be
measured on a five-point scale as part of the post-test evaluation at the conclusion of each workshop.

**Participants:** For this program, formative evaluations occur in the form of the pretest. This will inform the occupational therapist about the baseline level of knowledge each participant has on the subject material. Using that information, the occupational therapist can regulate the amount of detail provided during that workshop.

Outcome evaluations provide information on the results or effectiveness that programming had on participants during the program and following the program. In short, the outcome evaluation will determine if the programming had an effect on reducing the need. The outcome evaluation will occur in the form of a pretest and posttest designed for each workshop. The test serves as a summative evaluation of program success by measuring the outcome measures associated with each objective. In addition, follow up surveys will be mailed via email to participants 12 weeks after the workshop. The goal of the follow-up survey is to determine if the participant show an increase in knowledge about lymphedema over baseline measurement and demonstrates an increased level of self-efficacy is using the information gained during the workshops.

Baseline measures will occur in the form of pretest evaluations. Posttest evaluations will measure knowledge and self-efficacy acquired by the end of the workshops. And, the lasting impact will be measured at 12 weeks after the workshop using the same workshop posttest evaluations.

The change from pretests to posttests as well as the LBCQ® (Armer, n.d.) will serve as a measure of knowledge gained and as a good measure of self-efficacy. The LBCQ® (Armer,
n.d.) is useful tool of self-efficacy because it reveals whether the participant did anything about their symptoms during the previous year.

**Stakeholders:** Stakeholders, specifically the program director and staff at The Victory Center, will be given a brief formative evaluation for feedback on how the program is working half way through the program series at month two. In addition, regular communication with the program director will contribute to the formative evaluation. The Victory Center staff will be asked:

- How do you think the program is going?
- Do you think or have any evidence that the program is meeting the participants’ needs?
- Have you heard any feedback from participants?
- Are there any changes we should consider making to the programming in terms of content or logistics?

Other possible forms of evaluation could include a focus group of participants who have taken the workshops, which could occur at the end of each workshop cycle, four times a year. Likewise a formative evaluation could take the form of having a lymphedema therapist attend the workshop and provide input to the occupational therapist at The Victory Center about the content of the programming.

**Outcome Evaluation Procedure**

The goal of The Victory Center’s Lymphedema Program for the greater Toledo area is to increase participants’ knowledge about and self-efficacy for managing their risk for cancer related lymphedema. For each of the objects, an outcome procedure has been identified and is listed after the objective.

**Workshop I: Breast Cancer-related Lymphedema Education and Prevention**
Objectives 1. By the end of Workshop I, participants will demonstrate a significant increase in knowledge from baseline about the *signs and symptoms* of breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

Objectives 2. By the end of Workshop I, participants will demonstrate a significant increase in knowledge from baseline about *risk reduction behaviors* that can reduce their incidence of breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

Objectives 3. By the end of Workshop I, participants will demonstrate a significant increase in knowledge from baseline about *treatment options* for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

Objective 4: By the end of Workshop I, participants will assess themselves for signs and symptoms of BCRL by measuring arm circumference, completing a visual exam, and completing the LBCQ© (Armer, n.d.).

Outcome: A process evaluation will record participation in the self-exam. Using
the participation record, the therapist will compute the overall percentage of participation across subjects and sessions. In addition, a record will be kept of the number of participants who report a history of signs and symptoms of lymphedema. An overall percentage of the positive screens for lymphedema identified during the workshop, upon self-exam, across subjects and sessions will be recorded.

**Objectives 5.** By the end of Workshop I, participants will demonstrate a significant increase in their level of *self-efficacy* from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

**Objective 6.** Twelve weeks after the conclusion of the Workshop I, 80% of participants will demonstrate an increase in their level of *knowledge* from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: This objective will be measured as a follow-up with the goal of an improved score over baseline on the BCRL Education and Prevention Evaluation noting the percentage of change. The goal is to determine lasting effect of the program.

**Objective 7.** Twelve weeks after the conclusion of Workshop I, 80% of participants
will demonstrate an increase in their level of *self-efficacy* from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: This objective will be measured as a follow-up with the goal of an improved score over baseline on the BCRL Education and Prevention Evaluation noting the percentage of change. The goal is to determine lasting effect of the program.

**Workshop II: Cancer-Related Lymphedema Education and Prevention (non-breast cancers)**

**Objectives 1.** By the end of Workshop II, participants will demonstrate a significant increase in knowledge from baseline about the *signs and symptoms* of cancer-related lymphedema as measured by a change in the Cancer-Related Lymphedema (CRL) Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

**Objectives 2.** By the end of Workshop II, participants will demonstrate a significant increase in knowledge from baseline about *risk reduction behaviors* that can reduce their incidence of cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.
Objectives 3. By the end of Workshop II, participants will demonstrate a significant increase in knowledge about treatment options for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

Objective 4: By the end of Workshop II, participants will assess themselves for signs and symptoms of cancer related lymphedema by measuring leg circumference and completing a visual exam.

Outcome: A process evaluation will record participation in the self-exam. Using the participation record, the therapist will compute the overall percentage of participation across subjects and sessions. In addition, a record will be kept of the number of participants who report a history of signs and symptoms of lymphedema. An overall percentage of positive screens for lymphedema as identified during the workshop, upon self-exam, across subjects and sessions will be recorded.

Objectives 5. By the end of Workshop II, participants will demonstrate a significant increase in their level of self-efficacy from baseline for managing their risk for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

Objective 6. Twelve weeks after the conclusion of Workshop II, 80% of participants
will demonstrate an increase in their level of *knowledge* from baseline for managing their risk for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

Outcome: This objective will be measured as a follow-up with the goal of an improved score over baseline on the CRL Education and Prevention Evaluation noting the percentage of change. The goal is to determine lasting effect of the program.

**Objective 7.** Twelve weeks after the conclusion of Workshop II, 80% of participants will demonstrate an increase in their level of *self-efficacy* from baseline for managing their risk for cancer-related lymphedema as measured by a change in the CRL Education and Prevention Evaluation.

Outcome: This objective will be measured as a follow-up with the goal of an improved score over baseline on the CRL Education and Prevention Evaluation noting the percentage of change. The goal is to determine lasting effect of the program.

**Workshop III: Managing Breast Cancer Related Lymphedema**

**Objectives 1.** By the end of Workshop III, participants will demonstrate a significant increase in knowledge from baseline about the *chronic and progressive nature* of breast cancer-related lymphedema (including the stages and the symptoms) as measured by a change in the Managing BCRL Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.
**Objectives 2.** By the end of Workshop III, participants will demonstrate a significant increase in knowledge from baseline about the *treatment options* for breast cancer-related lymphedema as measured by a change in the Managing BCRL Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

**Objectives 3.** By the end of Workshop III, participants will identify in writing three *risk-reduction behaviors* that they want to implement to reduce their risk for aggravating cancer-related lymphedema.

Outcome: This objective will be measured with a summative evaluation (using the Managing BCRL Evaluation) at the end of the Workshop III. The participant will list in writing three *risk-reduction behaviors*. Results will be used to compute the overall number of correct answers per participant and across participants.

**Objective 4.** By the end of Workshop III, participants will identify in writing three *self-care behaviors* that they want to implement to reduce the effects of their lymphedema.

Outcome: This objective will be measured with a summative evaluation (using the Managing BCRL Evaluation) at the end of the Workshop III. The participant will list in writing three *self-care behaviors*. Results will be used to compute the overall number of correct answers per participant and across participants.

**Objective 5.** By the end of Workshop III, participants will review basic energy-conservation strategies and identify three strategies they could use to manage fatigue associated with BCRL.
Outcome: This objective will be measured with a summative evaluation (using the Managing BCRL Evaluation) at the end of the Workshop III. The participant will list in writing three self-care behaviors. Results will be used to compute the overall number of correct answers per participant and across participants.

**Objectives 6.** By the end of Workshop III, participants will demonstrate a significant increase in their level of self-efficacy from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the BCRL Education and Prevention Evaluation.

Outcome: The percentage of change will be recorded per participant and across participants. Program success will be indicated by 80% of participants showing an improved score over baseline.

**Objective 7.** Twelve weeks after the conclusion of Workshop III, 80% of participants will demonstrate an increase in their level of knowledge from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the Managing BCRL Evaluation.

Outcome: This objective will be measured as a follow-up with the goal of an improved score over baseline on the Managing BCRL Evaluation noting the percentage of change. The goal is to determine lasting effect of the program.

**Objective 8.** Twelve weeks after the conclusion of Workshop III, 80% of participants will demonstrate an increase in their level of self-efficacy from baseline for managing their risk for breast cancer-related lymphedema as measured by a change in the Managing BCRL Evaluation.

Outcome: This objective will be measured as a follow-up with the goal of an
improved score over baseline on the Managing BCRL Evaluation noting the percentage of change. The goal is to determine lasting effect of the program.

**Workshop IV: Objectives: The Basics of Manual Lymphatic Drainage Massage**

**Objectives 1.** By the end of Workshop IV, participants will demonstrate basic competence in deep breathing exercises to stimulate the lymphatic system with 100% accuracy ¾ trials per observation by the occupational therapist using criteria found on Workshop IV Competency Check-off (see Appendix N for the Workshop IV competency check-off).

Outcome: This objective will be measured as a competency check-off based on observation by the occupational therapist according to the criteria found in Workshop IV Competency Check-off. Results will be used to compute the percentage of participants who meet the goal. Program success will be indicated by 80% of participants meeting Objective 1.

**Objectives 2.** By the end of Workshop IV, participants will demonstrate basic competence in completing a lymphatic exercise routine with 80% accuracy per observation by the occupational therapist using criteria found on Workshop IV Competency Check-off.

Outcome: This objective will be measured as a competency check-off based on observation by the occupational therapist according to the criteria found in Workshop IV Competency Check-off. Results will be used to compute the percentage of participants who meet the goal. Program success will be indicated by 80% of participants meeting Objective 2.

**Objectives 3.** By at the end of the workshop IV, participants will demonstrate basic skill using manual lymphatic drainage massage to clear four major nodes with 80% accuracy per
observation by the occupational therapist using criteria found on Workshop IV Competency Check-off.

Outcome: This objective will be measured as a competency check-off based on observation by the occupational therapist according to the criteria found in Workshop IV Competency Check-off. Results will be used to compute the percentage of participants who meet the goal. Program success will be indicated by 80% of participants meeting Objective 3.

**Objective 4.** By the end of Workshop IV, participants will identify precautions and considerations related to lymphatic exercise and MLD with 80% accuracy using the post-test section found on the Workshop IV Competency Check-off.

Outcome: This objective will be measured with a summative evaluation (Workshop IV Competency Check-off) at the end of the Workshop III. Results will be used to compute the overall number of correct answers per participant and across participants. Program success will be indicated by 80% of participants meeting Objective 4.

### Timeline

<table>
<thead>
<tr>
<th>Task</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion of needs assessment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Assume office space at The Victory Center</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purchase office supplies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Develop advertising and marketing material</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advertise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Develop programming</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recruit clients for program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Purchase program supplies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review programming by TVC’s</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Advisory Board</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orient Staff to occupational therapy</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advertise and hire an occupational therapist</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Train occupational therapist</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Development of evaluation forms</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implement Process Evaluations</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct monthly workshop</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct formative evaluations</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(participants and staff)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct summative evaluations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(participants and staff)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct follow-up evaluation</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year-end evaluation and report</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grant writing</td>
<td></td>
<td>X</td>
<td>T</td>
<td>C</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>X</td>
<td>K</td>
<td>O</td>
<td>M</td>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>X</td>
<td>T</td>
<td>C</td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>X</td>
<td>K</td>
<td>O</td>
<td>M</td>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
References


Real Bodywork. (2004). Lymphatic drainage massage with Sean Riehl DVD.


http://www.healthypeople.gov/2020/about/default.aspx

http://www.cancer.gov/cancertopics/factsheet/Therapy/followup

http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/healthprofessional/page1

http://seer.cancer.gov


Appendix A

Organizational Structure
Appendix B

Interview Questions for Program Director at The Victory Center

- Introduce assignment/needs assessment.
- Find a quiet place for interview – office preferably.
- Statement of confidentiality.

- Explain Occupational Therapy
  - Explain that the programming developed will be occupation based

- Purpose of Interview: To determine current programming needs at TVC specifically for breast cancer and lymphedema.

  Questions:

- What are some of the characteristics of the population you serve that has an impact on programming?

- How does participation change over time with recovery?
  - What is the retention of participants as they recover?

- What kinds of programming are well attended by participants?

- How do you determine the needs for new programming?

- What potential programs are you considering?

- What are the current barriers to implementing new programming at TVC?
  - Does TVC have any plans to overcome these barriers?

- Are there any unmet programming needs from your perspective?
  - How about from participants perspectives?

- What are your funding sources? Not-for profit?
  - Do you think another grant would be awarded from Komen for other programming at TVC?

- How do you see the future of TVC in terms of programming or services offered?
  - What is the five-year plan for TVC?

- As I work on this assignment I will be reviewing relevant literature in the form of journal articles, websites, and current OT textbooks. Are there any resources you use in developing your programming that I may want to consider?
Appendix C

Interview Questions for Other Staff Members at The Victory Center

- Introduce assignment/needs assessment.
- Find a quiet place for interview – office preferably.
- Statement of confidentiality.

- Explain Occupational Therapy
  - Explain that the programming developed will be occupation based

- Purpose of Interview: To determine current participant needs related to programming at TVC specifically for breast cancer and lymphedema and understand successful programming at The Victory Center.

Questions:

- How does participation change over time with recovery?
  - What is the retention of participants as they recover?

- What kinds of programming are well attended by participants?

- What are the current barriers to implementing new programming at TVC?
  - Does TVC have any plans to overcome these barriers?

- Are there any unmet programming needs from your perspective?
  - How about from participants perspectives?

- Any other thoughts on how to create successful programming that will be well attended?
Appendix D

Interview Questions for Breast Patient Navigator

- Introduce self and assignment/needs assessment.
- Find a quiet place for interview – her office preferably.
- Statement of confidentiality.
- Explain Occupational Therapy.
- Purpose of Interview: To determine current needs related to breast cancer and lymphedema and understand how to create programming that will best meet patient’s needs in terms of timing of information, awareness about lymphedema, and treatment options.

1. Can you tell me about your role in working with breast cancer patients?

2. Do you think there is a need for lymphedema programming that is community-based?

3. I know back in 2009, Kristen Pitzen, a former UT student, worked with Cindy Robertson OT/L at Flower Hospital Total Rehab to develop a lymphedema awareness program pre-operatively. How did that work out?

4. Tell me more about what problems you see with patients in terms of lymphedema? For example, with their level of awareness about BCRL, with their knowledge and access to treatment?

5. As I think of developing programming for TVC, what information do you think is important for the clients to know in terms of BCRL?

6. Can you think of any unmet needs for this population that could be met by programming at TVC as it relates to BCRL? If so what?

7. Does health insurance or lack of health insurance create problems with access to care for your patients?

8. Do you think there is a need for free lymphedema screenings?

9. Is there anything else you can think of that would be important for me to know as I develop programming for TVC?
Appendix E

Interview Questions for Clinical OTR/L who Treat BCRL.

- Introduce assignment/needs assessment.
- Find a quiet place for interview – their office preferably.
- Statement of confidentiality.
- Explain Occupational Therapy.
- Purpose of Interview: To determine current needs related to breast cancer and lymphedema and understand how patients manage their treatment, how lymphedema has an effect on occupational engagement and programming needs for this population.

1. How long have you been treating lymphedema?
2. Can you make any generalizations about your BCRL patients?
3. Do you notice an increase in the risk or incidence of BCRL based on the kind of reconstruction performed?
4. Do you get referrals from doctors for patients to see you for prevention of BCRL?
5. When a patient has BCRL how do they find you? Has it been a challenge for patients to find their way to an OT for treatment?
6. What influences patient compliance with treatment?
7. Can you tell me more about how having BCRL impacts the patients’ ODLs and IODLs?
8. Can you comment on how having BCRL effects the patients’ engagement in work and leisure occupations?
9. Do you use models of practice with your BCRL patients? If so, which ones?
10. As I think of developing programming for TVC, what information do you think is important for the breast cancer clients to know?
11. Can you think of any unmet needs for this population that could be met by programming at TVC as it relates to BCRL? If so what?
12. Do you think there is a need for free lymphedema screenings?
13. If The Victory Center offered free lymphedema screenings would you be willing to volunteer your time (about 9-12 hours per year) to perform screenings?
14. Is there anything else you think is important for me to know?
Appendix F

Interview Questions for Patients in Treatment for BCRL

- Introduce self and assignment/needs assessment.
- Find a quiet place for interview – during treatment session in treatment room.
- Statement of confidentiality.
- Explain Occupational Therapy.
- Purpose of Interview: To determine current needs related to breast cancer and lymphedema and understand lymphedema’s effect on occupational engagement.

1. Tell me about your first experience with lymphedema?
   - Was it related to some activity or an infection?
   - How long after surgery did it begin?

2. When you discovered that your arm was showing signs of lymphedema, what did you do about it?

3. How was your lymphedema diagnosed?

4. Can you tell me about your experience with treatment?

5. How has lymphedema changed how you manage your daily occupations like your self-care, cooking, up keep around the house?

6. What leisure occupations or hobbies have you given up as a result of lymphedema?

7. I have heard that many women just live with the lymphedema and really dislike wearing a compression sleeve. Can you give us some insight about why some women tolerate lymphedema rather than treat it?
   - How aware were you of treatment options?
   - Do you think these women are not aware of options that are available to manage their symptoms?

8. Are you aware of The Victory Center? Have you attended any programs at The Victory Center? If yes, which ones?

9. Would you attend programming at The Victory Center that educated and or provided support with lymphedema?

10. As I consider creating programming related to lymphedema what do you wish you had known or what service do you wish you had access to that would make a positive difference for you and your lymphedema?

*Follow up questions to be determined based on the information provided during the interview.*
Appendix G

Interview Questions for Patients not Currently in Treatment Who Have Signs of BCRL

- Introduce assignment/needs assessment.
- Find a quiet place for interview – their home or enclosed room at coffee shop preferably.
- Statement of confidentiality.
- Explain Occupational Therapy.
- Purpose of Interview: To determine current needs related to breast cancer and lymphedema and understand lymphedema’s effect on occupational engagement.

1. Tell me about your first experience with lymphedema?
   - Was it related to some activity or an infection?
   - How long after surgery did it begin?

2. When you discovered that your arm was showing signs of lymphedema, what did you do about it?

3. How was your lymphedema diagnosed – were you aware of what it was?

4. Can you tell me about your experience with treatment?

5. If you have not had treatment or did not follow through with treatment can you tell me more about why?

6. How has lymphedema changed how you manage your daily occupations like your self-care, cooking, up keep around the house?

7. What leisure occupations or hobbies have you given up as a result of lymphedema?

8. I have heard that many women just live with the lymphedema and really dislike wearing a compression sleeve. Can you give us some insight about why you tolerate lymphedema rather than treat it?
   - How aware were you of treatment options?

9. Are you aware of The Victory Center? Have you attended any programs at The Victory Center? If yes, which ones?

10. Would you attend programming at The Victory Center that educated and or provided support with lymphedema?

11. As I consider creating programming related to lymphedema what do you wish you had known or what service do you wish you had access to that would make a positive difference for you and your lymphedema?
Appendix H
Participant Survey 2/2012 With Summary of Responses

1. Date/s (month and year) of breast cancer diagnosis: ___1987-October 2011___________

2. Did you have lymph nodes removed? _0%__ No ___73%__ Yes (check all that apply)  
   ___45%__ Sentinel node biopsy
   ___45%__ Axillary nodes (under the arm)
   ___36%__ not sure

3. Treatment Received (check all that apply)  
   ___73%___ Lumpectomy
   ___45%___ Mastectomy
   ___45%___ Radiation
   ___36%___ Chemotherapy

4. What type of reconstruction did you choose?  
   ___18%___ Expanders with implants
   ___ 9%___ TRAM flap
   ___18%___ Latissimus Dorsi Flap
   ___0%___ Other. Please specify: ________________________________________________
   ___72%___ None

5. Have you received any information about lymphedema? _____No ___11%__ Yes
   If yes, from who? (check all that apply)  
   ___90%___ Surgeon
   ___55%___ Oncologist
   ___18%___ Radiologist
   ___55%___ Nurse
   ___18%___ Occupational Therapist
   ___36%___ Other (Please specify): ___Hospital Tour, Oncology Seminar at Flower,  
   Seminar at TVC, Seminar at St. Anne, Literature, Susan G. Komen, For The Cure_____

6. Did any of your doctors refer you to occupational therapy for lymphedema education and prevention? _81%__ No   _18%__ Yes

7. If yes, did you go to see an occupational therapist about lymphedema? ____No   _100%_ Yes

8. Do you have symptoms of lymphedema? __45%__ No   _27%__ Yes   _27%__ not sure

9. Have you received active treatment for lymphedema? __73%__ No   _9%__ Yes   _9%__ not sure

10. Are you aware of the risk factors for breast cancer related lymphedema? _9%_ No _81%__ Yes

11. Are you interested in learning more about lymphedema? _20%__ No   _80%__ Yes
12. If offered, would you be interested in attending a workshop at The Victory Center to learn more about preventing breast cancer related lymphedema? __27%__No __73%__Yes

13. If offered, would you be interested in attending a 4-week class that would meet one time a week at The Victory Center that focuses on lymphedema prevention? __25%__No __75%__Yes

If no why not: _not relevant, no current lymphedema_ __________________________________________________________________________

14. If available would you attend a one-on-one appointment at The Victory Center with an occupational therapist to learn more about preventing breast cancer related lymphedema? __25%__No __75%__Yes

15. Are you concerned about developing breast cancer related lymphedema? _43%_ No _57%_ Yes

16. Do you take any steps in your daily life to prevent lymphedema?

__14%__ No __86%__ Yes

__83%__ avoid needles and blood pressure in affected arm

__50%__ wear a compression sleeve

__50%__ other (please list) _when doing heavy work/lifting, when flying, when exercising, wear a bracelet_ __________________________________________________________________________

17. Do you avoid using your arm on the side where lymph nodes were removed?

__43%__ No __57%__ Yes

18. Do you limit your activities to avoid getting lymphedema? __43%__ No __57%__ Yes

18a. If yes, what activities do you avoid? Please list on lines below.

_carrying my purse on that arm, lifting heavy objects, when doing heavy lifting or work, avoid arm use, not carrying heavy things in that arm, watch about cuts_ __________________________________________________________________________

19. Are there hobbies or activities that you no longer participate in due to fear of developing lymphedema? _62%_ No _12%_ Yes _25%_ not sure

19a. If yes, please list. _avoid arm use_ __________________________________________________________________________

20. Are there hobbies or activities that you no longer participate in due to symptoms of lymphedema? _57%_ No _28%_ Yes _14%_ not sure

20a. If yes, please list.

_ __________________________________________________________________________

21. Does either having lymphedema or the risk for lymphedema effect your ability to complete your daily self-care activities (dressing, bathing, toileting, grooming)?

__86%__ No __14%__ Yes ______ not sure

21a. If yes, please list.

_avoid arm use often_ __________________________________________________________________________
Appendix I

Participant Survey 2/2011 With Summary of Responses

1. Date/s (month and year) of breast cancer diagnosis: ___1992-2/2011 ____________

2. Did you have lymph nodes removed? ___0% No  ___100% Yes (check all that apply)
   __66%__ Sentinel node biopsy
   __58%__ Axillary nodes (under the arm)
   __8%__ not sure

3. Treatment Received (check all that apply)
   __58%__ Lumpectomy
   __42%__ Mastectomy
   __75%__ Radiation
   __66%__ Chemotherapy

4. Have you received any information about lymphedema? _____No  _100%_Yes
   If yes, from who? (check all that apply)
   __58%__ Surgeon
   __42%__ Oncologist
   __33%__ Radiologist
   __50%__ Nurse
   __25%__ Occupational Therapist
   __42%__ Other (Please specify): __family doctor, research reading, pamphlet________

5. Did any of your doctors refer you to occupational therapy for lymphedema education and prevention? __42%__ No  __58%__ Yes

6. If yes, did you go to see an occupational therapist about lymphedema? _43%_No  _57%_Yes

7. Do you have symptoms of lymphedema? __42%__ No  __25%__ Yes  ___33%__ not sure

8. Have you received active treatment for lymphedema? __58%__ No  __42%__ Yes

9. Are you aware of the risk factors for breast cancer related lymphedema? _18%_No _82%_Yes

10. Are you interested in learning more about lymphedema? _____No  _100%____Yes

11. Would you attend a workshop to learn more about preventing breast cancer related lymphedema? _____No  _83%__ Yes  ___16%__ Maybe

12. Did you come to the support group tonight specifically to learn more about lymphedema?  __25%__ No  __75%__ Yes
13. Would you attend a one-on-one appointment with an occupational therapist to learn more about preventing breast cancer related lymphedema? __9%___No __66%___Yes __16%___Maybe

14. Do you take any steps in your daily life to prevent lymphedema? _10%_No    __90%_Yes
    __100%___avoid needles and blood pressure in affected arm
    __25%___wear a compression sleeve
    __50%___other (please list) _no heavy lifting X3, no purse on arm, careful lifting heavy objects, self-massage every night, attend Healthy Steps exercise class with lymphatic warm-up, exercises for lymphedema,

THANK YOU FOR YOUR TIME AND HELP!
Appendix J

Needs Assessment: Results of the Semi-Structured Interviews

Overall Themes

When speaking with women at risk for cancer-related lymphedema they fall into one of three groups:

- Women with BCRL who simply live with it.
- Women who are aware of the risk and take proactive steps to avoid BCRL.
- Women who are not aware that they are at risk (never informed, doctor downplayed, forgot/denial).

Participant Survey Results

- Other cancers were interested in being a part of the data collection and felt left out.
- One woman shared that her friend was having a terrible time with lower extremity lymphedema after treatment for ovarian cancer.
- One woman expressed, “My doctor really downplayed the risk for lymphedema so I have never really worried about it.”
- Another woman expressed, “I am so sorry I can’t help you with your survey, I don’t have lymphedema.” The more we talked the more she remembered the precautions she was told about and took during the first year after treatment. She was surprised at what she had forgotten and was very appreciative for being reminded of simple precautions.
- See Appendix B and C for specific results.

Interview with Program Director and Staff at The Victory Center

- The role of TVC is to “Get people to where they need to go and to not duplicate services.” Also it was emphasized by both the executive director and program director that programming in non-medical. The executive director expressed, “The mission of The Victory Center is educational and non-medical.” Another staff member expressed, “The Victory Center provides support service. We do not provide treatment of any kind - support services only!” However there is a medical advisory board that approves programming and services.

- Over time the needs of participants becomes less however programs are still well attended over time by survivors. About 30% continue on participating in programming. However, according to the program director, “The main purpose is to support participants during cancer treatment and care for them when things are most crisis oriented.” The survivors’ needs become less over time.
• It is unclear whether screening could be included in this program. The idea of performing screenings for lymphedema was initially vetoed by the executive director and feels that it is too medical for a facility that is non-medical.

• Other staff advocated for outreach. A fitness instructor expressed, “People who attend The Victory Center are more proactive in their care. How do you connect with people who are not connected?” She explained that in the outlaying communities there is nothing. For example, the Oregon area of Toledo is a missed population in terms of support services for cancer patients and survivors.

• Staff also voiced that having the doctor’s backing is critical due to women deferring to their recommendations regarding care.

• A staff member felt that there is a need for more discussion of health and diet. Perhaps include this component in terms of the lymphatic system.

• Lori Brandt the Healthy Steps instructor is willing to participate as a guest to teach lymphatic warm-up exercises and provide a poster handout of the exercises.

Logistical Aspects of Programming

• As participants end active treatment, they become more involved in the exercise and monthly programs.

• Some people have a hard time coming for services during active treatment secondary to needing to work to keep insurance.

• Programming that is well attended includes the fitness related classes such as belly dancing, yoga, and Healthy Steps.

• Considering programming:
  • People have to be told or invited to new programming.
  • How things are worded is important so people understand what the program is about.
  • Timing is important; some people won’t come in the winter in the dark.
  • Evening work better than during day.
  • The 2-3:30 time frame does not work because people are picking up kids.
  • It is not uncommon for people to get inspired by programming but then cancel.
  • Saturdays is not the best time to offer programming.
  • A medical advisory board approves all new programming.
  • A lot of people ask about lymphedema.
Patients with Lymphedema in Treatment and Out of Treatment

- Two women were interviewed who currently have BCRL. One woman developed lymphedema within a few months of treatment while the other woman developed lymphedema within a few years after treatment. Both women tolerate their lymphedema. Both have had minimal treatment but poor follow through with management. The impetus for returning to treatment for one woman occurred when her clothes no longer fit. The other woman only manages her lymphedema when it interferes with her functional abilities. Despite the lymphedema, one woman continues with all her occupations. It is likely that her current work occupation and IODLs are aggravating her lymphedema. However, she is unwilling to make any changes to her habits and roles to accommodate her lymphedema.

- Both voiced problems with obtaining properly fitted compression garments. One was measured for a compression sleeve with the fitter measuring her non-affected arm for a sleeve that was to fit her affected arm. It did not fit. The patient tried to question if measuring this way made sense? The other woman received a poor fitting glove that turned her fingers blue – it never fit.

- Both women expressed that their lymphedema becomes worse in summer and aggravated by lifting and pulling. Walking around a lot also leads to increased swelling.

- Despite the lymphedema and management protocol to use a sleeve one woman has had one sleeve she purchased 8 years ago and never replaced it. Sleeves are generally good for 6 months.

- Both women felt that it is helpful to be informed and they still have questions about precautions. For example, does massage help or hurt are hot tubs okay?

Clinical OTR who Treat Lymphedema

- Medicare and most other medical insurance do not cover bandages used for treatment. Most clinics charge the patient for bandages, which cost about $100.00 to begin treatment.
- Visits can be from 2 times a week to 5 days a week for an intensive period of time with the goal of getting the lymphedema under control.
- Patients have limited number if visits to occupational therapy and the number of visits if insurance driven.
- The co-pays for the therapy intense treatment can be a financial burden especially for those on a fixed income.
- There is a need for free screenings.

- Poor fitting compression sleeves are a problem.
- Sleeves that are comfortable to wear and good fitting is critical.
- Medicare does not cover compression garments except for breast cancer.
• An inexpensive alternative is comperm, tubagrip. Barton Carey makes a reasonable priced sleeve at 30/40 compression but they don’t make a 40/50 sleeve.
• Other local suppliers are very expensive.
• There is a need for more qualified and competent fitters in the Toledo area.
• Coverage of garments by insurance and good fit leads to compliance.
• Poor fitting sleeve huge problem to compliance

• At one site, 75-80% of patients seen for BCRL are for patient education, educating about signs of BCRL, and to establish a baseline.
• Outlaying areas have a harder time finding way to treatment
• Considering programming – patients follow doctors’ advice. Therefore, it is important to develop relationships with the doctors.
• Co-morbidity like walker use makes treatment and compliance harder and age.

Interview with Breast Cancer Navigator, RN at Local Hospital

• When developing programming consider how to teach women to be advocates for themselves.
• If you do free screenings, make it easy for the patient to go back to their doctor to obtain a referral to OT for treatment. For example, provide an assessment slip to give to the doctor to make transition to care easier.
• Educate about who is at risk. It is possible that doctors downplay the risk of developing cancer-related lymphedema.
• Developing relationships with surgeons could be helpful.
• Small grants from Komen are easy to get (Becky Royer at Komen).
• If a grant is successful it can lead to larger grant.
• Partnership with Promedica
• Marketing – consider how to recapture people after surgery/chemo in order to reconnect these people to services.

The Victory Center

The Victory Center is a non-profit community advocacy setting. The mission is “to support and educate cancer patients and those closest to them by providing individual and group services in northwest Ohio and southeast Michigan.” Four, local, women philanthropists established the Victory Center in 1996. The Victory Center began as a Cancer Wellness Center, which is a national program. At some point, the decision as made to break off from The Wellness Community. The decision was made to focus programming on providing individual services (massage, reiki, healing touch, reflexology) to help the body deal with the symptoms of cancer
and treatment and to provide a mental break for participants. According to Penny, the Program Director, no other program in the country offers this level of individual services free of charge to cancer patients. The Victory Center is supported through grants, foundations, donations, fundraising, and a very limited United Way funds.

Services provided by The Victory Center include individual and group services. Individual services are available once per week, with up to three individual services per month and last 30-60 minutes each. Individual services are available during cancer treatment and up to six months after treatment has ended. Group services available one or two times a month and last 1.5 hours. Special groups meet weekly or monthly for 1-2 hours. Group services are open to anyone.

- **Individual services available:**
  - Massage
  - Reiki
  - Healing touch
  - Reflexology
  - Chi reflexology
  - Sound therapy
  - Facial
  - Individual meditation
  - Spiritual Support
  - Short-term counseling
  - Journey Work

- **Support groups include:**
  - Currently in treatment
  - Family
  - Survivors
  - Breast Cancer
  - Breast Cancer Co-Survivor
  - Lung Cancer
  - Blood Cancer
  - Colon Cancer

- **Special groups include:**
  - Yoga
  - Gentle Exercise
Crafts and Conversation

The population is primarily adolescent and adult population with the majority ages 20-80. It includes men and women from point of cancer diagnosis on. Services are provided for people in treatment and also for survivors. Recently, The Victory Center has been serving more men with typical diagnosis being, prostate, colorectal, blood, and lung cancers. For the history of The Victory Center, 57% of people served have been for breast cancer. No men with a diagnosis of breast cancer have sought services at The Victory Center.

Performance skill deficits during treatment include:

- constant fatigue
- nausea
- loose of function
- depression

Occupational performance deficits during treatment include:

- Disruption of habits, roles, and routines due to fatigue, treatment side effects and doctor’s appointments.
- Many older adults suddenly lose their pre-diagnosis ability level, which is discouraging to them both physically and or disrupts their ability to provide for themselves economically.
- Not able to maintain pre-cancerous ability level in multiple areas including ODL, IODL and physical exercise.

Some other characteristics of this population include:

- Majority have good support systems
- Participants without a good support system are the ones that The Victory Center can do the most for.
- Desire for connection.
- Place to be relaxed with cancer because The Victory Center is a place where it is normal to be a cancer patient.
- Can let guard down, it is normal, very calming

I asked about the retention of participants after they recover. The Program Director explained that it is normal to see participants more while they qualify for individual services during their cancer treatment. Returning to normal life, moving along, is considered successful.
Although, some participants feel cancer has so affected their lives that they stay engaged longer, and engage in programming to feel more self-acceptance.

The Program Director was been promoted to Program Director in 2009. Since then, programming has increased 30%. She has tried to diversify the programming offered. She is constantly try to look for new programming because every patient different. Her first goal is to bring cancer patients through door. She wants participants to come away feeling support – that is the main criteria. Programming also strives to include education, exercise, and exposing people to new ideas or forms of self-expression. The Program Director believes people need a reason to come and connect and do something that may be new for them. Programming is developed to catch as wide a variety of people as possible, to find ways to make connections with other people, and to allow participants to express themselves during their cancer journey.

When determining the needs for new programming, Penny explained you have to be fearless and have great enthusiasm and excitement. She puts everything new programming knowing it may not work. However she believes in trying new things. New programming is given about three months to determine success. If support groups are not serving enough people, as was the case recently with the advanced cancer group, it is cancelled. The support group ran for one year before being cancelled. All new therapies or disciplines for group or individual services go through a medical advisory council proposal for approval. Currently, yoga, belly dancing, the knitting group and the Healthy Steps class are good examples of successful programs.
Appendix K

Workshop I: BCRL Education and Prevention Evaluation

Note: Use blue pen for pre-test. Use red pen for post-test.

<table>
<thead>
<tr>
<th>1.) Signs and symptoms of breast cancer-related lymphedema include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
<tr>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
</tr>
<tr>
<td>6.</td>
</tr>
<tr>
<td>7.</td>
</tr>
<tr>
<td>8.</td>
</tr>
<tr>
<td>9.</td>
</tr>
<tr>
<td>10.</td>
</tr>
</tbody>
</table>

| 2.) An arm circumference difference in measurement between my arms of _____________ centimeters is cause for monitoring. |

| 3.) An arm circumference difference in measurement between my arms of _____________ centimeters is considered lymphedema and should be treated. |

<table>
<thead>
<tr>
<th>4.) Risk reduction behaviors to reduce breast cancer-related lymphedema include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
<tr>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
</tr>
<tr>
<td>6.</td>
</tr>
<tr>
<td>7.</td>
</tr>
<tr>
<td>8.</td>
</tr>
<tr>
<td>9.</td>
</tr>
<tr>
<td>10.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.) Treatment options for breast cancer-related lymphedema include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
<tr>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.) I have examined myself for breast cancer-related lymphedema in the past 30 days:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>
7.) After I examined myself for breast cancer-related lymphedema, I determined that I have signs and symptoms of lymphedema. If yes, please list signs and symptoms below

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>

8. *I am confident that I know the signs and symptoms of breast cancer related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

9. *I am confident that I know risk-reduction behaviors that will reduce my risk of developing breast cancer-related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

10. *I am confident that I will practice risk-reduction behaviors that will reduce my risk of developing breast cancer-related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

11. *I am confident that I know the treatment options available for breast cancer-related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

12. *I am confident that I will seek treatment for breast cancer-related lymphedema if needed.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

13. *I am confident that I know how to measure my arms and hands in order to monitor for breast cancer-related lymphedema*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

14. *I am confident that I will measure my arms and hands in order to monitor for breast cancer-related lymphedema.*
related lymphedema on a regular basis.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

15. I am confident that I know how to visually inspect my arms and hands for signs and symptoms of breast cancer-related lymphedema.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

16. I am confident that I will visually inspect my arms and hands for signs and symptoms of breast cancer-related lymphedema on a regular basis.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

17. I am confident in my ability to manage breast cancer-related lymphedema should it develop.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

18. I was satisfied with this program.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

Scoring Workshop I: BCRL Education and Prevention Evaluation

**Scoring for Knowledge**
(For items 1-7 give a score of 1 for each correct answer)

<table>
<thead>
<tr>
<th>Item (Objective)</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1 (Objective 1)</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 2 (Objective 1)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 3 (Objective 1)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 4 (Objective 2)</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 5 (Objective 3)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 6 (Objective 4)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 7 (Objective 4)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>/15</td>
<td>/15</td>
<td></td>
</tr>
</tbody>
</table>

**Scoring for Self-Efficacy**
For items 8-18 score as follows:
1= strongly disagree
2= disagree
3= undecided
4= agree
5= strongly agree

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 8</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 9</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 10</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 11</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 12</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 13</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 14</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 15</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 16</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 17</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>/45</td>
<td>/45</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Score for Knowledge</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
<th>Follow-up Evaluation</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>/15</td>
<td>/15</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Score for Self-Efficacy</th>
<th>/45</th>
<th>/45</th>
<th></th>
</tr>
</thead>
</table>

| Total Score | /60 | /60 | |

Scoring for Program Satisfaction (Item 18) ____________
Appendix L

Workshop II: Cancer-Related Lymphedema Education and Prevention (non-BCRL) Evaluation

*Note: Use blue pen for pre-test. Use red pen for post-test.*

<table>
<thead>
<tr>
<th>1.) Signs and symptoms of cancer-related lymphedema include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
<tr>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
</tr>
<tr>
<td>6.</td>
</tr>
<tr>
<td>7.</td>
</tr>
<tr>
<td>8.</td>
</tr>
<tr>
<td>9.</td>
</tr>
<tr>
<td>10.</td>
</tr>
</tbody>
</table>

2.) A leg circumference difference in measurement between my legs of ____________ centimeters is cause for monitoring.

3.) A leg circumference difference in measurement between my legs of ____________ centimeters is considered lymphedema and should be treated.

<table>
<thead>
<tr>
<th>4.) Risk reduction behaviors to reduce cancer-related lymphedema include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
<tr>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
</tr>
<tr>
<td>6.</td>
</tr>
<tr>
<td>7.</td>
</tr>
<tr>
<td>8.</td>
</tr>
<tr>
<td>9.</td>
</tr>
<tr>
<td>10.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.) Treatment options for cancer-related lymphedema include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
</tr>
<tr>
<td>3.</td>
</tr>
<tr>
<td>4.</td>
</tr>
<tr>
<td>5.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.) I have examined myself for cancer-related lymphedema in the past 30 days:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
7.) After I examined myself for cancer-related lymphedema, I determined that I have signs and symptoms of lymphedema. If yes, please list signs and symptoms below

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8. *I am confident that I know the signs and symptoms of cancer related-lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

9. *I am confident that I know risk-reduction behaviors that will reduce my risk of developing cancer-related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

10. *I am confident that I will practice risk-reduction behaviors that will reduce my risk of developing cancer-related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

11. *I am confident that I know the treatment options available for cancer-related lymphedema.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

12. *I am confident that I will seek treatment for cancer-related lymphedema if needed.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

13. *I am confident that I know how to measure my arms and hands in order to monitor for cancer-related lymphedema*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>
14. I am confident that I will measure my arms and hands in order to monitor for cancer-related lymphedema on a regular basis.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

15. I am confident that I know how to visually inspect my arms and hands for signs and symptoms of cancer-related lymphedema.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

16. I am confident that I will visually inspect my arms and hands for signs and symptoms of cancer-related lymphedema on a regular basis.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

17. I am confident in my ability to manage cancer-related lymphedema should it develop.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

18. I was satisfied with this program.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

Scoring Workshop II: CRL Education and Prevention Evaluation

**Scoring for Knowledge**

*(For items 1-7 give a score of 1 for each correct answer)*

<table>
<thead>
<tr>
<th>Item</th>
<th>Objective</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1</td>
<td>Objective 1</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 2</td>
<td>Objective 1</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 3</td>
<td>Objective 1</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 4</td>
<td>Objective 2</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 5</td>
<td>Objective 3</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 6</td>
<td>Objective 4</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 7</td>
<td>Objective 4</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td></td>
<td>/15</td>
<td>/15</td>
<td></td>
</tr>
</tbody>
</table>
Scoring for Self-Efficacy
For items 8-18 score as follows:
1= strongly disagree
2= disagree
3= undecided
4= agree
5= strongly agree

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 8</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 9</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 10</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 11</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 12</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 13</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 14</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 15</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 16</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 17</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>/45</td>
<td>/45</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
<th>Follow-Up Evaluation</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score for Knowledge</td>
<td>/15</td>
<td>/15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score for Self-Efficacy</td>
<td>/45</td>
<td>/45</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>/60</td>
<td>/60</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Scoring for Program Satisfaction (Item 18) ____________
## Appendix M

### Workshop III: Managing Breast Cancer–Related Lymphedema Evaluation

Note: Use blue pen for pre-test. Use red pen for post-test.

**Questions 1 – 6 serve as a formative evaluation.**

1.) *Signs and symptoms* of breast cancer-related lymphedema include:

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2.) An arm circumference difference in measurement between my arms of _____________ centimeters is cause for monitoring.

3.) An arm circumference difference in measurement between my arms of _____________ centimeters is considered lymphedema and should be treated.

4.) *Risk reduction behaviors* to reduce breast cancer-related lymphedema include:

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.) I have examined myself for breast cancer-related lymphedema in the past 30 days:  

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

6.) After I examined myself for breast cancer-related lymphedema, I determined that I have signs and symptoms of lymphedema. If yes, please list signs and symptoms below:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

1. |   |   |   |   |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7.) Lymphedema is a chronic condition. True__________ False__________

8.) How many stages of lymphedema are there? ______________________

9.) Lymphedema will get better without treatment in the early stage. True_______ False______

10.) Lymphedema will get better without treatment in the advanced stage. True___False____

11.) Treatment options for breast cancer-related lymphedema include:

1. 
2. 
3. 
4. 
5. 

12.) At the end of the workshop please list: three risk reduction behaviors you want to implement to reduce your breast cancer-related lymphedema.

1. 
2. 
3. 

13.) At the end of the workshop please list: three self-care behaviors you want to implement to reduce breast cancer-related lymphedema.

1. 
2. 
3. 

14.) At the end of the workshop please list: three energy-conservation strategies you could implement to manage fatigue associated with breast cancer-related lymphedema.

1. 
2. 
3. 

15. I am confident that I know the signs and symptoms of breast cancer related-lymphedema.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>16. I am confident that I know risk-reduction behaviors that will reduce my risk of developing breast cancer-related lymphedema.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>17. I am confident that I can implement risk-reduction behaviors that will reduce my risk of developing breast cancer-related lymphedema.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>18. I am confident that I know the treatment options available for breast cancer-related lymphedema.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>19. I am confident that I would seek treatment for breast cancer-related lymphedema as needed.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>20. I am confident that I know how to measure my arms and hands in order to monitor for breast cancer-related lymphedema.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>21. I am confident that I will measure my arms and hands in order to monitor for breast cancer-related lymphedema on a regular basis.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>22. I am confident that I know how to visually inspect my arms and hands for signs and symptoms of breast cancer-related lymphedema.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
<tr>
<td>23. I am confident that I will visually inspect my arms and hands for signs and symptoms of breast cancer-related lymphedema on a regular basis.</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither agree nor disagree</td>
<td>Agree</td>
</tr>
</tbody>
</table>
24. *I am confident in my ability to manage breast cancer-related lymphedema should it develop and/or progress.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

25. *I was satisfied with this program.*

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

**Scoring Workshop III: Managing Breast Cancer –Related Lymphedema Evaluation**

**Scoring for Knowledge**
*(For items 1-7 give a score of 1 for each correct answer)*

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1 (Formative)</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 2 (Formative)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 3 (Formative)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 4 (Formative)</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 5 (Formative)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 6 (Formative)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Formative Sub-total</td>
<td>/14</td>
<td>/14</td>
<td></td>
</tr>
<tr>
<td>Item 7 (Objective 1)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 8 (Objective 1)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 9 (Objective 1)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 10 (Objective 1)</td>
<td>/1</td>
<td>/1</td>
<td></td>
</tr>
<tr>
<td>Item 11 (Objective 2)</td>
<td>/5</td>
<td>/5</td>
<td></td>
</tr>
<tr>
<td>Item 12 (Objective 3)</td>
<td>/3</td>
<td>/3</td>
<td></td>
</tr>
<tr>
<td>Item 13 (Objective 4)</td>
<td>/3</td>
<td>/3</td>
<td></td>
</tr>
<tr>
<td>Item 14 (Objective 5)</td>
<td>/3</td>
<td>/3</td>
<td></td>
</tr>
<tr>
<td>Objective Sub-total</td>
<td>/18</td>
<td>/18</td>
<td></td>
</tr>
</tbody>
</table>

**Scoring for Self-Efficacy**
*For items 15-24 score as follows:*

1= strongly disagree
2= disagree
3= undecided
4= agree
5= strongly agree

<table>
<thead>
<tr>
<th>Item</th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
<th>Follow-Up Evaluation</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 15</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 16</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 17</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 18</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item</td>
<td>Pre-test</td>
<td>Post Test</td>
<td>Percentage Change</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>-----------</td>
<td>-------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 19</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 20</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 21</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 22</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 23</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 24</td>
<td>/5</td>
<td>/5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>/50</td>
<td>/50</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Pre-test</th>
<th>Post Test</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formative Knowledge</td>
<td>/14</td>
<td>/14</td>
<td></td>
</tr>
<tr>
<td>Score for Knowledge</td>
<td>/18</td>
<td>/18</td>
<td></td>
</tr>
<tr>
<td>Score for Self-Efficacy</td>
<td>/50</td>
<td>/50</td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>/72</td>
<td>/72</td>
<td></td>
</tr>
</tbody>
</table>

**Scoring for Program Satisfaction** (Item 25) ____________
Appendix N

Workshop IV: Competency Check-off

**Objectives 1.** Deep Breathing Competency Check-off

<table>
<thead>
<tr>
<th>Objective</th>
<th>Successful</th>
<th>Needs Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathes in through the nose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blows out through the mouth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expands belly on inhale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contracts belly on exhale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Repeats 5 times</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathes deeply</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breaths slowly</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Objectives 2.** Lymphatic Exercise Routine Competency Check-off

<table>
<thead>
<tr>
<th>Objective</th>
<th>Successful</th>
<th>Needs Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follows instructor’s directions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performs movements slowly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintains proper position for exercises</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Objectives 3.** Manual Lymphatic Drainage Massage Competency Check-off

<table>
<thead>
<tr>
<th>Objective</th>
<th>Successful</th>
<th>Needs Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Massages the nodes above the collar bone 10 times</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Massages directly on the skin for the nodes above the collar bones</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performs massage using short stretching motions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Massages the arm pit nodes 10 times</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Massages directly on the skin for the nodes in the arm pit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performs massage using short stretching scoop motions up towards collar bones</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Massages the groin nodes 10 times (can be over clothes for demonstration purpose)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Massages groin with scoop motion up towards belly button</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses a light pressure for MLD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses full surface area of fingers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Objective 4. Precautions and considerations related to lymphatic exercise and MLD

Please mark true or false to the following statements.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lymphatic exercises should be performed slowly.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Lymphatic exercises should be performed with a trained instructor by attending a Healthy Steps Class, purchasing a DVD or following along with U-Tube video.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Performing the lymphatic exercises with proper form is important.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>MLD should be performed in a certain sequence.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>MLD should be done directly on the skin not over clothing</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>MLD uses only enough pressure to deform the skin</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>MLD uses short stretching motions</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>It is ok to slide fingers over the skin</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>IF I have swelling it must be lymphedema</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Swelling could be caused from a blood clot in my arm or leg</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Swelling could be caused from problems with the heart, kidneys or liver</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>I should NOT perform MLD if I have open wounds, bruises, broken skin, tumors that are on the skin surface, a blood clot, and area of sensitive skin due to radiation.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>I should NOT perform MLD if I have the presence of acute inflammation, major heart problems, kidney problems, asthma, thyroid problems, undergoing chemotherapy, in the first three months of pregnancy, menstruation and having a removed spleen.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>I should avoid using MLD at the neck if I have thyroid problems or if I have had my thyroid removed.</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Scoring Workshop IV: Competency Check-off

Each item is worth one point.

Objective 1: Meeting the goal is a score of 100% during ¾ trials.

Objectives 2 -- 4. Meeting the goal is a score of 80% or better.
Appendix O

Marketing Flyer

Survivorship Care at The Victory Center

Workshops in Education, Prevention & Management of Cancer-Related Lymphedema

Increase Knowledge and Self-efficacy Through an Occupation Based Approach to the Prevention and Management of Cancer-Related Lymphedema.

Workshops held monthly.

For more information and a schedule of workshops, contact
The Victory Center at 419-531-7600
Appendix P

Lymphedema Breast Cancer Questionnaire© (LBCQ)

The LBCQ© is being used with permission by Jane Armer PhD, Rn, FAAN. For a copy of the questionnaire, contact her directly at the contact information listed below.

Jane Armer, PhD, RN, FAAN
Professor  Director, Nursing Research, Ellis Fischel Cancer Center
Co-Director, Health Communication Research Center
E-mail: armer@missouri.edu
Phone: 573-882-0287
Fax: 573-884-4544
S312 School of Nursing Building
University of Missouri
Columbia, MO 65211
Appendix Q

Summary Evaluation

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pretest</th>
<th>Posttest</th>
<th>% Change from baseline</th>
<th>Follow-Up</th>
<th>% Change from baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix R

Resource List


http://www.lymphedema-therapy.com/lymphedema-pictures.html


Appendix S

UE Arm Measurement Record

**Note:** Take measurements in centimeters
Include date, weight, and measurements for right and left arms.

<table>
<thead>
<tr>
<th>Date Measured</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Weight</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Starting at the tip of the third finger, mark your arm using washable marker at the locations listed below starting at the palm and ending at the upper arm. Record the distance in centimeters from the tip of your finger to each location on the measurement column. You will use these measurement landmarks as the locations where you will measure the circumference of your arm. This will ensure you are measuring your arm in the exact location each time you measure.

<table>
<thead>
<tr>
<th>Measurements</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palm</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wrist</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Forearm</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper Forearm</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elbow</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mid-Upper Arm</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper Arm</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix T

LE Leg Measurement Record

*Note:* Take measurements in centimeters
Include date, weight, and measurements for right and left legs.

<table>
<thead>
<tr>
<th>Date Measured</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Weight</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>

Starting at the tip of the third toe, mark your leg using washable marker at the locations listed below starting at the arch of the foot and ending at the upper leg. Record the distance in centimeters from the tip of your toe to each location on the measurement column. You will use these measurement landmarks as the locations where you will measure the circumference of your leg. This will ensure you are measuring your leg in the exact location each time you measure.

<table>
<thead>
<tr>
<th>Measurements</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
<th>Right</th>
<th>Left</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foot Arch</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ankle</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Calf</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper Calf</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knee</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mid-Upper Leg</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper Leg</td>
<td>cm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix U

Occupation and Lymphedema Algorithm

Occupation or goal:

Considerations

<table>
<thead>
<tr>
<th>Does the occupation make your arm feel...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tired?</td>
</tr>
<tr>
<td>Sore?</td>
</tr>
<tr>
<td>Achy?</td>
</tr>
</tbody>
</table>

Limitations

<table>
<thead>
<tr>
<th>Limitations</th>
<th>Tools to Manage Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range of Motion</td>
<td>Stretch daily. Use of assistive devices.</td>
</tr>
<tr>
<td>Strength</td>
<td>Use the affected arm as much as possible in daily occupations. Use of assistive devices.</td>
</tr>
<tr>
<td>Endurance</td>
<td>Progressively increase exercise. Use energy conservation techniques.</td>
</tr>
</tbody>
</table>

Risks:

<table>
<thead>
<tr>
<th>Risks</th>
<th>Tools to Manage Risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burn</td>
<td>Wear gloves</td>
</tr>
<tr>
<td>Drying to the skin</td>
<td>Moisturize with low ph lotion</td>
</tr>
<tr>
<td>Cuticle injury</td>
<td>Wear gloves</td>
</tr>
<tr>
<td>Cuts to hands or arm</td>
<td>Wear gloves, use electric shaver</td>
</tr>
<tr>
<td>Splinters</td>
<td>Wear gloves</td>
</tr>
<tr>
<td>Insect bites</td>
<td>Wear insect repellant like Skin so Soft – avoid alcohol.</td>
</tr>
<tr>
<td>Vigorous use of muscles</td>
<td>Use a Compression sleeve</td>
</tr>
<tr>
<td>Repetitive use of muscles</td>
<td>Take frequent breaks or AVOID</td>
</tr>
<tr>
<td>Risk of sunburn</td>
<td>Cover arm with clothing and use sunscreen</td>
</tr>
<tr>
<td>Flying</td>
<td>Use a Compression sleeve</td>
</tr>
<tr>
<td>High elevation</td>
<td>Use a Compression sleeve</td>
</tr>
<tr>
<td>Extreme temperature?</td>
<td>AVOID</td>
</tr>
<tr>
<td>(sauna, shower, heating pad, hot pack)</td>
<td></td>
</tr>
<tr>
<td>Alternating between extreme hot and cold temperatures.</td>
<td>AVOID</td>
</tr>
<tr>
<td>Deep massage</td>
<td>AVOID</td>
</tr>
<tr>
<td>Carrying heavy objects with arms hanging down</td>
<td>AVOID for long periods of time</td>
</tr>
<tr>
<td>Wearing a heavy purse</td>
<td>AVOID on affected side</td>
</tr>
<tr>
<td>Are the clothing sleeves tight or restrain movement?</td>
<td>AVOID</td>
</tr>
</tbody>
</table>

Are the clothing sleeves tight or restrain movement?
<table>
<thead>
<tr>
<th>Condition</th>
<th>Solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>A watch or other jewelry feels tight and leaves marks in the skin.</td>
<td>Wear on the other hand</td>
</tr>
<tr>
<td>Bra is too tight</td>
<td>Get a larger size.</td>
</tr>
<tr>
<td>Prosthesis is heavy</td>
<td>Find a lightweight model</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>Use other arm</td>
</tr>
<tr>
<td>Blood draw or shots</td>
<td>Use other arm</td>
</tr>
</tbody>
</table>
Appendix V

Advertisement for Occupational Therapist

**Occupational Therapist**

The Victory Center in Toledo, OH seeks part-time, PRN, occupational therapist for administering cancer survivorship programming in lymphedema.

Licensed in Ohio. Experienced with lymphedema and or oncology preferred.

For more information
Contact Penny McCloskey, Program Manager
(419) 531-7600

Or visit:
www.TheVictoryCenter.org
Appendix W

Funding Application Information

1. Susan G. Komen for the Cure Northwest Ohio Community Grants
   1a. Susan G. Komen for the Cure Northwest Ohio Small Grants

2. Savage & Associates Charitable Donation

3. Toledo Community Foundation, Inc., Community Grants

   Process for Application: First Source

   1. Susan G. Komen for the Cure Northwest Ohio Community Grants
      1a. Susan G. Komen for the Cure Northwest Ohio Small Grants

Either of these two grants would be an option. The application announcement for the Community Grant is available in April 2012 and the Community Grant application is available June/July 2012. Based on the anticipated budget, the Small Grant may be most appropriate.

Address and Contact Information

   Northwest Ohio Affiliate, Susan G. Komen for the Cure
   Attn: Small Grants
   3100 Central Avenue, Suite 235
   Toledo, OH  43606

Amount of Dollars Awarded

   $10,000 per calendar year for a non-profit organization for Small Grant

Due Dates

   January 15
   May 15
   September 15

Complete Application Process
The grant must be for one or more of the 23 Northwest Ohio counties and must be specific for breast health and/or breast cancer. Applicant must be a non-profit. Allowable expenses include:

- Salaries and fringe benefits
- Clinical services or patient care costs
- Educational materials
- Supplies
- Travel
- Other direct program expenses
- Equipment for educational purposes
- (Does not include medical equipment)

Small Grant categories include three areas: educational grants, travel grants, and conference grants. The purpose of the educational grant is to support awareness of breast cancer and effective breast health programs.

Application process for an educational grant includes completing an application to include:

- Cover Page
  - Includes contact information and signatures.
- Proposal narrative (not to exceed 4 double spaced pages)
  - Includes:
    - Description of organization
    - Statement of need/problem to be addressed
    - Description of target population
    - Project goals and objectives
    - Timeline
    - Program marketing/promotion plan
    - Evaluation plan
    - Collaborating partners

- Budget
  - Outline both request amount from Komen and amounts provided from other funding sources.
    - Personnel (can not exceed 10% of program)
    - Supplies
    - Equipment (can not exceed 205 of program costs)
    - Travel
    - Patient Care Costs
    - Other expenses
- Budget narrative
  - A brief explanation of how funds are intended to be used.
- Proof of non-profit status

**Review Process**

Susan G. Komen for the Cure Northwest Ohio reviews small grants three times a year. Notification will be made within 30 days and made in the form of a written letter.

**Process for Application: Second Source**

**Address and Contact Information**

Savage & Associates  
4427 Talmage Road  
P.O. Box 8526  
Toledo, OH 43623

**Amount of Dollars Awarded**

Not specified. The committee will look at an annualized giving plan to fairly and evenly distribute funds.

**Due Dates**

By the last day of the month. To be reviewed each month (mid-month) by a committee.

**Complete Application Process**

There is a request form to be completed. It is fairly basic and includes the project title, description and objective. What is significant about this funding source is that it has to be submitted by a Savage & Associate agency employee to the donation committee. In addition, the donation committee expects that the employee presenting the request on behalf of the non-profit organization will also be making a donation. It is also expected that the employee presenting the application to the committee is involved with the not-for profit organization as a
board member, volunteer, or financial contributor. Thus, the charitable donation request form asks about the Savage & Associates employee’s level of involvement with the requesting organization and also asks how much that employee is personally contributing (financially) to the requesting organization.

**Review Process**

The charitable donation requests are reviewed once a month by the committee that is comprised of the two co-presidents, Kelly Savage, Wayne Milewski, and Jerri Ryan.

**Process for Application: Third Source**

**Address and Contact Information**

Sarah Harrison, Senior Program Officer  
Toledo Community Foundation, Inc.  
300 Madison Avenue, Suite 1300  
Toledo, OH 43604  
419-241-5049  
sarah@toledocf.org

**Amount of Dollars Awarded**

Amount not specified

**Due Dates**

- January 15
- May 15
- September 1

**Complete Application Process**

Applications are submitted online at [www.toledocf.org](http://www.toledocf.org)

Proposals must include and address:

- **Purpose and Need** (750 word limit)
  - Including: goals, objectives, identification of need, population
- **Implementation** (250 word limit)
  - Including: plans, timeframe, supervising individual, their qualifications
- **Evaluation** (250 word limit)
Criteria and procedure for evaluating success as related to the goals and objectives

- Future Support (250 word limit)
  - Plan for securing ongoing support for program including other potential sources of funding

- Project Budget Information
  - One page projected budget
  - Include income, expenses, all sources of income

**Review Process**

Applications are reviewed by the Foundation’s professional staff and Board of Trustees. Decisions are made within 3 ½ months after the submission deadline. Applicants are notified in writing within one week of a decision being made. Any expense incurred prior to receiving an award notification cannot be paid for by the Foundation.
Appendix X

Letter of Support

The Victory Center
5532 West Central Avenue, Suite B
Toledo, OH  43615

Northwest Ohio Affiliate, Susan G. Komen for the Cure
Attn: Small Grants
3100 Central Avenue, Suite 235
Toledo, OH  43606

Dear Granting Committee:

Since 1996, The Victory Center has been providing individual and group services to cancer patients and their families who live in northwest Ohio and southeast Michigan.

Traditionally the primary focus of The Victory Center is to meet the physical and emotional needs of those in active cancer treatment. According to a report released by the Centers for Disease Control and Prevention and the National Cancer Institute, in 2007 there were 11.7 million cancer survivors – up from 9.8 million cancer survivors in 2001. With the increase in survivorship, there has been a call for survivorship care. The Victory Center wants to play a greater role in that care of cancer survivors.

Breast cancer survivors make-up the largest group of cancer survivors. Likewise, half of all participants served by The Victory Center are women who have a breast cancer diagnosis. We believe that Survivorship Care and Lymphedema Education programming is a great first step in creating a survivorship program at The Victory Center. About 30% of women who attend The Victory Center have experienced symptoms of breast cancer-related lymphedema. Likewise, women who attend our breast cancer support group have expressed unanimous interest in learning more about lymphedema education and prevention.

We have worked for over a year in partnership with Mary Pollock, a doctoral student from the University of Toledo Occupational Therapy Program to create a holistic, occupational therapy approach to lymphedema education. This programming has been developed based on evidence based research with a focus of increasing women’s quality of life. We strongly support this survivorship care programming and will provide many in-kind donations to make this programming a reality.

Based on the other lymphedema education programs supported by Komen for the Cure, we hope that you will also see the importance of this survivorship care and lymphedema education program by supporting our grant application. Thank you for you time in your thoughtful consideration.

Sincerely,   Penny McCloskey, MEd
Appendix Y

Additional Resources for Letters of Support

1. Dr. Anita Leininger, M.D.
   Assistant Professor
   Surgical Director, Center for Breast Care
   The University of Toledo Medical Center
   3000 Arlington Avenue
   Mail Stop 1197
   Toledo, OH 43614

   Dr. Leininger supports the use of occupational therapy for the prevention of lymphedema for her patients. She sits on the UTMC Cancer Committee and is a strong advocate for breast cancer education in the community.

2. Dr. Iman Mohamed, M.D., FACP, MRCP (UK), MPH
   Associate Professor
   Medical Director for the Comprehensive Breast Center
   The University of Toledo Medical Center
   3000 Arlington Avenue
   Mail Stop 1186
   Toledo, OH 43614

   Dr. Mohamed has a large practice of which about 90% are breast cancer patients. She is well educated on the effects of lymphedema and would provide a very educated letter of support for a preventative program that addresses survivorship care and lymphedema.

3. Kelly Farley, BS, OTR/L, MLDT/C
   The University of Toledo Medical Center
   3000 Arlington Avenue
   Toledo, OH 43614

   Mrs. Farley is a trained therapist in the treatment of lymphedema. She has first-hand experience with this population and could provide personal examples that would make the need for preventative programming vivid and real.

4. Amy Huntsman, BS, OTR/L, CLT
   Total Rehab at Flower Hospital
   5150 Harroun Road
   Sylvania, OH 43560

   Mrs. Huntsman is a trained therapist in the treatment of lymphedema. She has extensive experience treating lymphedema. Her first-hand experience with this population can provide personal examples that would make the need for preventative programming vivid and real.
Capstone Annotations

Mary R. Pollock

Faculty Mentor: Beth Ann Hatkevich, PhD., OTR/L

Department of Rehabilitation Sciences

Occupational Therapy Doctorate Program

The University of Toledo

May 2012
Demographics


Abstract

This secondary data analysis was designed to explore the age differences in lymphedema (LE) occurrence and self-reported symptoms in post-breast cancer LE. A descriptive-exploratory cross-sectional design was used with a convenience sample composed of 102 women treated and followed for breast cancer at a Midwestern cancer center. Sequential circumferential arm measurement was used to estimate limb volume differences. Self-reported symptoms were assessed by the Lymphedema and Breast Cancer Questionnaire (LBCQ) designed and tested by the research team. Lymphedema occurrence was relatively higher (41.2%) in breast cancer survivors younger than 60 than in those older than 60 (30.6%). Six subjectively reported symptoms were found to occur more often (P <= .05) in the younger women with LE: numbness now and in the past year, tenderness in the past year, aching now and in the past year, increased temperature in arm now. Numbness, tenderness, and aching were the most prevalent symptoms among women in both age groups regardless of LE presence. Our findings suggest that younger breast cancer survivors may have increased LE risk and report LE-related symptoms more often. Future research should focus on age differences in LE risk, occurrence, and perceptions of LE-related symptoms in women treated for breast cancer.

Summary and Significance

This research found an increased incidence of BCRL in women younger than 60. Because younger women have an increased risk for BCRL providing them with information to manage their risk could be helpful. Symptoms reported to occur more frequently in the younger women with lymphedema include numbness, tenderness, and aching. Although these same symptoms were also present among both groups. What is also significant about the symptoms noted in this research is that other research has found that these symptoms may be an indication of lymphedema in the sub-clinical state. In other words having these symptoms may indicate a need for increased risk and monitoring of that risk by the individual.


Abstract

Background: Secondary lymphedema is a debilitating, chronic, progressive condition that commonly occurs after the treatment of breast cancer. The purpose of the current study was to perform a systematic review and meta-analysis of the oncology-related literature excluding breast cancer to derive estimates of lymphedema incidence and to identify potential risk factors among various malignancies.

Methods: The authors systematically reviewed 3 major medical indices (MEDLINE, Cochrane Library databases, and Scopus) to identify studies (1972-2008) that included a prospective assessment of lymphedema after cancer treatment. Studies were categorized according to malignancy, and data included treatment, complications, lymphedema measurement criteria, lymphedema incidence, and follow-up interval. A quality assessment of individual studies was performed using established criteria for systematic reviews. Bayesian meta-analytic techniques were applied to derive summary estimates when sufficient data were available.

Results: A total of 47 studies (7779 cancer survivors) met inclusion criteria: melanoma (n = 15), gynecologic malignancies (n = 22), genitourinary cancers (n = 8), head/neck cancers (n = 1), and sarcomas (n = 1). The overall incidence of lymphedema was 15.5% and varied by malignancy (P < .001): melanoma, 16% (upper extremity, 5%; lower extremity, 28%); gynecologic, 20%; genitourinary, 10%; head/neck, 4%; and sarcoma, 30%. Increased lymphedema risk was also noted for patients undergoing pelvic dissections (22%) and radiation therapy (31%). Objective measurement methods and longer follow-up were both associated with increased lymphedema incidence.

Conclusion: Lymphedema is a common condition affecting cancer survivors with various malignancies. The incidence of lymphedema is related to the type and extent of treatment, anatomic location, heterogeneity of assessment methods, and length of follow-up.

Summary and Significance

This source is significant because it provides current documentation regarding the
incidence of cancer-related lymphedema for non-breast cancers. This study supports expanding the initial idea for my program which was going to just address breast cancer-related lymphedema to addressing all cancer survivors. Lymphedema secondary to cancer related treatment can affect anywhere from 4% to 31% with an average of 15.5% incidence rate. The incidence is related to the type of cancer, location and types of treatment. This research also shows that radiation in addition to node dissection results in an increased rate of lymphedema. Finally the research also points out that length of follow-up impacts the reported rate of cancer-related lymphedema. Longer follow-up resulted in a higher incidence of reported lymphedema providing evidence for that fact that the education program I propose is relevant to all cancer survivors regardless of how long they have been out of treatment.


Abstract

Every year in the United States, breast cancer is diagnosed in more than 200,000 women. Because of the prevalence of breast cancer, treatment-related sequelae are of importance to many survivors of the disease. One such sequela is upper extremity lymphedema, which occurs when fluid accumulates in the interstitial space and causes enlargement and usually a feeling of heaviness in the limb. Axillary surgery contributes considerably to the incidence of lymphedema, with the incidence and severity of swelling related to the number of lymph nodes removed. Lymphedema after standard axillary lymph node dissection can occur in up to approximately 50% of patients. However, the risk of lymphedema is decreased substantially with newer sentinel lymph node sampling procedures. Adjuvant radiotherapy to the breast or lymph nodes increases the risk of lymphedema, which has been reported in 9% to 40% of these patients. Management of lymphedema requires a multidisciplinary approach to minimize the effect on the patient's quality of life. This review presents an overview of the pathophysiology, diagnosis, prevention, and treatment of breast cancer-related lymphedema.
Summary and Significance

This source is important because it provides statistics about the population of women diagnosed with breast cancer as well as the rate of women who develop lymphedema. The article stresses the importance of quality of life, which is an indirect factor I want to address in my program development via increased knowledge about lymphedema and self-efficacy for managing the risk of developing cancer related lymphedema. The article stresses a multidisciplinary approach to minimizing the effects of lymphedema.

Lymphedema Screening and Factors That Contribute to Development


Abstract

Objectives: This study aimed to determine the accuracy of using self-reported signs and symptoms to identify the presence of lymphedema as well as the usefulness of identifying clinically measurable lymphedema on the basis of certain symptoms elicited by the Lymphedema Breast Cancer Questionnaire (LBCQ).

Methods: This analysis used logistic regression to identify symptoms predictive of differences between symptom experiences of participants belonging to two distinct groups (study A): those with known post-breast cancer lymphedema (n = 40) and those in a control group of women with no history of breast cancer or lymphedema (n = 40). Symptoms in this model of best fit were used to examine their relation to limb circumferences of breast cancer survivors in a second independent data set (study B; n = 103) in which a diagnosis of known lymphedema was not previously determined using
Results: The presence of lymphedema was predicted by three symptoms comprising a model of best fit for study A (c = .952): "heaviness in past year," "swelling now," and "numbness in past year." Using this model, prediction of absolute maximal circumferential limb difference (i.e., \( \geq 2 \) cm) in study B showed that "heaviness in the past year" (\( p = .0279 \)) and "swelling now" (\( p = .0007 \)) were predictive. "Numbness in the past year" was not predictive. However, those with lesser limb differences reported this symptom more often.

Conclusions: The findings suggest that changes in sensations may be indicators of early lymphedema or other treatment-related sequelae that must be assessed carefully at each follow-up visit and over time. A combination of symptom assessment and limb volume measurement may provide the best clinical assessment data for identifying changes associated with post-breast cancer lymphedema.

Summary and Significance

This research found that two symptoms including “heaviness in the past year” and “swelling now” were predictive of lymphedema. The research suggests that educational programming for monitoring the onset of cancer-related lymphedema should include not just regularly measuring to monitor for circumferential limb difference but that sensation changes should also be taken into account. This is an excellent source. The author is actively engaged in extensive cancer-related lymphedema research. She has developed a BCRL questionnaire that is a useful assessment tool for the program.


Abstract

We examined factors that may influence the development of arm lymphedema following breast cancer treatment including the specific mode of therapy, patient occupation and life style. Medical record data and a questionnaire were used to collect
information after surgery concerning such issues as wound seroma, infection, adjuvant treatment, vessel string (phlebitis), body mass index, smoking habits and stress. Occupational workload was assessed after surgery whereas housework, exercise, hobbies and body weight were assessed both before and after surgery. Seventy-one breast cancer treated women with arm lymphedema lasting more than 6 months but less than 2 years were matched to women similarly treated for breast cancer but without arm lymphedema (controls). The matching factors included axillary node status, time after axillary dissection, and age. In the lymphedema group, there was a higher body mass index at time of surgery (p=0.03) as well at time of study (p=0.04). No differences were found in occupational workload (n=38) or housework, but the lymphedema group reduced their spare time activities including exercise after surgery compared with the controls (p<0.01). In conclusion, women treated for breast cancer with axillary node dissection with or without adjuvant radiotherapy could maintain their level of physical activity and occupational workload after treatment without an added risk of developing arm lymphedema. On the other hand, a higher BMI before and after operation increases the lymphedema risk.

Summary and Significance

This article shows that even though women can engage in a normal occupational workload including housework without an increased risk for lymphedema, these women were self-limiting their engagement. Thus, one role of my proposed program development plan is to encourage women at risk for breast cancer related lymphedema to engage in occupations. Allowing women to understand their habits including how they use or avoid their arm would play a part in the program development to encourage occupational engagement. There is a need for more research that is evidence based in terms of risk-reduction behaviors. Survivors should be informed with research-based information about what is safe and what could be risky for developing lymphedema. In short, this program should be committed to providing information from the most reliable sources!

Lymphedema is a common and troublesome problem that can develop following breast cancer treatment. As with other quality-of-life and nonlethal conditions, it receives less research funding and attention than do many other areas of study. In 1998, an invited workshop sponsored by the American Cancer Society reviewed and evaluated the current state of knowledge about lymphedema. Recommendations and research initiatives proposed by the 60 international participants are presented in the conclusion section of the article, following a summary of current knowledge of the anatomy, physiology, detection, and current treatment of lymphedema.

The etiology of lymphedema is multifaceted; all of the factors that contribute to the condition and the nature of their interaction have not yet been identified. To compound the problem, methods of assessing the degree of arm and hand swelling vary and are not agreed upon, and reliable methods of assessing the functional impact of lymphedema have not yet been developed. In the absence of a cure for lymphedema, precautions and prevention are emphasized. Current treatments include elevation, elastic garments, pneumatic compression pumps, and complete decongestive therapy; surgical and medical techniques remain controversial.

Elements and details of these treatments are described. Approximately 15% to 20% of breast cancer patients develop lymphedema following breast cancer treatment. This means that of perhaps two million US breast cancer survivors, after lymphadenectomy, approximately 400,000 cope on a daily basis with the disfigurement, discomfort, and disability associated with arm and hand swelling. Lymphedema is among the most dreaded sequelae of breast cancer treatment.

Summary and Significance

In 1998, this workshop sponsored by the American Cancer Society reviewed and evaluated the current state of knowledge about lymphedema. Recommendations and research initiatives proposed by the 60 international participants were presented in *CA-A Cancer Journal for Clinicians*. The workgroup had many recommendations. Significant to this needs assessment are some of recommendations put forth that include:

All patients treated for breast cancer should be assessed for signs and symptoms of lymphedema at an early interval following completion of healing from breast cancer therapy (within the first 12 weeks). Clinicians should pay attention to physical signs of lymphedema as well as to the patient’s subjective awareness of symptoms, as the latter may reveal early signs of an underlying pathology (Petrek, Pressman, & Smith, 2000, p. 304).

This source also expresses the fact that since there is no cure for lymphedema, prevention and precautions are necessary. Finally, this source also cites that currently 400,000 women...
may be affected by lymphedema. What is great about this source that the ACS really addressed the state of knowledge about lymphedema in their workgroups. There are numerous reports and recommendations. These efforts have helped to increase awareness and are a source of advocacy for survivors and those who treat them.


Abstract

Background: Upper extremity (UE) use has been related to breast cancer-related lymphedema (BCRL). Our aim was to evaluate severity of BCRL in different occupation groups, according to upper extremity use.

Methods: Fifty-five women with BCRL were recruited. Group-1 (n = 21), with a mean age of 59, included patients who worked continuously <30 min at a time and ≤8 h per day. Group-2 (n = 15), with a mean age of 54, were patients who worked continuously between 30 to 60 min at a time, and ≤8 h per day. Group-3 (n = 19), who had a mean age of 51, included patients who were working continuously for >1 h and >8 h per day.

Results: The age, operation type, infection occurrence, radiotherapy status, and the operation on the side of the dominant hand were not statistically different between the groups. The stage and grade of the BCRL in group-3 were higher than the other groups (both p < 0.001). The restriction of shoulder movements on the operation side (p = 0.04) and shoulder physiotherapy need (p < 0.001) were the highest in group-3. Arm pain (p = 0.004) and pain medicine needs (p = 0.028) in group-1 were lower than the other groups.

Conclusion: Group-3 had the worst BCRL clinical stage and grade status and other breast cancer treatment related morbidities. Occupations that require greater use of the upper extremities.

At present there is a need for closer monitoring of patients with more severe BCRL. Potential exacerbating and maintaining factors of functional limitations and pain need to considered so that clinical management addresses these in relation to daily use of the affected UE.

Summary and Significance

This article supports the need for monitoring as well as considerations for treatment that accounts for management of occupations of daily living. Again this information will help drive the program development in terms of assessing women’s roles and work habits.
Changes to the occupational forms the women engage in may need to be considered as part of the program development. This article also addresses the need for closer monitoring of and by those with more severe lymphedema. Again the push is to educate survivors so that they can seek immediate treatment should symptoms develop. The goal is to avoid lymphedema developing into the severer stages.


It is estimated that as many as 4 million Americans suffer from primary or secondary lymphedema. According to the American Cancer Society, of the two million breast cancer survivors in the U.S., approximately 400,000 must cope with lymphedema on a daily basis. *100 Questions & Answers About Lymphedema* provides answers to the most common questions from patients and family members about lymphedema, a painful chronic swelling of the extremities, often associated with cancer treatment.

**Summary and Significance**

This is a well written and easy to understand book that answers questions about lymphedema. It would be a very useful resource for The Victory Center to have on hand in their library.


http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/healthprofessional/page1

**Abstract**

No Abstract.

**Summary and Significance**

This is an incredible source of current evidence based information with references to other valuable sources. Based on the information presented in the quote below there
are three main points that are of value to this needs assessment. First, the recommendation has been made for a “survivorship care plan” that would include information about late effects of treatment. The source also points out that lymphedema education is critical due to the high incidence and the resulting impact on functional abilities, mental health, and quality of life.

Lymphedema is one of the most poorly understood, relatively underestimated, and least researched complications of cancer or its treatment. The Institute of Medicine of the National Academies published a report in 2006 recommending a “survivorship care plan” for cancer patients that incorporates information about late effects of treatment, health management behaviors, disease management, and recurrence monitoring. [2] The Institute of Medicine also highlighted critical shortfalls in the transition to survivorship, particularly in providing education about late effects of treatment.

Lymphedema is an important consideration for clinicians who care for cancer patients because of its relatively high frequency and significant functional and quality of life implications for patients. Lymphedema is an independent predictor of decreased quality of life, even when other predictive factors such as socioeconomic status, decreased range of motion, age, and obesity are taken into account. [3]

Breast cancer survivors with arm lymphedema have been found to be more disabled, experience a poorer quality of life, and have more psychological distress than do survivors without lymphedema. [8,9] In addition, women reporting swelling have reported significantly lower quality of life with multiple
functional assessments.

[10](http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/health professional/page1, 2008)

**Impact of Lymphedema on Quality of Life**


**Abstract**

This book will help you: * Understand the emotional challenges of lymphedema * Overcome these challenges and avoid common pitfalls * Recognize problems and know where to go for help * Communicate effectively with family, friends, coworkers, and healthcare professionals * Set and prioritize your goals * Identify where you are in the process of changing * Choose specific actions for reaching your goals * Monitor your progress and maintain your gains * Learn the ten signs of good coping and six warning signs of ineffective coping This comprehensive guide includes sections for people with lymphedema, friends and family, parents of children with lymphedema, healthcare professionals, and psychotherapists. Dr. McMahon is a clinical psychologist with Kaiser Permanente, coauthor of Living Well With Lymphedema, and on the editorial board of LymphNotes.com.

**Summary and Significance**

This book deals specifically with the emotional and psychological aspects of living with lymphedema – a chronic condition. Each section outlines normal emotional reactions as well as worrisome reactions that may require help from a professional. There are a lot of charts and ideas about how to identify feelings and how to set goals to improve one’s emotional response and behaviors as they relate to lymphedema. The book addresses anger, coping, feeling about the physical body, relating to others and more. The book also addresses thinking skills, action skills, and communication skills. The book gives examples of how angry some people are after developing lymphedema when they felt that they were not informed of the risks or realities of cancer-related
lymphedema. This book shows how much of an impact lymphedema can have on a person’s emotional and physical well-being. This is important knowledge realizing that when offering these workshops at TVC the OT may be in a position where they need to refer a participant to someone who can help with the psychological aspects of cancer-related lymphedema.

In the clinic, I noted that for people diagnosed with lymphedema while still completing their initial surgery and treatment for cancer, the development of lymphedema was devastating. These people were drained emotionally and did not have the reserves to take on the increased level of self-care required with lymphedema treatment. Many of them looked dazed and expressed grief. The people who were farther out from diagnosis and treatment were better able to handle the development of lymphedema.


Abstract

Introduction: A Canadian research team is conducting a multi-centered, non-interventional national study with the objective of charting the course of arm morbidity after breast cancer surgery. This paper examined the relationship between arm morbidity and leisure and recreational activities of affected women.

Methods: Five hundred and forty seven women with stage I-III breast cancer were recruited in four centers across Canada: Surrey (BC); Winnipeg (MB), Montreal (QB) and Fredericton (NB). Participants were enrolled in the study 6–12 months post surgery. Physical examination was used to assess arm and shoulder functioning and questionnaires were used to assess disability, pain, and participation in recreational and leisure activities.
Results: At the first clinical assessment (T1), the mean number of months post breast cancer surgery was 8.4. At T1 49% of women reported difficulty with recreational activities that involved “some force or impact” and 29% experienced negative changes to their involvement in leisure activities. A hierarchical multiple regression analysis found that several arm morbidity variables were significant predictors of difficulty with participation in recreational activities. A second hierarchical regression found also that arm morbidity factors were significant predictors of negative changes in leisure activities. Follow-up analyses found that arm morbidity, was most closely related to difficulty with recreational activities requiring free movement of the arm and using force.

Conclusion: Many women treated for breast cancer experience arm morbidity. Arm morbidity is related to difficulties with recreational activities and negative changes in leisure activity participation.

Implications: Breast cancer survivors should engage in recreational and leisure activities that are compatible with reduced range of motion and pain, and avoid those that exacerbate their arm morbidity.

Summary and Significance

This study found that almost 30% of breast cancer survivors at 6-12 months post surgery had problems with arm morbidity including lymphedema, pain and decreased ROM. This morbidity had a negative impact on engagement in recreational and leisure activities. Pain and reduced ROM had the most impact on occupational engagement. This is important because what this research notes is that changes to the arm have a negative impact on a person’s engagement with occupation. Clearly the goal of this program is to reduce the incidence of arm morbidity and to make sure survivors are empowered to manage any morbidity that may develop so that ultimately this group of people continue to be engaged with all levels of occupation.

Abstract

Introduction: Most longitudinal breast cancer studies have found that treatment-related sequelae such as arm morbidity [lymphedema, pain, and range of motion (ROM) restrictions] can have a significant impact on quality of life. In a previous study, we found that at 6–12 months after breast cancer surgery, 49% of participants had difficulties engaging in recreational activities and that arm morbidity significantly predicted difficulties with participation in recreation.

Methods: A longitudinal national study employing clinical assessments and survey methods followed 178 women over 43 months (3.6 years) to assess issues related to arm morbidity post-breast cancer surgery. Hierarchical multiple regression analyses were conducted to identify which variables were predictive of recreational difficulties experienced by women 8 and 43 months post-surgery.

Results: Between 8 months (T1) and 43 months (T2) post-breast cancer surgery, women demonstrated slight increases in lymphedema. Conversely, a significant decrease was observed in the number of ROM restrictions and pain when using the arm. Despite the overall improvements in arm morbidity, some women continued to report moderate pain and ROM restrictions. The two arm morbidity factors were found to be statistically significant (p < 0.001) predictors of recreational difficulties at both 8 and 43 months post-surgery, with pain accounting for the greatest proportion of variance.

Discussion/conclusion: Pain and ROM restrictions were the only significant predictors of recreational difficulties during the first 3.6 years after breast cancer surgery. Specifically, women who still experience pain years after breast cancer surgery report difficulties in their recreational pursuits.

Implications for cancer survivors: Pain and ROM restrictions may prohibit participation in recreational activity and targeted intervention should be sought.

Summary and Significance

This research found that women between 8 and 43 months post surgery for breast cancer had a slight increase in lymphedema. However, in this study lymphedema was not found to be a significant “unique predictor of recreational difficulties.” The research also points out that it is important to be aware that pain and reduced ROM which can be associated with cancer treatment and have a negative impact on engagement in recreational activities. This research also shows that during the first year after treatment the primary concerns are pain and reduced range of motion and that these have a direct
negative impact on engagement in occupations. However, over time this research shows that the pain and reduced range of motion from the first year improves. Over time there was also an increase in the development of lymphedema noted. This article is important because it demonstrated how the needs of people going through treatment change over time. Because this program will be open to all survivors from 3 weeks to 30 years post treatment it will be important to realize that the needs of the group members may be different depending on how long it has been since their treatment. Also, participants could be encouraged to attend other fitness programs including yoga and healthy steps to help address and improve ROM at TVC.


Abstract

This study involves secondary analysis of an existing qualitative data set (in-depth interviews with survivors \[n=6\] and health professionals \[n=2\], observations of a support group \[n=3, and field notes\]. Based on previous findings from this data set, new questions arose regarding why only some of post–breast cancer lymphedema women who were interviewed appeared resilient within the context of their families. In the present study, we reinvestigate this data set using the resiliency model of family stress, adjustment, and adaptation to guide our investigation via the construction of an a priori template used in analyses. Three stressors are identified that contribute to the vulnerability of these women. Resiliency in the women is characterized as adjustment, adaptation, or crisis. The present findings provide a foundation for assisting women with lymphedema and their families and underscore practitioners’ need to serve the patient and the family.

Summary and Significance

This article underscores the psychosocial impact that breast cancer related lymphedema could have not only on the women affected but also on her family. This research can contribute to the assessment of roles by the women as part of the program
development. During my time in the clinic it was very apparent that lymphedema does not just affect the person with the lymphedema. For treatment to be successful there needs to be support of family or friends. Family members become the first source for assisting with massage bandaging at home. The skills needed to manage the massage and bandaging can be complicated and intimidating. Likewise, perhaps there is a place for adding a family member support group to the program in the future.


Abstract

Objectives: The aim of this study was to compare quality of life and symptoms between breast cancer survivors who have developed and undergone treatment for chronic lymphedema with those who have not developed lymphedema.

Patients and methods: The cross-sectional, mixed-methods design included 64 breast cancer survivors with lymphedema and 64 breast cancer survivors without lymphedema. Variables assessed quantitatively included sociodemographic information, medical data, body mass index (BMI), arm extracellular fluid volume, quality of life (QOL), and physical and emotional symptoms. For the qualitative component, individuals with lymphedema responded in writing to the question: During the past week what other difficulties have you experienced because of your lymphedema?

Results: Compared with those without lymphedema, breast cancer survivors with lymphedema reported poorer QOL. A symptom cluster that included alteration in limb sensation, loss of confidence in body, decreased physical activity, fatigue, and psychological distress was identified. Perception of limb size influenced the cumulative symptom experience more than objective arm volume. Qualitative data revealed multiple QOL, physical health, and psychological concerns. BMI correlated with multiple outcomes.

Conclusions: Findings suggest that current lymphedema treatments, although beneficial, may not provide complete relief of symptoms associated with lymphedema and complementary interventions are needed. The poorer QOL in breast cancer survivors with lymphedema may relate to the presence of an untreated symptom cluster.

Summary and Significance
This article points out the relationship between BMI and lymphedema thus suggesting the need to promote healthy eating and exercise as a strategy for preventing and managing cancer-related lymphedema. She noted in the discussion that women with BCRL tend to become less physically active. So programming could encourage taking advantage of other exercise and fitness programs at The Victory Center. In addition, this research further validated previous research, which has found that lymphedema has a negative impact on a person’s quality of life. This research also noted that current treatment does not relieve all of the lymphedema symptoms. Many of the concerns noted here were psychosocial. Programming could be expanded to included the use of the Lifestyle Redesign model of practice to more formally address how to integrate living with lymphedema into the survivor’s life. The drawback to this is time and cost. Nevertheless, clearly psychosocial concerns should be anticipated and addressed during programming. Finally, one of the untreated symptoms that were shown to be of concern is fatigue, which can be addressed in the program through energy conservation techniques.


Abstract

Purpose: This study estimated the economic burden of breast cancer–related lymphedema (BCRL) among working-age women, the incidence of lymphedema, and associated risk factors.

Methods: We used claims data to study an incident cohort of breast cancer patients for the 2 years after the initiation of cancer treatment. A logistic regression model was
used to ascertain factors associated with lymphedema. We compared the medical costs and rate of infections likely associated with lymphedema between a woman with BCRL and a matched control. We performed nonparametric bootstrapping to compare the unadjusted cost differences and estimated the adjusted cost differences in regression analysis.

Results: Approximately 10% of the 1,877 patients had claims indicating treatment of lymphedema. Predictors included treatment with full axillary node dissection (odds ratio [OR] = 6.3, P = .001) and chemotherapy (OR = 1.6, P = .01). A geographic variation was observed; women who resided in the West were more likely to have lymphedema claims than those in the Northeast (OR = 2.05, P = .01). The matched cohort analysis demonstrated that the BCRL group had significantly higher medical costs ($14,877 to $23,167) and was twice as likely to have lymphangitis or cellulitis (OR = 2.02, P = .009). Outpatient care, especially mental health services, diagnostic imaging, and visits with moderate or high complexity, accounted for the majority of the difference.

Conclusion: Although the use of claims data may underestimate the true incidence of lymphedema, women with BCRL had a greater risk of infections and incurred higher medical costs. The substantial costs documented here suggest that further efforts should be made to elucidate reduction and prevention strategies for BCRL.

Summary and Significance

This source shows that there is a real financial burden associated with the development of breast cancer related lymphedema (BCRL) with medical costs of ($14,877 to $23,167) as compared to a matched control group. Also, the women with BCRL were twice as likely to have lymphangitis or cellulitis as compared to their matched controls. What is significant is that programming at The Victory Center is all provided for free to participants who qualify for services. Given the financial burden of developing lymphedema, there is a real role for OT to educate women at risk for developing BCRL. In addition, a program at TVC for BCRL would allow women without insurance to access services of an occupational therapist.

Abstract

Background and Objectives: This pilot project assessed the acceptability of a mixed-type, moderate-intensity exercise programme following breast cancer treatment, and the impact on presence of lymphoedema, fitness, body composition, fatigue, mood and quality of life.

Methods: Ten women completed the programme and measures of fitness (sub-maximal ergometer test), body composition (bio-electrical impedance), lymphoedema (bio-electrical impedance and arm circumferences), fatigue (revised Piper Fatigue Scale), mood (Hospital Anxiety and Depression Scale), quality of life (FACT-B) and general well-being, at baseline, completion of the programme, and 6-week and 3-month follow-up.

Results: Participation in the programme caused no adverse effect on the presence of lymphoedema. There was a trend towards reduction in fatigue and improved quality of life across the testing phases. Women rated the programme extremely favorably, citing benefits of the support of other women, trained guidance, and the opportunity to experience different types of exercise.

Conclusions: A mixed-type, moderate-intensity exercise program in a group format is acceptable to women following breast cancer treatment, with the potential to reduce fatigue and improve quality of life, without exacerbating or precipitating lymphoedema. This pilot work needs to be confirmed in larger randomised studies.

Summary and Significance

It was not until 1996 that research began to challenge the notion that exercise and use of the affected arm was a risk factor for the development of breast cancer related lymphedema. This source shows that engaging in a group exercise program did not exacerbate or precipitate the development of lymphedema. Also, this article shows support for organizing my program development plan in a group format. In this study women appreciated the support of the other women.

Current Research Related to Lymphedema


Abstract
No abstract

Summary and Significance

This article describes prevailing recommendations that were based on avoidance rather than rehabilitation of the affected arm -- recommendations not challenged until 1996.

Three widely disseminated recommendations cautioned against vigorous, repetitive arm movements (“[do not engage in] scrubbing, pushing, pulling, and hammering”), heavy lifting (“never carry heavy handbags and grocery bags…[and] do not lift more than 15 pounds”), and resistance training exercises that ‘overtire an arm at risk.’ Though the recommendations advocated exercise, suggested activities were limited to walking, swimming, light aerobics, bike riding, and ‘specially designed ballet or yoga’ (Denmark-Wahnefried, 2009, p. 710).

This details the impact that the risk for breast cancer related lymphedema has had on occupations of daily living for affected women. Furthermore, not all these recommendations are supported by evidence-based research. There is a role for occupational therapy to encourage engagement in occupations rather than avoidance.

What is also very important about this article is that it outlines some of the recommendations that have been and are still being made to women that are not based on evidence. The recommendations limit occupational engagement. I am curious to know if use or infection plays a greater role in the onset of lymphedema.

Abstract
Breast cancer-related lymphoedema (BCRL) is a debilitating, distressing condition affecting approximately one in five breast cancer survivors (Clark B, Sitzia J, Harlow W. Incidence and risk of arm oedema following treatment for breast cancer: a three-year follow-up study. QJM 2005;98:343-8). The evidence-base for breast cancer-related lymphoedema risk reduction advice is scant and contradictory, with most studies in the area limited by small numbers, retrospective design and other methodological inadequacies. Current advice has the capacity to profoundly alter quality of life following treatment for breast cancer. Health professionals should review the risk reduction advice they provide to reflect the current understanding of aetiology and risk factors. Further research is required to provide more evidence for the content, to identify optimal methods of precautionary education delivery and to determine the effect of the advice on the patient's quality of life and perception of recovery.

Summary and Significance
This research echoes what has been seen in other research that advice people are given regarding lymphedema treatment and precautions is not always evidence-based. As I develop this program I need to be should consider sources of information for reliability and validity. Likewise, as the program continues it is important for the therapist in charge of the program to be informed of up-to-date research regarding risk reduction behaviors.

Lymphedema and Patient Education
DOI: 10.1016/j.pec.2007.01.004.

Abstract
Objective: Assessment and adequate treatment of lymphedema is required by the European Society of Mastology.
For the purpose of our study was the evaluation of self-reported incidences of lymphedema in breast cancer survivors and the effect of providing the patients with information about lymphedema on the extent to which lymph-drainage massage services and compression garments were used.

Methods: A total of 742 breast cancer survivors were analyzed in this questionnaire-based survey. The associations between lymphedema and the patients’ medical history; morbidity located in the breast, axilla, and arm; the amount of information the patients had received concerning lymphedema; and the extent to which lymph-drainage massage services and compression garments were analyzed.

Results: 31.67% of the patients stated to have lymphedema. Radiotherapy was identified as a significant risk factor. Pain, paresthesia, and functional limitations were associated with the occurrence of lymphedema. The only independent positive predictive factor found to be associated with the use of lymph-drainage massage services (OR 5.74) was the provision of information about the condition.

Conclusions: Self-reported assessment of lymphedema is feasible. The observed lymphedema incidence of approximately 30% may be able to serve as a basis for benchmarking in quality-assurance procedures at breast centers.

Practice implications: Control mechanisms are required to assess if the indication for lymph drainage is adequate and the compliance to this subject is sufficient.

Summary and Significance

This article confirms functional limitations that can occur with lymphedema. The article also verifies the need for women at risk for breast cancer-related lymphedema to receive education about occupational therapy services of manual drainage lymphatic massage.


Abstract

Lymphedema is the treatment-induced buildup of extra lymph fluid in tissues that causes discomorting and potentially debilitating swelling of the limbs. In an abstract presented at the 36th Annual Oncology Nursing Society Congress in Boston,
Massachusetts, researchers from the American Lymphedema Framework Project (ALFP) presented their analysis, “What Oncology Nurses May Not Know About Cancer-Related Lymphedema.”

Lymphedema is most frequently associated with breast cancer, which ALFP Director Jane M. Armer, RN, PhD, School of Nursing, University of Missouri, Columbia, suggested may simply be due to the disproportionate amount of breast cancer data available. Non-breast cancers associated with lymphedema include genitourinary and head and neck cancers, as well as melanoma.

The ALFP research sought to establish a baseline of knowledge about lymphedema treatment to address a general lack of awareness about managing the condition. Lymphedema is primarily treated by trained therapists, so the ALFP decided to conduct a survey of these experts.

The survey was completed by 419 lymphedema therapists from 46 states. Physical therapists comprised the largest number of respondents and nurses made up the smallest number.

The survey found that the majority of lymphedema patients are being treated in hospital outpatient clinics. A breakdown of anatomical treatment sites included the upper extremities (59%), lower extremities (30%), trunk (16%), head and neck (6%), and genitals (4%).

The survey revealed that comprehensive decongestive therapy (CDT) is the gold standard of primary treatment for lymphedema. Used by 97% of therapists, CDT involves, “Manual lymphatic drainage, compression bandaging, compression garments, self-care teaching about risk reduction and skin care, and a program of exercise,” said Armer. Sixty-eight percent of therapists also reported using soft tissue mobilization, which Armer said is an “advanced technique.”

Armer said the ALFP survey revealed an opportunity for oncology nurses to specialize in lymphedema therapy. She stressed 2 important roles for oncology nurses. The first is patient education on risk reduction and self-care. The other is taking the advanced training and becoming a nurse lymphedema therapist. The recommended training for lymphedema therapists includes 135 hours of classroom and online training.

Regarding the future plans for the ALFP, Armer said they intend to repeat the survey to see what has changed in the field since the initial survey was conducted 2 years ago. This time, the ALFP hopes to survey lymphedema therapists who have “an even broader training background than those that we reached in the first survey,” Armer said.

Summary and Significance

This abstract was significant for a few reasons. First it showed the prevalence of
those being treated: “A breakdown of anatomical treatment sites included the upper extremities (59%), lower extremities (30%), trunk (16%), head and neck (6%), and genitals (4%).” This is important to have a general idea of the percentage breakdown for those receiving treatment for lymphedema. The abstract again emphasizes the need for patient education on risk-reduction and self care. Also of note is that nowhere is OT mentioned. Physical therapists are mentioned as treating therapists but the article failed to mention that occupational therapists are also lymphedema therapists. Lymphedema therapists can be either PTs or OTs or even oncology nurses as this abstract advocates. In short, lymphedema therapy is another practice area without clear practice boundaries and potentially up for grabs. In NW Ohio most lymphedema therapists are OTs while towards Columbus area most are PTs. There is a real need for occupational therapists to take a larger role in advocacy by being better trained (not all treating OTs have certification in lymphedema) more active with research, actively educating other medical professionals and taking roles of leadership with organizations such as The National Lymphedema Network.


**Abstract**

Purpose: To explore the effect of providing lymphedema information on breast cancer survivors' symptoms and practice of risk-reduction behaviors.

Design: A cross-sectional design was used to obtain data from 136 breast-cancer survivors in New York City from August 2006 to May 2007. Descriptive statistics, t tests, chi-square tests, and correlations were calculated.

Methods: Data were collected using a demographic and medical information interview tool, two questions regarding status of receiving lymphedema information, the
Lymphedema and Breast Cancer Questionnaire, and Lymphedema Risk-Reduction Behavior Checklist.

Findings: Fifty-seven percent of the participants reported that they received lymphedema information. On average, participants had three lymphedema-related symptoms. Only 18% of participants were free of symptoms. Participants who received information reported significantly fewer symptoms ($t=3.03; p<0.00$) and practicing more risk-reduction behaviors ($t=2.42; p=0.01$).

Conclusion: Providing lymphedema information has an effect on symptom reduction and more risk-reduction behaviors being practiced among breast cancer survivors.

Clinical Relevance: In clinical practice, nurses and other healthcare professionals could consider taking the initiative to provide adequate and accurate information and engage breast-cancer survivors in supportive dialogues concerning lymphedema risk-reduction.

Summary and Significance

The article has a great overview of the issues of concern associated with lymphedema. The article lists the physical symptoms and functional limitations resulting from lymphedema. The article is a real advocate for patient education to prevent lymphedema. The study found that women who reported receiving information about lymphedema reported significantly fewer symptoms of lymphedema. “Accordingly, 41% of participants who did not receive information could be diagnosed with State I of lymphedema and 27% with latent stage, while only 19% of those who received information could be diagnosed with Stage I lymphedema and 10% with latent stage.”

Also the research dispels the myth that women who only have a SLNB are not at risk for lymphedema. The group of women who have only a SLNB are not receiving education about lymphedema, but are still at risk. In short, this study found that women who received education reported practicing significantly more risk-reduction behaviors.

Finally, two useful tools to use for my program include the Lymphedema and Breast
Cancer Questionnaire and Lymphedema Risk-Reduction Behavior Checklist, which were used in this research. The Lymphedema and Breast Cancer Questionnaire is available by contacting the author – which I will do. The Lymphedema Risk-Reduction Behavior Checklist is provided in this article.

Supportive Care in Cancer, 19(5), 631-637. doi: 10.1007/s00520-010-0870-5

Abstract

Purpose: The primary purpose of this study was to cross-sectionally examine breast cancer treatment-related lymphedema self-care education, self-care practices, and perceived self-care barriers, burdens, and benefits. We also explored the associations among self-care education, practices, symptoms, and quality of life (QOL) in breast cancer survivors with known lymphedema.

Methods: A cross-sectional design was used to obtain data about lymphedema self-care education, self-care practices, perceived self-care barriers, burdens, and benefits, symptoms, and QOL. Frequency distributions and Spearman rank-order correlations were used to analyze quantitative data. Thematic qualitative analysis of perceived barriers, benefits, and burdens of self-care was also undertaken.

Results: Surveys were completed and returned by 51 of 58 eligible individuals. Of the 51 responding, 48 had received some self-care education, but three did not think it was adequate. Wearing a compression garment was the most frequently cited self-care activity, and 18 of the 51 required help with self-care. Thirty-three percent, 17/51, spent 15 minutes or less per day on self-care. Multiple barriers to self-care were identified. Those with more symptoms spent more time on self-care activities and had a poorer QOL.

Conclusions: Opportunities exist to improve lymphedema self-care education. Breast cancer survivors with lymphedema experience symptoms beyond that of simple
swelling of the affected limb. Self-care is burdensome. Barriers to providing lymphedema self-care exist and may vary across patients. A multidisciplinary approach to lymphedema management, including self-care education and monitoring, is likely needed to improve QOL in this population.

Summary and Significance

This research notes that participants are not spending a lot of time on self-care related to their lymphedema. The study notes that while most people received lymphedema education during treatment a significant portion felt the information to be inadequate. The author suggests on-going lymphedema self-care education and risk reduction should be multi-disciplinary and provided by nurses, therapists, physicians, and social workers. This further validates what was found during my needs assessment that information provided to women is inconsistent. Likewise this study validates that lymphedema management is a self-care occupation and the higher the degree of self-care management required the lower the quality of life. This research supports the development of a component of the program at The Victory Center to help support women increase their knowledge for managing their breast cancer-related lymphedema.


Abstract

Objective: In 1998, the American Cancer Society (ACS) Lymphedema Workshop, called for a three phase approach to patient lymphedema education: (1) pretreatment, (2) postoperatively, and (3) continuing education. The objectives of this study were: to compare recalled pretreatment lymphedema education before and after the 1998 ACS call; compare recalled lymphedema pretreatment education between women with and without breast cancer treatment-related lymphedema; and identify breast cancer survivors perceived sources of lymphedema education.
Methods: One hundred and forty-nine breast cancer survivors (74 with lymphedema and 75 without lymphedema) were asked: (1) Prior to having breast cancer treatment did anyone talk to you about your risk for lymphedema? If yes, who? (2) Prior to having breast cancer treatment did anyone talk to you about ways to decrease your risk for lymphedema? If yes, who? (3) If you want to learn more about lymphedema occurring after breast cancer treatment who would you ask or where would you look for information?

Results: Individuals with lymphedema consistently recalled receiving less education and a decline in recalled risk reduction education in the lymphedema group occurred after 1998.

Discussion: Barriers exist to the integration of ACS suggested pretreatment lymphedema educational protocols and risk reduction education may influence risk of developing lymphedema.

Conclusion: Pretreatment lymphedema education may improve breast cancer survivor’s recall of educational information received about lymphedema.

Practice implications: Healthcare providers must be well versed about breast cancer treatment-related lymphedema and communicate this knowledge to patients on a consistent basis.

Summary and Significance

Ridner explains that based on self-regulation theory, people’s ability to cope (in this case with cancer-related lymphedema) is dependent on being given information to understand their risk for and management of lymphedema. Knowledge and understanding of lymphedema provides people with the foundation from which to make informed decisions about their healthcare. This knowledge serves to improve coping, decrease levels of stress, and reduce the feelings of abandonment by healthcare professionals, which many women with BCRL report. Women reported that they perceive healthcare professionals to be ill informed about lymphedema. In this study, they found that women after treatment for breast cancer looked to the internet, their oncologists and lymphedema therapists for information about lymphedema. Good internet sources that would be recommended by my program would include American
Cancer Society and National Lymphedema Network for up-to-date and clinically accurate information. This research also advocated for the role of pre-treatment education about lymphedema to increase people’s efficacy for coping and making decisions. This finding would support the program at TVC being open to anyone including those pre-surgery/treatment for cancer.

Lymphedema Treatment


Abstract

Evidence-based exercise and relaxation recommendations for people with breast cancer–related lymphedema (BCRL) are needed. We report a randomized controlled study of one program, designed to achieve synergistic improvements in physical and emotional BCRL symptoms. People in the treatment group received an exercise and relaxation program, The Breast Cancer Recovery Program (N = 16). The control participants (N = 16) continued with health professionals’ recommendations. Participants were tested at entry, 2.5 weeks, 5 weeks, and 3 months. Treatment group participants, compared with control participants, demonstrated significant treatment effects for improved bioimpedance z, arm flexibility, quality of life, mood at 3 months, and weight loss. Adherence was high for this safe and effective program, which improved lymphedema physical and emotional symptoms.

Summary and Significance

This is an occupational therapy program that addresses breast cancer related lymphedema. The article shows that there is good potential for adherence to a program and that quality of life and mood can be improved based on occupational therapy treatment. As mentioned before there needs to be more research and publications by occupational therapists in relation to lymphedema. While OTs treat lymphedema it is the nurses who publish about lymphedema and the physical therapists who get credit for
Models of Practice


Abstract
No Abstract.

Summary and Significance

MOHO is a holistic model that “views a person as an open system, which has the capacity to reorganize itself or be reorganized” (Cole, 2005, p. 263). MOHO identifies three levels of occupational functioning including: exploration, competence, and achievement. There are also three levels of occupational dysfunction including inefficacy, incompetence, and helplessness. (Cole, 2005). MOHO is concerned with occupational adaptation, which is defined as, “Constructing a positive occupational identity and achieving occupational competence over time in the context of one’s environment” (Kielhofner, 2009, p. 169). Given the physical and emotional changes associated with a cancer diagnosis and the ensuing treatment, it is hoped that this programming that focuses on education and self-efficacy will serve to help participants have a positive occupational identity that will in turn improve their quality of life.


Abstract
No Abstract.

**Summary and Significance**

The biomechanical model of practice is concerned with musculoskeletal dysfunction and how this impairs normal occupational performance. Taking measurements of arm circumference would fall under the biomechanical model of practice and is a tool that will be practiced by program participants. Assessment related to manual muscle strength testing and range of motion may be appropriate during an individual screening session with an occupational therapist. Likewise the lymphatic exercises to be performed by the program participants will serve to addresses not only stimulating the lymphatic system but in addition provides the opportunity to improve range of motion. Finally, because lymphedema can be chronic in nature, it is possible that the therapist will have to offer participants compensatory techniques that allow them to perform and engage in occupation despite the lymphedema.

The biomechanical model of practice is important to this program for two other reasons. First, lymphedema in the advanced state can have a negative impact on range of motion, strength, and endurance. The physical limitations that accompany lymphedema in turn place limitations on engagement in occupation. Likewise, the bandaging that is required for treating lymphedema also limits range of motion. Because of the negative impact lymphedema (in the more severe forms) places on engagement with occupation educating people on how to prevent and treat lymphedema is a significant goal. As mentioned in other research proactively managing lymphedema in the earlier states can help to prevent the progression to more severe stages. The other reason this model of practice is significant for this program is because the self-assessment of inspecting the
arms and measuring them on a regular basis would be grounded in the biomechanical model of practice.


Abstract

Significance and Background: Despite advances in treatment, many breast cancer survivors still face permanent disruption of their lymphatic system which predisposes them to the risk for lymphedema. Lymphedema has changed the triumph over breast cancer with distressing and life-changing impacts on survivors’ quality of life. For decades, the salient issue influencing the impact of lymphedema on breast cancer survivors is survivors’ perception of lack of support from healthcare providers.

Purpose: The purpose of this study was to explore the effects of survivors’ perceived healthcare provider support on lymphedema risk reduction in terms of perceived competence, motivation, cognitive, and behavior outcomes.

Conceptual or Clinical Model/Philosophic or Theoretical Framework: Based on the Self-Regulation theory and the Information-Motivation-Behavioral Model, the conceptual framework for the study emphasizes the need for patients to have adequate information to gain understanding of lymphedema risk, make decisions about risk reduction, and implement risk reduction behaviors. The framework proposes that perceived provider support is key to patients’ motivation, competence, cognitive and behavior outcomes.

Methods & Analysis: Data was collected from 133 breast cancer survivors using a Demographic and Medical Information, a Scale for Lymphedema Risk Reduction Competence, and Motivation, a Scale for Perceived Support from Healthcare Providers, a Knowledge Test, and the Lymphedema Risk Reduction Behavior Checklist. Data analysis included descriptive statistics, multiple linear regression models, and assessment of moderation and mediation. Model fit was evaluated through the R2 for the overall model and incremental change in R2.

Findings and Implications: Cognitive outcome was a significant predictor for survivors’ competence, motivation, and behavior outcome. A model was created and evaluated with final model fit indices suggested a good fit to the sample data [X2(3, N=133) = 3.94 (p=.268); CFI = .99; RMSEA=.05 (0 to .16); AIC = 29.94; X2(diff) = .181, p = .913]. This model supports that provider support directly associated with participants' competence and motivation, which are directly related to behavior outcome.
Nurses and other healthcare professionals should take the initiative to provide survivors with accurate lymphedema information to insure survivors’ cognitive outcome. Healthcare providers should be trained and encouraged to increase survivors’ perceptions of provider support, in turn, this will help to promote competence and motivation, resulting in a positive impact on behavior outcome.

**Summary and Significance**

This research uses a model of practice theory that is self-regulation theory (Bandura) and information-motivation-behavior model. A good description of the information-motivation-behavior model was found Northeastern University’s website at http://www.northeastern.edu/geriatricsbiger/health_behavior_change/motivation_behavior/ and follows:

The IMB model provides a multi-dimensional approach. The “information” component of the model targets the cognitive domain to provide knowledge to support the behavior change. The “motivation” aspect addresses the affective domain and allows opportunity for developing a favorable attitude towards regular physical activity or other positive health behaviors and capitalizing on existing social support systems to enhance motivation. Identification of barriers and effective strategies to overcome limitations also serve to enhance motivation. The third component, the behavior aspect of the model aligns with the psychomotor domain. Through instruction, repeated demonstrations and practice, older adults acquire the physical skills necessary to maintain the behavior change.

The self-regulation theory (Bandura) and information-motivation-behavior model are not very different from the MOHO model of practice, which will be used for this program development. This research, “emphasizes the need for patients to have adequate information to gain understanding of lymphedema risk, make decisions about risk
reduction, and implement risk reduction behaviors.” By understanding risk people can make decisions and implement behaviors that reduce the risk for cancer-related lymphedema. By providing support through this program to people at risk for cancer-related lymphedema serves to promote competence and motivation or self-efficacy which in turn will promote positive behavioral outcomes for managing lymphedema risk.


**Abstract**

This article describes an innovative preventive occupational therapy intervention for well older adults, the Well Elderly Treatment Program. In a previously reported large-scale randomized effectiveness study, this intervention was found to be highly successful in enhancing the physical and mental health, occupational functioning, and life satisfaction of multicultural, community-dwelling elders. In this article, the philosophical background, manner of development, topical content, methods of program delivery, and mechanisms underlying the program’s positive effects are discussed, along with implications for occupational therapy practice. The treatment was based on application of occupational science theory and research and emphasized the therapeutic process of lifestyle redesign in enabling the participants to actively and strategically select an individualized pattern of personally satisfying and health-promoting occupations. The wide-ranging effectiveness of the program supports the occupational therapy profession’s emphasis on occupation in affecting health and positions practitioners to extend their services to the realm of preventative interventions.

**Summary and Significance**

The Lifestyle Redesign model of practice is based on four core ideas. The first premise is that occupation is necessary for life. Second, occupation can be used to create a new self. Third, occupation can have a curative effect on both physical and mental health and facilitate a sense of order and routine to one’s life. Finally occupation has a role in preventative care. Likewise, there are four key ideas to the Lifestyle Redesign programming. First, engagement in occupation produces radiating change not linear
change. Second, is that occupational self-analysis is possible and is a key component of programming that allows participants to identify barriers and solutions to those barriers. Third, is that the ability to understand the elements of occupation gives people the tools they need to redesign their lives. Finally, it is occupation that moves people forward.

While this model of practice is not entirely suited to this program, it is a model that could be used to develop other survivorship programming. Or, if the lymphedema program is successful it could be expanded and modeled more after the Lifestyle Redesign model of practice. The main drawback with this model is that it is time intensive to conduct and therefore more costly. In addition, it would require regular weekly commitment by participants to be most effective. Being able to make such a commitment is not realistic for many people who attend programming at TVC due to unexpected changes with treatment and medical management of their cancer.


Abstract

No Abstract.

Summary and Significance

The Model of Human Occupation (MOHO) “is concerned with individuals’ participation and adaptation in life occupations” (Kielhofner, 2009, p. 149). Cancer survivors who have received treatment for cancer are at risk for developing cancer-related lymphedema. Recommendations for survivors are often related to what not to do so as to avoid cancer related lymphedema. The goal of this program is to ensure survivors’ full participation in their life through adaptation as guided by MOHO. MOHO “stresses that
occupation results from an interaction of the inner characteristics of the person (volition, habituation, and performance capacity) with the environment” (Kielhofner, 2009, p. 152).

MOHO outlines three concepts related to the person including volition, habituation, and performance capacity. Volition describes the process that motivates people to engage in occupation. Volition considers thoughts and feelings. For example, personal causation considers the thoughts and feelings a person has about their own capacities and effectiveness as they engage in occupation. Volition also considers values and interests. Kielhofner points out, “How people experience life and regard themselves and their world is largely a function of their volition. Importantly, when people experience impairments, their volition can be severely affected. People may experience themselves as losing capacities and being unable to perform as they feel is important” (Kielhofner, 2009, p. 150). Volition will be addressed in the program by providing the opportunity to reflect on how to safely engage in occupation. Furthermore, participants will be able to reflect upon any limitations they have adhered to (related to occupational engagement) as a means of avoiding or managing lymphedema.

Participants will be provided with the opportunity to consider if those self-imposed limitations are supported by current lymphedema research. Ultimately, the goal is for people to regard themselves as empowered by being provided with the knowledge and skills needed to make educated choices about how they manage their risk for cancer-related lymphedema.

Habituation relates to how people organize their life into patterns and routines. Habits are learned and automatic. Roles guide actions people take and provide a sense of identity. Habits and roles guide how people interact with their environment.
Impairments can have a negative impact on habits and roles. Redefining habits and roles are an important aspect of promoting engagement in occupation. One aspect of being a cancer survivor is the need to change certain habits and routines in order to reduce the risk of cancer-related lymphedema. The program will provide the opportunity to assess current habits and determine safer alternatives. The program will also encourage the development of new habits and routines including the practice of lymphatic exercises and manual lymphatic drainage massage that will support a healthy lymphatic system.

Performance capacity relates to the physical and mental abilities that are used for engaging in occupation. This aspect of MOHO would be addressed by another model of practice, in this case, the biomechanical model of practice.


Abstract

No Abstract.

Summary and Significance

This resource is excellent for just about anything related to cancer and also for survivorship. This source points out that even when people are educated about possible effects of treatment (such as lymphedema) many people do not recall that information at a later date secondary to the stress of making life and death decisions about immediate cancer treatment.

While many patients are told about the long-term health effects of treatment before starting, they often don't recall or didn't concern themselves with them at that time. This is understandable, because when you're presented with treatment
options to save your life, thinking about what could happen ten or twenty years
down the road isn't as much of a priority. So what to do now? Learn what your
risks are based on the treatment you received, learn what you can do to prevent
them, if possible, and learn how to monitor for them (LiveStrong Care Plan, The
“New Normal” – Life as a Cancer Survivor, n.d.).