Lymphedema Education and Awareness for Pre-Surgical Patients (L.E.A.P.P.) to Recovery from Breast Cancer program development plan

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Lymphedema Education and Awareness for Pre-surgical Patients (L.E.A.P.P.) to Recovery from Breast Cancer Program Development Plan

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Table of Contents

Executive Summary 5

Introduction 6

Program Goal 6

Site 6

Organizational Structure 6

Investigation of Need 7

Breast Cancer and Lymphedema 11

Review of Literature 12

Occupational Therapy-Based Programming 13

Models of practice 14

Federal Initiatives and National Trends 15

Objectives 17

Program Goal 17

Objectives 17

Marketing and Recruitment of Participants 20

Marketing 20

Inclusion Criteria for Potential Participants 24

Programming 25

Budgeting and Staffing 28

Budgeting 28

Staffing 28

Marketing 29
Programming

In-Kind Support

Indirect Costs

Total Costs

Funding

Self-Sufficiency Plan

Program Evaluation

Evaluation Procedures

Stakeholders

Timeline

Letters of Support

References

Appendix A: Organizational Structure

Appendix B: Systematic Field Observation Notes

Appendix C: Lymphedema Education and Support Survey

Appendix D: L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire

Appendix E: Sample Flier

Appendix F: Sample Brochure

Appendix G: How Arm Lymphedema Happens

Appendix H: Signs and Symptoms

Appendix I: Treatment Options for Lymphedema

Appendix J: Lymphedema Risk Factors

Appendix K: How to Avoid Lymphedema
Appendix L: Post-Operative Positioning
Appendix M: Appropriate Post Surgery Therapeutic Exercises
Appendix N: Total Rehab Lymphedema Clinic’s Lymphedema Support Group
Appendix O: Occupational Therapist Job Description
Appendix P: Sample Occupational Therapist Advertisement
Appendix Q: Participant to Patient Interview
Appendix R: Stakeholder Feedback Form
Appendix S: Letter of Support
Appendix T: Contact Information for Support Letters
Appendix U: Annotated Bibliography
Executive Summary

Breast cancer is the most common cancer among American women, with the exception of skin cancers (Department of Health and Human Services, 2004). The chance of developing invasive breast cancer at some time in a woman's life is about 1 in 8 (12%). The most common treatment approach is surgery which is then followed by radiation therapy, chemotherapy, and/or drug therapy (Breastcancer.org, 2007a). The more treatment methods used, the greater the risk of experiencing additional negative side effects, such as arm lymphedema. Lymphedema is a condition that occurs when fluid accumulates due to insufficiency of the lymphatic system which causes swelling. Once an individual is diagnosed with breast cancer he/she has a 25% chance of developing lymphedema following treatments (Breastcancer.org, 2007b).

The goal of the L.E.A.P.P. to Recovery from Breast Cancer program is to reduce the risk of developing lymphedema by providing pre-operative education to women with breast cancer. The program will be located at the Total Rehab Lymphedema Clinic on the campus of Flower Hospital. The program’s objectives focus on educating participants on the cause, warning signs, and symptoms of lymphedema. The components of a lymphedema treatment program will also be addressed along with risk factors and prevention techniques to reduce the possibility of developing lymphedema, proper post-operative positioning of the affected extremity, and appropriate therapeutic exercises. The program expects to have 390 participants in its first year. Potential participants include individuals of all ages in the Northwest Ohio area who have been diagnosed with breast cancer and are scheduled to undergo surgical intervention. The program is a one session process provided through one-on-one delivery. This session will take place prior to the patient’s surgery. Formative and summative evaluations of the program will be conducted analyzing participants’ pre-session post-session knowledge scores.
Program Plan

Introduction

Program Goal

The goal of the Lymphedema Education and Awareness for Pre-surgical Patients (L.E.A.P.P.) to Recovery from Breast Cancer program at the Total Rehab Lymphedema Clinic on the Flower Hospital Campus is to reduce the risk of developing lymphedema by providing pre-operative education to women with breast cancer.

Site

Located in Flower Hospital, the Total Rehab Lymphedema Clinic’s mission is to provide comprehensive outpatient treatment and education for individuals with lymphedema to allow them to be able to manage and control their condition long term. A typical treatment program is provided by specially trained occupational therapists and lasts for 1 to 1½ hours, 5 days a week, for 2-3 weeks and includes; massage, specialized exercises, and instruction in the use and application of special bandages. The occupational therapists at the Total Rehab Lymphedema Clinic on the campus of Flower Hospital provide treatment to about 10-12 patients per day.

Organizational Structure

The organizational structure (Appendix A) of the Total Rehab Lymphedema Clinic on the campus of Flower Hospital is quite simple within itself, but becomes fairly complex when viewed in the context of its governing non-profit health care system, ProMedica. The Lymphedema Clinic is located in the same building as the Total Rehab Outpatient Clinic which provides outpatient services for individuals who require occupational, physical, and/or speech therapy. The Lymphedema Clinic is run by two part-time lymphedema trained occupational therapists, Cindy Robertson, OT/L and Amy Huntsman, OTR/L, and two part-time lymphedema...
trained occupational therapy assistants, Diana Bergquist, COTA/L and Lauren Mocniak, COTA/L.

The L.E.A.P.P. to Recovery from Breast Cancer program will be a new addition to the Lymphedema Clinic. An additional part-time occupational therapist will be hired to run this new program. This is an ideal location for the program because the lymphedema clinic personnel work closely together to provide comprehensive therapy. Therefore the proposed L.E.A.P.P. to Recovery from Breast Cancer program therapist will work in conjunction with the current therapists, but will be under the direction of Leslie Vassar, the clinical coordinator for the Total Rehab Outpatient Clinic. The hope for the future would be to extend the program to the Hickman Cancer Center also located on the Campus of Flower Hospital.

Investigation of Need

To ensure thoroughness throughout the investigation of need, multiple methods to gather data were chosen. A social indicators analysis was performed, as well as systematic field observations, and a survey. Each method of data collection was chosen for the comprehensive benefit that it adds to the collection of knowledge.

A social indicators analysis was performed because it is vital for any new program to obtain and utilize regularly collected data on social and health status indicators to validate the importance of developing their new program. Two specific documents used to accomplish this method are Breast Cancer Facts & Figures (American Cancer Society, 2007) and 2004 Breast Cancer Statistics (Department of Health and Human Services, 2004). This method of data collection is very appropriate for this needs assessment because it provides specific scientific information about the breast cancer population to justify the need for my proposed program.
Also, numerous systematic field observations were conducted throughout the data collection process. A systematic field observation form (Appendix B) was created to help organize and validate my findings. The majority of observations took place at the Total Rehab Lymphedema Clinic on the Flower Hospital Campus, but I also spent time at Bedford Total Rehab in Bedford, Michigan and Bay Park Total Rehab in Oregon, Ohio. Clients were observed at these clinics during initial/admitting interviews, treatment sessions, discharge sessions, and support groups. At these sites observations of occupational therapists and occupational therapy assistants during initial/admitting interviews, treatment sessions, discharge sessions, and team meetings were also made. Observing both clients and therapists at this site provided a better understanding of the overall services provided to patients receiving lymphedema treatment. This is an appropriate method of data collection for this needs assessment because the results of these observations help to validate that there is a need at the Lymphedema Clinic for a new program to be developed entailing pre-operation education for women who have been diagnosed with breast cancer and who are undergoing surgical intervention.

The final method of data collection was conducting surveys. With such a specific area of study, it is important to not only research literature, document social indicators, and conduct systematic observations, but to also devote time to collecting data directly from the population the program wishes to serve. Forsyth and Kviz (2006) propose two main advantages of conducting a survey. It allows you to reach a large number of respondents, and it helps you collect data from numerous variables. This method of data collection is extremely appropriate for this population and the proposed program because it allowed me to gain an intimate view of the perceived needs of the clinic’s clients and their thoughts on my proposed program.
A survey (Appendix C) was created and administering to ten clients who have/had breast cancer and have developed upper extremity lymphedema as a result of surgical intervention and/or radiation treatments. The survey was given to clients during one of their treatment sessions in a formal interview format.

The survey participants’ ages ranged from 31 to 80 years old and all participants were female. The survey participants’ breast cancer diagnosis dates ranged from less than 1 year to 22 years ago. The stage of breast cancer and types of surgeries varied between all participants. All survey participants reported having lymph nodes removed during surgery. The number of lymph nodes removed ranged from 2 to 24. Four participants reported that they completed chemotherapy, six participants reported that they received radiation treatments, and three participants reported that they received treatment medications. Six participants reported having more than one type of treatment and only one participant reported that she received no other treatment methods after surgery.

Survey participants’ first noticed the effects of lymphedema from as soon as one day after surgery to ten years after treatment ended. Only three participants agreed that before their surgery they knew what lymphedema was. Each participant reported a different source of obtaining information on lymphedema prior to surgery. One participant stated a nurse practitioner as her source. The second reported a friend who also had breast cancer as her source, and the third reported her surgeon as her source. Eight of the ten participants reported that they received no information on the prevention and management of lymphedema prior to surgery. The two participants who responded yes to receiving information on the prevention and management of lymphedema prior to surgery reported that the information received was very brief.
All ten survey participants reported that they would have benefited from receiving education on lymphedema prior to their surgery. All ten participants said that they would not have attended an educational support group, but nine survey participants reported that they would have benefited from having a one-on-one session with a lymphedema therapist.

When participants were surveyed on what they wish they had known about lymphedema before surgery a variety of answers were provided. Participants’ responses included; general information on lymphedema, the cause, limitations, precautions, warning signs, risk factors, symptoms, compression garment information, and the possibility that lymphedema could develop days to years after surgery and radiation treatments. Participants also reported that they wish they had been provided with an informative brochure on lymphedema, contact information, and support group information.

Three participants were currently employed during the time the survey was conducted. Two of these three participants reported experiencing complications from having lymphedema that affected their employment. One participant reported that extensive keyboard typing and writing was more difficult after the development of lymphedema. The second participant reported that she was unable to complete the physical demands required by her job description after the development of lymphedema.

Six participants reported that they experience problems performing occupations of daily living due to lymphedema. Participants reported experiencing problems during dressing, cooking, house hold maintenance, grocery shopping, and child care.

The results of this survey were instrumental in the development of the L.E.A.P.P. to Recovery from Breast Cancer program. Originally, the program was designed to reduce the risk of developing lymphedema by providing pre-operative educational support groups to women
with breast cancer. As previously stated, all ten survey participants reported that they would not have attended an educational support group, but nine survey participants reported that they would have benefited from having a one-on-one session with a lymphedema therapist. Therefore the program’s method of providing education changed from a support group format to a one-on-one session. Also, the survey results confirmed the basis of the program when all ten survey participants reported that they would have benefited from receiving education on lymphedema prior to their surgery. Finally, the results of the survey confirmed that the education that the program was planning on providing was the type of education that the surveyed participants desired (i.e. general information on lymphedema, the cause, limitations, precautions, warning signs, risk factors, etc.).

Breast Cancer and Lymphedema

The United States Department of Health and Human Services: Centers for Disease Control and Prevention (2004) found that breast cancer is the most common cancer among American women, with the exception of skin cancers. The chance of developing invasive breast cancer at some time in a woman's life is about 1 in 8 (12%). The most common treatment approach is surgery which is then followed up by radiation therapy, chemotherapy, and/or drug therapy (Breastcancer.org, 2007a). The more treatment methods used, the greater the individual’s chance is for defeating the cancer. On the contrary, with more treatment methods used, the individual is more likely to experience additional negative side effects, such as upper extremity lymphedema.

Lymphedema is a condition that occurs when fluid accumulates in the interstitial space due to insufficiency of the lymphatic system causing swelling (Morrell et al., 2005). Chronic inflammation results in a feeling of heaviness, numbness, discomfort, and sometimes infection.
Lymphedema has the power to change functional abilities, affect patients’ psychosocial adjustment, and overall quality of life. Lymphedema is a frequent side effect of a mastectomy or lumpectomy because of the removal of lymph nodes for biopsy. Once an individual is diagnosed with breast cancer he/she has a 25% chance of developing lymphedema following breast cancer treatments (Breastcancer.org, 2007b). It may appear weeks to years after lymph node dissection.

Review of Literature

In 2005, Thomas-MacLean, Miedema and Tatemichi sought to research women’s experiences with breast cancer related lymphedema. A diverse sample of twenty two women with breast cancer related lymphedema was obtained based on a set of selection criteria. The authors’ research began with a focus group of seven women that was facilitated by two of the authors to gather ideas for developing a guide for one-on-one in-depth interviews. Fifteen other women participated in the in-depth interviews guided by the development of the focus group discussion. Four themes emerged from the interviews. First, participants reported receiving very little or no information about the possibility of developing breast cancer related lymphedema. Second, a variety of debilitating triggers and symptoms of lymphedema were identified including; numbness, heaviness, tingling, aching, hardness, tightness, and limited mobility. Third, participants stated that access to proper treatment is poor. Finally, the women described the profound effect that breast cancer related lymphedema played on daily life stating that it interfered with both work and activities of daily living. The results of this study clearly show the lack of pre-operative education women with breast cancer are receiving. Participants in this study were unaware of both the risk factors and treatment options for breast cancer related lymphedema.
Johnstone and Mondry (2007) stated that the management of lymphedema should always begin with preoperative evaluation and education. Evaluation should include recording circumferential measurements of the upper extremities to form baseline measurements. Preoperative education should include lymphedema risk factors, lymphedema prevention techniques, lymphedema treatment and long-term management techniques, and possible complications with surgery in relation to occupational performance. Lymphedema risk factors include: traumas to the muscle or skin of the arm that can lead to infection, gaining a significant amount of weight after breast cancer treatment, heat, long plane flights, extensive breast cancer in the lymph nodes, etc. (Breastcancer.org, 2007b). There is an extensive list of prevention techniques that include learning the warning signs of lymphedema and maintaining proper skin care. Lymphedema treatment and maintenance techniques need to be provided by trained professionals to help the patients learn to live with this incurable, but manageable, condition.

In 2006 Ridner sought to compare recalled lymphedema pretreatment education between women with and without breast cancer treatment-related lymphedema. A structured interview was given to 149 breast cancer survivors (74 with lymphedema and 75 without lymphedema). The results of the study showed that individuals with lymphedema consistently recalled receiving less education and a decline in recalled risk reduction education. Ridner concluded her study by stating that pretreatment lymphedema education may improve breast cancer survivor's recall of educational information received about lymphedema.

**Occupational Therapy-Based Programming**

The L.E.A.P.P. to Recovery from Breast Cancer program will provide pre-operative education to women with breast cancer to reduce the risk of developing lymphedema. Education on lymphedema risk factors, lymphedema prevention techniques, lymphedema treatment and
long-term management techniques will be provided by occupational therapy-based programming. Participants will be taught how to incorporate these techniques into his/her ADL’s and IADL’s.

Living with breast cancer and lymphedema will alter many aspects of the individual’s life. It can affect a person physically, mentally, and spiritually. Therefore, occupational therapists are the ideal profession to provide treatment to these patients. They have been specially educated to address physical changes such as, reduced range of motion and lymphedema in the affected arm. To address these physical changes, occupational therapy also could look at occupations of daily living and instrumental occupations of daily living that may need to be adapted, along with any possible adaptations that need to take place in the home, work place, and/or leisure activities.

Breast cancer often brings emotional changes in addition to the physical changes. Emotional changes may cause the person to become less motivated to engage in usual activities and there may be a decline in the value a person holds in completing activities such as grooming, home maintenance, and/or other leisure activities. Other psychosocial issues that could present themselves are depression, loss of self-esteem, fear of rejection, loss of appetite, decreased interest in sex, decreased feelings of femininity, etc. Occupational therapists are educated to help people address and overcome these feelings so they can return to a productive life.

Models of practice

Two occupational therapy models of practice have been identified to guide the L.E.A.P.P. to Recovery from Breast Cancer program. The first model of practice is the Canadian Model of Occupational Performance, better known as, the client centered model (Law, Baptiste, & Mills, 1994). This model was chosen for its focus on the process of therapy and the relationship between client and therapy. Therapist and client work together to create goals related to physical,
mental, and spiritual occupational performance. The L.E.A.P.P. to Recovery from Breast Cancer program revolves around the direct needs of client. An alliance will be formed between the client and therapist and together they will use their combined skills and strengths to work toward reducing the client’s risk of acquiring lymphedema.

The second model of practice chosen to guide the L.E.A.P.P. to Recovery from Breast Cancer program is Ann Mosey’s Role Acquisition (Mosey, 1986). This model was chosen for its emphasis on active participation in the learning process. Like the previously mentioned client centered model (Law, Baptiste, & Mills, 1994), the client provides a great deal of input in goal setting and the overall direction of therapy. As with the proposed program, this model focuses on long term goals that are set with the client’s naturalistic environment in mind to facilitate carryover of skills learned in therapy.

*Federal Initiatives and National Trends*

Healthy People 2010 describes the need for an increase in the quality, availability, and effectiveness of educational programs designed to prevent disease and improve health of our country by the year 2010 (United States Department of Health and Human Services, 2000). The L.E.A.P.P. to Recovery from Breast Cancer program will meet three objectives of this federal initiative’s goal. Objective 7-7 states that there needs to be an increase in the proportion of health care organizations that provide patient and family education. Objective 7-8 states that there needs to be an increase in the proportion of patients who report that they are satisfied with the patient education they receive from their health care organization. The proposed program meets both of these objectives by increasing the patient and family education at the Lymphedema Clinic. Increasing the amount of education provided in a patient centered manner will lead to higher patient satisfaction with their health care organization. Objective 7-11 states that there needs to
be an increase in the proportion of local health departments that have established culturally appropriate and linguistically competent community health promotion and disease prevention programs. The proposed program will also meet this objective by developing an education program culturally and linguistically appropriate for all patients.

Healthy People 2010 also describes a need for health communication to encompass and use communication strategies to inform and influence individual decisions that enhance health. The L.E.A.P.P. to Recovery from Breast Cancer program will meet objective 11-6 of this federal initiative’s goal. Object 11-6 states that there needs to be an increase in the proportion of persons who report that their health care providers have satisfactory communication skills. The proposed program will meet this objective in a similar way that it met object 7-8. Increasing the amount and type of education may lead to greater patient satisfaction with their health care provider’s communication skills.

The National Breast Cancer Coalition (2006) has also developed a national initiative. Their initiative aims to improve the quality of breast cancer care in the country. The initiative is guided by the National Breast Cancer Coalition’s vision statement which has six overlapping core values:

1. Access to all the care you need when you need it;
2. Information that is complete and correct;
3. Choice about your doctors and your treatment;
4. Respect from everyone in the health care system;
5. Accountability so there is a way to fix problems; and
6. Improvement in the system so breast cancer care continues to get better.

(National Breast Cancer Coalition, 2003).
The second core value of their vision statement can be met through the development of the L.E.A.P.P. to Recovery from Breast Cancer program. Their core value states that influencing health care providers need to embrace and implement the National Breast Cancer Coalition’s vision statement for quality of care. The proposed program will do this by providing access to complete and correct pre-operative education. Through the provision of education, patients will be able to make informed decisions with their doctors about their treatment and plan of care. Patients will provide their respected input on ways to improve the comprehensive treatment of breast cancer which will allow breast cancer care to continue to get better.

Objectives

Program Goal

The goal of the Lymphedema Education and Awareness for Pre-surgical Patients (L.E.A.P.P.) to Recovery from Breast Cancer program at the Total Rehab Lymphedema Clinic on the Flower Hospital Campus is to reduce the risk of acquiring lymphedema by providing pre-operative education to women with breast cancer.

Objectives

1. At the end of the program, participants will demonstrate knowledge of the cause of lymphedema as measured by a change in pre-session post-session score on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D).

   i. The rationale for this objective came as a result of personally speaking with numerous patients who have breast cancer related lymphedema. All reported having no prior knowledge of the cause of lymphedema until the condition had already developed.
2. At the end of the program, participants will demonstrate knowledge of the warning signs of lymphedema as measured by a change in pre-session post-session score on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D).
   i. The rationale for this objective came as a result of personally speaking with numerous patients who have breast cancer related lymphedema. All reported having no prior knowledge of the warning signs of lymphedema until the condition had already developed.

3. At the end of the program, participants will demonstrate knowledge of the symptoms of lymphedema as measured by a change in pre-session post-session score on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D).
   i. The rationale for this objective came as a result of personally speaking with numerous patients who have breast cancer related lymphedema. All reported having no prior knowledge of the symptoms of lymphedema until the condition had already developed.

4. At the end of the program, participants will demonstrate knowledge of the components of a lymphedema treatment program as measured by a change in pre-session post-session score on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D).
   i. The rationale for this objective came as a result of personally speaking with numerous patients who have breast cancer related lymphedema. All reported having no prior knowledge of the components of a lymphedema treatment program until the condition had already developed and they began treatment.
5. At the end of the program, participants will demonstrate knowledge of factors that put a woman at a higher risk of developing lymphedema and lymphedema prevention techniques as measured by a change in the pre-session post-session score on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D).
   i. The rationale for this objective came as a result of personally speaking with numerous patients who have breast cancer related lymphedema, and was reinforced through a review of literature I found that patients were receiving very little or no information about risk factors and the techniques used to help prevent developing breast cancer related lymphedema (Thomas-MacLean, Miedema & Tatemichi, 2005).

6. At the end of the program, participants will exhibit competence in post-operative positioning of the potentially affected upper extremity, as measured by a demonstration to the occupational therapist and documented on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D).
   i. The rationale for this objective also came as a result of conducting a literature review. Ridner (2006) found that pretreatment lymphedema education can help prevent lymphedema from occurring including post-operative positioning.

7. At the end of the program, participants will exhibit competence in therapeutic exercises that can be performed post surgery, as measured by a demonstration to the occupational therapist and documented on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire.
Program Plan

i. The rationale for this objective also came as a result of conducting a literature review. It was found that pre-operative education should include long-term management techniques such as therapeutic exercises to help manage this incurable condition (Johnstone & Mondry, 2007).

Marketing and Recruitment of Participants

Marketing

Marketing for the L.E.A.P.P. to Recovery from Breast Cancer program is vital for its survival. The marketing campaign should not only be directed towards possible participants, but to the families and caregivers, referring oncologists, and the general public of Northwest Ohio. The marketing campaign will consist of fliers, brochures, a link on ProMedica’s official website, an in-service for referring oncologists, and participation in community events.

The majority of the marketing campaign is focused on participants, and the families and caregivers of participants. It is also essential to direct part of the marketing campaign to referring oncologists, radiologists, and surgeons because they are the primary contact between potential participants and the program. They will be the main source of informing clients of the services the program provides. It is also important to develop and provide marketing material appropriate for the general public of Northwest Ohio.

A flier (Appendix E) was created that identifies the name of the program, the goal of the program, the location of the program, and a phone number to call for more information. The flier was kept simple for a reason. The plan is to hang these fliers all over Sylvania, Toledo, and the Greater Toledo Area. The majority of the fliers will be personally delivered to local oncologist’s and physician’s offices with a brief description of the program and a request for the flier to be displayed in their waiting rooms. The flyers will also be personally delivered to two local stores
that provide specialty items for women with breast cancer; Renee’s Survivor Shop and That Special Woman. Additional fliers will be available through facilities that provide services to women in the area such as; Senior Centers, local pharmacies, the YWCA, fitness facilities, etc.

A brochure (Appendix F) was created that compliments the flier but provides much more information. The brochure goes beyond the flier’s content and provides a brief definition of lymphedema, as well as a description of the benefits individuals will gain from participating in the L.E.A.P.P. to Recovery from Breast Cancer program. The brochure is a good supplement to the flier. The plan is to personally deliver these brochures to local oncologists and physicians along with an introduction to the program and a request for clinic staff to distribute them to their clients who would benefit from the program’s services. The brochure will educate potential clients, oncologists and physicians about the services provided by the program.

The flier and brochure were created for the L.E.A.P.P. to Recovery from Breast Cancer program because they are the most cost-effective way to reach numerous potential participants and educate them about the program. Both the flier and the brochure were designed to compliment each other in physical appearance. They are deliberately accented in pink to express the breast cancer color. It is my hope that most of the participants will be given this brochure at their initial doctor’s appointment where breast cancer is identified as the diagnoses. No one from the program will be at this appointment to advertise services but the brochure can consistently be there to provide basic information.

The third method of marketing focuses on working with ProMedica administration and using technology to add a link on their official website describing the L.E.A.P.P. to Recovery from Breast Cancer program. The public will be able to go to ProMedica’s website, find the hospital heading, choose Flower Hospital, and under the services sub heading see a link to the
program. There are two currently established sections of the website where it would be appropriate to have a link to the program’s services, Breast Cancer Care and Lymphedema Management. The style of ProMedica’s website is to provide concise descriptions of services, their locations, and contact information. Therefore, the link would follow suit by providing the public with the title of the program, a brief overview of the L.E.A.P.P. to Recovery from Breast Cancer program’s goal and services, the location of the program, and contact information.

A link would be created on ProMedica’s official website for the L.E.A.P.P. to Recovery from Breast Cancer program because many people these days obtain the majority of their information via the internet. Even though there would only be a brief description of the program, it would educate the public on the services provided to participants. The cost of this marketing method is currently unknown, but it is expected that ProMedica would cover any expenses to advertise a service that they provide in one of their facilities. It would make their healthcare services more comprehensive.

The fourth method of marketing that will be developed is an in-service for local oncologists and oncology support staff educating them about the L.E.A.P.P. to Recovery from Breast Cancer program. The hour long in-service will take place during the afternoon and lunch will be provided for those who attend. The aim of our program is to give an in-service at all local hospitals that have an oncology unit. The in-service will include an in-depth description of the need for the program, an overview of past and present research and statistics that validate the need of the program, and a detailed description of program’s services. At the end of the in-service any questions the attendees have will be entertained and any suggestions or recommendations that they have for the program will be discussed. Copies of the previously
mentioned fliers and brochures will be provided in bulk to pass out to the oncologists in hopes that they will begin to pass them out to their patients.

An in-service for local oncologists will be developed to educate them about the L.E.A.P.P. to Recovery from Breast Cancer program because they are the primary contact between potential participants and the program. These oncologists are also the main source of referring participants to the program. Although this is one of the more expensive methods of marketing for the program, it is vital to get the oncologists to work with us to reach program participants. Oncologists, like most doctors, have extremely busy schedules. For that reason we will conduct the in-services during the afternoon and provide lunch in hopes of attracting more attendees. A flier will be developed and distributed two weeks prior to the in-service to inform potential attendees. Also, phone call reminders will be made one week in advance, and one day prior to help increase the number of attendees.

The fifth and final method of marketing will focus on participating in community events to help promote the L.E.A.P.P. to Recovery from Breast Cancer program. Community events that spotlight breast cancer will be the main focus. For example, in Toledo the Susan G. Komen Race for the Cure takes place every year on the last weekend in September. It is an event that brings thousands of Ohioans to downtown Toledo to support breast cancer organizations. A table would be rented at the race which will be adorned with a L.E.A.P.P. to Recovery from Breast Cancer poster. Copies of the previously described fliers and brochures will be available in bulk to pass out to the public. In effort to decrease the cost of the table rental, it would make sense to partner with the Lymphedema Clinic and share the table. This would be a great way to promote our services to thousands of potential participants and their families.
Participating in community events will help promote the L.E.A.P.P. to Recovery from Breast Cancer program via word of mouth. Most people who find out that they have been diagnosed with cancer want to talk to others who shares their story and to seek advice. By participating in community events that attract breast cancer survivors, we are able to educate them about our services, and they will in turn educate the recently diagnosed. This is the most expensive method that will be utilized to market the L.E.A.P.P. to Recovery from Breast Cancer program, but when you break down the cost to how many people who are reached by this method, it becomes extremely cost and time effective.

*Inclusion Criteria for Potential Participants*

The potential participants of this program include individuals of all ages in the Northwest Ohio area who have been diagnosed with breast cancer. Specified inclusion criteria will be employed. Participants must be diagnosed with breast cancer and scheduled to undergo surgical intervention such as a mastectomy or lumpectomy with axillary node dissection. Participants must also have a referral from a physician to take part in our program. The L.E.A.P.P. to Recovery from Breast Cancer program expects to have an average of five to ten participants each week which provides a range of 260 to 520 participants per year. By taking the average of this range, it can be estimated that a total population sample size of 390 participants per year will be expected. Once these participants have been recruited for the program I will gather information on the individual’s name, age, date of breast cancer diagnosis, the name of the referring physician, the specific type of breast cancer diagnosis, and the surgical intervention he/she are scheduled to undergo.
Programming

The Lymphedema Education and Awareness for Pre-surgical Patients (L.E.A.P.P.) to Recovery from Breast Cancer program at the Total Rehab Lymphedema Clinic on the Flower Hospital Campus is a one session process provided through one-on-one delivery. The session takes approximately 1½ hours to complete, but a two hour block of time is scheduled for each individual session to provide patients extra time for questions/discussion and to allow time for the therapist to complete paperwork. Once a client has been referred for services, their session is scheduled to take place prior to the client’s surgery. During this initial contact with the client, he/she is given information on the location of the Lymphedema Clinic within Flower Hospital, along with the recommendation to bring a friend or family member to their session with them. With all of the information that is provided to people when first diagnosed with a condition as serious as cancer, having a friend or family member accompany the client in the session will not only help to calm the client’s nerves, but help with retention of the new information our program provides.

When the participant arrives at the clinic for his/her session they are asked to complete the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire to the best of their abilities. After about ten minutes, the therapist retrieves the participant and the Knowledge Questionnaire and the participant is escorted from the waiting area into a patient care room. The session begins with a brief introduction by the therapist and an overview of what will be discussed throughout the session. Next, circumferential measurements of the client’s potentially affected upper extremity are completed and documented by the occupational therapist. This is done to obtain a baseline in case the participant develops lymphedema in the future (Johnstone & Mondry, 2007; Armer, 2005).
The remainder of the session is dedicated to educating the client on all aspects of lymphedema (Kelly, 2001; Morrell et al., 2005; Paskett & Stark, 2000). As previously discussed, Thomas-MacLean, Miedema and Tatemichi (2005) found that women with breast cancer were unaware of the cause, risk factors and treatment options for lymphedema. Therefore, the first area of lymphedema education includes the cause (Appendix G), warning signs and symptoms (Appendix H), and the components of treatment and treatment options of lymphedema (Appendix I). Next, factors that put you at a higher risk of developing lymphedema (Appendix J) are addressed followed by lymphedema prevention techniques (Appendix K). This information is provided through discussion and reinforced through the provision of handouts that the client is able to take home. Any questions related to this section of lymphedema education are welcomed and answered at any point throughout the first session.

The second area of lymphedema education includes instruction on post-operative positioning of the potentially affected upper extremity (Appendix L) and therapeutic exercises that can be performed post surgery (Appendix M). Ridner (2006) found that pretreatment lymphedema education in breast cancer patients should include techniques that can help prevent lymphedema from occurring and improve breast cancer survivor’s recall of education information received about lymphedema. Again, to assist with recall of information, this information is provided through verbal and hands on demonstration, and reinforced through the provision of handouts that the client is able to take home. Demonstrations are first shown on the therapist and then on the participant. The participant then independently practices the techniques and demonstrates competence to the therapist. Once again, any questions related to this section or the previous section of lymphedema education are welcomed and answered at any point throughout the session.
At the end of the session a folder is provided to the participant with all of the handouts that were referenced throughout the session. In addition, a handout is provided with a list of websites that offer additional lymphedema information and a list of local lymphedema supply vendors. A brochure, explaining the Total Rehab Lymphedema Clinic’s lymphedema support group is also provided (Appendix N).

At this time, the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire is scored by the occupational therapist. Each correct answer provided by the participant earns him/her one point. Therefore, the highest possible total score on the Knowledge Questionnaire is 23. Once the participant’s pre-session score is determined, the Knowledge Questionnaire is reviewed with the patient in an informal interview format. Participants are asked to verbally, and when appropriate, physically convey competence in all areas of the Knowledge Questionnaire. Each correct answer provided by the participant earns him/her one point towards their post-session score. If the participant can not recall the correct answer, the therapist will show him/her where to find the answer in the handouts provided. This is done to ensure that the education provided during the session was understood.

Participants are discharged from the program at the end of the session. The completed Knowledge Questionnaire, circumferential measurements of the potentially affected upper extremity and a copy of the physician referral are kept in the patient’s file and stored on site. The file is kept on site for the two years and then placed in storage.

The development and intended implementation of the L.E.A.P.P. to Recovery from Breast Cancer program has been guided by the Canadian Model of Occupational Performance (Law, Baptiste, & Mills, 1995) and Ann Mosey’s Role Acquisition Model (Mosey, 1986). This is illustrated in how the program revolves around the direct needs of the client and the program’s
emphasis on active participation in the learning process. An alliance is formed between the client and therapist and together they use their combined skills and strengths to work toward reducing the client’s risk of acquiring lymphedema.

Budgeting and Staffing

**Budgeting**

The following budget provides a breakdown of the estimated costs for the first year of the L.E.A.P.P. to Recovery from Breast Cancer program.

**Staffing**

<table>
<thead>
<tr>
<th>Position</th>
<th>Hours Per Week</th>
<th>Salary</th>
<th>Fringe Benefits</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapist</td>
<td>20</td>
<td>$33,373</td>
<td>$8,343</td>
<td>$41,716</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td></td>
<td>$41,716</td>
</tr>
</tbody>
</table>

The L.E.A.P.P. to Recovery from Breast Cancer program will be run by a part time occupational therapist. The occupational therapist will be in charge of all aspects of the program. During lulls of the L.E.A.P.P. to Recovery from Breast Cancer program, the occupational therapist will also be responsible for providing standard treatment to other (including non-breast cancer related) lymphedema patients in the clinic. A description of the position (Appendix O) along with an advertisement (Appendix P) for the position have been provided. It was determined that this program would require a part time therapist to work 20 hours a week. This was determined from taking the estimated 5-10 clients per week and multiplying it by 1½-2 hour educational session providing a range of 7½ -20 hours of direct patient care hours each week. After factoring in five hours per week for marketing and recruitment an estimated average of 20 hours of work seemed appropriate to ask of the occupational therapist in this position. The salary for the occupational therapist position was determined utilizing the estimate for the field in Toledo, Ohio from www.salary.com. The salary for this part time position was determined by
taking the median salary of a full time occupational therapist, $66,745, and dividing it in half. Fringe benefits have been included in the total salary. Fringe benefits were determined by taking 25 percent of the salary. As previously mentioned, the occupational therapist will also be responsible for providing standard treatment to lymphedema patients in the clinic when L.E.A.P.P program needs are not scheduled. It is expected that ten percent of the occupational therapist’s time will be reallocated to standard lymphedema treatment time. This has the possibility of decreasing the salary of the L.E.A.P.P program occupational therapist’s salary by $4171.60. This $4171.60 will be covered by Total Rehab.

*Marketing*

<table>
<thead>
<tr>
<th>Item</th>
<th>Justification</th>
<th>Quantity</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fliers</td>
<td>Copies of the flier will be made at the local FedEx Kinko’s. There is a discount rate of $0.49 when ordering 1001-10,000 color copies. It is estimated that 200 copies will be needed for distribution to local oncologists’, radiologists’, and surgeons’ offices, 350 copies will be needed to distribute at In-services, and 10,000 copies will be needed to distribute at Community Events. <a href="http://www.kinkos.com">www.kinkos.com</a></td>
<td>10,550 (at $0.49 each)</td>
<td>$5,170</td>
</tr>
<tr>
<td>Brochures</td>
<td>Copies of the brochure will be made at the local FedEx Kinko’s. There is a discount rate of $0.49 when ordering 1001-10,000 copies and a folding rate of $0.03 per copy. It is estimated that 200 copies will be needed for distribution to local oncologist’s offices, 350 copies will be needed to distribute at In-services, and 10,000 copies will be needed to distribute at Community Events. <a href="http://www.kinkos.com">www.kinkos.com</a></td>
<td>10,550 (at $0.52 each)</td>
<td>$5,486</td>
</tr>
<tr>
<td>Poster for Community Events</td>
<td>The poster is necessary to adorn our station with when participating in</td>
<td>1</td>
<td>$320</td>
</tr>
</tbody>
</table>
### In-service Expense: Lunch Provided to Attendants

In-services will be given at the seven ProMedica hospitals that have oncology units. To encourage these oncology staffs to attend the in-services which explain our program, lunch will be provided. The estimated attendance rate is 20 people per hospital. Boston market provides a catered lunch that easily feeds a group of 20 people for $154. 

| Quantity (at $154 each) | Total Cost  
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>$1,078</td>
</tr>
</tbody>
</table>

### In-service Expense: Laptop Computer

A laptop computer is needed when giving in-services at the seven ProMedica hospitals that have oncology units. The laptop computer will store and present the power point presentation.

| Quantity | Total Cost  
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>$900</td>
</tr>
</tbody>
</table>

### Travel Expenses

Necessary to cover travel costs of trips to/from local oncologist’s offices and to/from ProMedica hospitals that will receive in-services. The calculated miles necessary to complete all trips is 750 miles. Mileage rate is assumed to be $0.50 per mile.

| Quantity | Total Cost  
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>n/a</td>
<td>$375</td>
</tr>
</tbody>
</table>

| **Total** | **$13,329** |

---

**Programming**

<table>
<thead>
<tr>
<th>Item</th>
<th>Justification</th>
<th>Quantity</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calendar - Planner</td>
<td>For organizing tasks and scheduling appointments. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td>1</td>
<td>$40</td>
</tr>
<tr>
<td>File Folders</td>
<td>Based on the previously stated population sample size range, it was estimated that 520 patients would be the most served within one year’s time. Therefore, 520 file folders will be needed. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unit cost - $19</td>
<td>21 packs</td>
<td>$399</td>
</tr>
<tr>
<td>Item</td>
<td>Description</td>
<td>Quantity</td>
<td>Unit Cost</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>----------</td>
<td>-----------</td>
</tr>
<tr>
<td>Filing Cabinet</td>
<td>To store and organize patient files. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td>1</td>
<td>$150</td>
</tr>
<tr>
<td>White Office Paper</td>
<td>Necessary for making copies of the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Test that will be administered to all participants at the beginning and end of the program. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td>5 packs</td>
<td>(500 sheets per pack)</td>
</tr>
<tr>
<td>Color Office Paper</td>
<td>Necessary for making copies of the L.E.A.P.P. to Recovery from Breast Cancer handouts that will be provided to participants. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td>13 packs</td>
<td>(200 sheets per pack)</td>
</tr>
<tr>
<td>Folders</td>
<td>One folder will be provided to each patient to take home with them at the end of the program. The folder will contain all the educational handouts that were discussed during the program sessions. Based on the previously stated population sample size range, it was estimated that 520 patients would be the most served within one year’s time. Therefore 520 folders will be needed. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td>21 boxes</td>
<td>(25 folders per box at $8 each)</td>
</tr>
<tr>
<td>Pens</td>
<td>For patients to fill out the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Test and take notes throughout the sessions. <a href="http://www.officemax.com">www.officemax.com</a></td>
<td>8 packs</td>
<td>(12 pens per pack at $3 each)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**In-Kind Support**

The following items will be provided by the Total Rehab Lymphedema Clinic on the campus of Flower Hospital as in-kind support: work space, copy privileges, phone with voicemail service, internet server use, and support by means of lymphedema clinic therapists and lymphedema clinic tools and materials.

**Indirect Costs**

The Total Rehab Lymphedema Clinic on the campus of Flower Hospital will be reimbursed for the indirect costs that include: air conditioning, heat, maintenance, water, electricity, and bathroom facilities. This cost was estimated by calculating 25 percent of the program’s costs.

**Total Costs**

<table>
<thead>
<tr>
<th>Expense Areas</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staffing</td>
<td>$41,716</td>
</tr>
<tr>
<td>Marketing</td>
<td>$13,329</td>
</tr>
<tr>
<td>Programming</td>
<td>$923</td>
</tr>
<tr>
<td>In-Kind Support</td>
<td>$0</td>
</tr>
<tr>
<td>Indirect Costs</td>
<td>$13,992</td>
</tr>
</tbody>
</table>

**Total Program Cost** **$69,960**

**Funding**

An estimated total cost of $69,960 will be necessary for the L.E.A.P.P. to Recovery from Breast Cancer program, as detailed in the previous budgeting section. Three potential funding sources have been identified as appropriate matches for the L.E.A.P.P. to Recovery from Breast Cancer program.

The first prospective funding source that was found is a grant provided by the National Institutes of Health (NIH), in coordination with the National Cancer Institute (NCI). The title of the grant is Cancer Education Grants Program (R25). This funding opportunity is available to
non-profit organizations to support the development of effective and innovative education approaches to translate knowledge gained from science. The total amount awarded and the number of awards will depend on the quality, duration, and costs of the applications received. The direct costs have a ceiling limited of $300,000 for one year, and no stated floor limit. Any individual with the skills, knowledge, and resources necessary to carry out their proposed program is invited to apply and will be viewed as an eligible program director. Applications must be submitted electronically at www.grants.gov/applicants. It is believed that the L.E.A.P.P. to Recovery from Breast Cancer program would have a high probability at receiving the Cancer Education Grants Program. The proposed program fits all of the Cancer Education Grants Program’s guidelines and eligibility criteria. Also, the National Cancer Institute has provided numerous grants in the past to support programs educating breast cancer survivors.

The second prospective funding source that was found is a grant provided by the Kroger Company Foundation. The purpose of the Kroger Company Foundation is to enhance the quality of life in communities with a concentration of Kroger customers and employees. Only organizations that serve the geographic areas where Kroger operates are eligible. The Foundation will consider only proposals from nonprofit organizations. Support will be provided only to programs that address a clearly identified need in the community. Breast cancer and women’s health is an area of eligibility for grant request. No award amount information was provided. Proposals may be submitted at any time through the operating divisions of the company. The Foundation has no research staff and relies exclusively on the management of Kroger operating units to make recommendations on the most appropriate and effective use of the Foundation’s resources in the communities they serve. It is believed that the L.E.A.P.P. to Recovery from Breast Cancer program has a good possibility of receiving financial support from the Kroger
Company Foundation. The Foundation is very eager to enhance the quality of life in communities with a concentration of Kroger customers and employees. In 2005 alone, the Kroger Company Foundation contributed $142 million to local communities and non-profit organizations throughout the country. The L.E.A.P.P. to Recovery from Breast Cancer program’s services will directly assist women in the community and the proposed program fits all of the Foundation’s guidelines and eligibility criteria.

The third prospective funding source that was found is a grant provided by the Northwest Ohio Affiliate of Susan G. Komen for the Cure. The purpose of their program is to address the breast health and/or breast cancer screening, treatment, and education needs of women in Northwest Ohio and Monroe County Michigan. After conducting a needs assessment, they found that programs need to be developed focusing on breast health education, breast screening services, and treatment services for breast cancer survivors. The application for this grant can be found on the internet at http://www.komennwohio.org/affiliate_info/grants.html. This is an annual grant and through research I found that the 2010 grant application will be available at the previously mentioned website sometime in August of 2009. The application for this particular grant is very extensive and detail specific. When the application is completed it needs to be sent to the Northwest Ohio Affiliate of Susan G. Komen for the Cure, 3100 West Central Avenue, 2nd floor, Toledo, Ohio 43606. All components of the application need to be included along with proof of nonprofit status, a list of current board of directors for the organization, and a current operating budget for the organization. There needs to be one signed original copy with all attachments and ten copies of the proposal without attachments. It is believed that the L.E.A.P.P. to Recovery from Breast Cancer program has a great chance of receiving financial support from the Northwest Ohio Affiliate of Susan G. Komen for the Cure. In a community profile conducted
by this foundation, there were more than 1,025 newly diagnosed cases of invasive breast cancer last year. 192 women died from breast cancer in the same year which leaves over 833 new survivors living with the effects of breast cancer treatments in Northwest Ohio. The L.E.A.P.P. to Recovery from Breast Cancer program’s services will directly assist survivors in the community. The proposed program also fits all of the Foundation’s guidelines and eligibility criteria.

Self-Sufficiency Plan

It is imperative that a plan is prepared for the continuation of the L.E.A.P.P. to Recovery from Breast Cancer program. It is predicted that once the program had effectively made it through the first year, ProMedica, the governing health system, will be able to take on most of the maintenance costs for the program.

The self-sufficiency plan for the years following the initial year is based on charging participants a fee for our services. The initial grant money will cover the development costs of the program. Therefore, the leftover costs that will need to be covered in subsequent years will be $52,300 per year. This amount will cover the cost for fliers, brochures, programming materials, and the salary of the part-time occupational therapist. With this in mind the fee charged for participants of the L.E.A.P.P. to Recovery from Breast Cancer program will be relatively low, encouraging future patients to participate. It can roughly be estimated by dividing $52,300 by the average total population sample size of 390 participants that each participant will need to be charge $135 to cover the cost of the program. To allow for a small profit at the end of the year the charge would be increased to $150 per patient.

Based on conversations with Lymphedema Clinic staff, I learned of another opportunity for the future of the program. There is a high possibility of getting the costs of the L.E.A.P.P. to
Recovery from Breast Cancer program covered by internal grants through the ProMedica System. These internal grants are have been used in past years to pay for educational programming throughout ProMedica affiliated hospitals. Lymphedema Clinic staff feel that it would be highly probable that my program would be covered an internal grant, therefore making the cost to participants $0.

Program Evaluation

Evaluation Procedures

The L.E.A.P.P. to Recovery from Breast Cancer program will utilize four program evaluation methods, two formative evaluations and two summative evaluations. The first formative evaluation will be continuously performed throughout the life of the program to determine the overall effectiveness of the program. As previously stated, the goal of the L.E.A.P.P. to Recovery from Breast Cancer program at the Total Rehab Lymphedema Clinic on the Flower Hospital Campus is to reduce the risk of developing lymphedema by providing pre-operative education to women with breast cancer. Therefore we need to determine how many of our program’s participants end up developing lymphedema. To accomplish this, all breast cancer related lymphedema patients that are admitted to the Total Rehab Lymphedema Clinic on the Flower Hospital Campus will be asked at his/her initial evaluation if they had previously participated in the L.E.A.P.P. to Recovery from Breast Cancer program. If the patient responds yes, they have participated in the L.E.A.P.P. to Recovery from Breast Cancer program, his/her name will be documented in a file entitled Participant to Patient that will be kept on site in the L.E.A.P.P. to Recovery from Breast Cancer filing cabinet. A structured interview (Appendix Q) will be conducted with the patient discussing compliance with education material. This interview will be also be placed in the file entitled Participant to Patient and the Total Rehab Lymphedema
Clinic occupational therapist will notify the L.E.A.P.P. to Recovery from Breast Cancer program occupational therapist of the patient.

The second formative evaluation will be continuously performed throughout the first year of the program to help improve the program and identify the program’s strengths and weaknesses. An analysis of the patient’s pre-session post-session scores on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D) will be performed within one day of the patient’s discharge. This formative evaluation will help judge if the seven objectives of the program were met.

The third evaluation of the L.E.A.P.P. to Recovery from Breast Cancer program will be a summative evaluation and take place at the end of the first year in the month of December. An analysis of all patients’ pre-session post-session scores on the L.E.A.P.P. to Recovery from Breast Cancer Knowledge Questionnaire (Appendix D) will be performed. This summative evaluation will help judge the overall quality of program and its seven objectives. It will also provide a starting point for deciding the program’s future. Through the completion of this evaluation we will be able to identify patterns across the program to locate areas of weakness in the program that need to be tweaked or changed.

The forth and final evaluation of the L.E.A.P.P. to Recovery from Breast Cancer program will also be a summative evaluation and take place at the end of the first year in the month of December. An analysis of participants’ referral sources will be conducted. Patient referral sources will then be compared to the sites where in-services were conducted for oncologists and oncology support staff. This summative evaluation will help judge the overall effectiveness of our marketing tools and help determine our main referral sources. Appropriate changes will be made to the program’s marketing campaign reflecting the findings of this evaluation.
Stakeholders

The key stakeholders for the L.E.A.P.P. to Recovery from Breast Cancer program are the breast cancer patients themselves. The overall effectiveness of the program will depend on the feedback and input of the patients. Any feedback and/or input offered by a patient during or anytime after a treatment session will be systematically documented on the Stakeholder Feedback Form (Appendix R) and filed on site. The clinical coordinator of the Total Rehab Outpatient Clinic, Leslie Vassar, OTR/L, will also be a key stakeholder for the program along with the Lymphedema Clinic therapists; Cindy Robertson, OT/L, Amy Huntsman, OTR/L, Diana Bergquist, COTA/L, and Lauren Mocniak, COTA/L. Any feedback and/or input offered by a clinician at anytime during the program will be systematically documented on the Stakeholder Feedback Form (Appendix R) and filed on site in the same folder as patient feedback. Quarterly reviews of stakeholders’ feedback will be reviewed, summarized and searched for themes. Appropriate adjustments will be made to the program reflecting the findings.

Timeline

<table>
<thead>
<tr>
<th>Task</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>February</td>
</tr>
<tr>
<td>March</td>
<td>April</td>
</tr>
<tr>
<td>May</td>
<td>June</td>
</tr>
<tr>
<td>July</td>
<td>August</td>
</tr>
<tr>
<td>September</td>
<td>October</td>
</tr>
<tr>
<td>November</td>
<td>December</td>
</tr>
</tbody>
</table>

- **Receive Grant**
- **Hire an Occupational Therapist**
- **Marketing: in-services**
- **Marketing: to potential participants**
- **Program Implementation**
- **Monthly Meetings with Lymphedema Clinic Staff**
- **Formal Evaluation**

*Represents times of strong emphasis on task*

*Represents times of maintaining task with decreased emphasis*
Letters of Support

A letter supporting the L.E.A.P.P. to Recovery from Breast Cancer program (Appendix Q) was completed by Cindy Robertson, OT/L in 2008. Cindy is an occupational therapist who works at the Total Rehab Lymphedema Clinic. Cindy was a fundamental component in the creation of this new program. She has worked at the clinic for over ten years and has seen the correlation between breast cancer and upper extremity lymphedema. She has treated numerous breast cancer related lymphedema cases and fully understands the need for preventative education. Cindy Robertson was chosen to write the first letter of support due to her complete understanding of the program and her eloquence to explain the need of the program to others.

Five additional sources have been identified as appropriate supporters of the L.E.A.P.P. to Recovery from Breast Cancer program and would be approached to provide the program with a letter of support (Appendix R). The first is Leslie Vassar, OTR/L. She is the clinical coordinator of Total Rehab Outpatient Clinic. She will be the direct supervisor for the L.E.A.P.P to Recovery from Breast Cancer program. Leslie has been aware of the program from its earliest conception. She has always been in full support of the program and understands the importance of providing education to patients as a key method of prevention.

The second is Denise Braden. Denise is a lymphedema therapist certified through the Lymphedema Association of North America who works throughout the Northwest Ohio Area. She has spent much time throughout her professional history working with breast cancer related lymphedema and fully understands its debilitating effects on patients. Denise has recently become aware of the L.E.A.P.P to Recovery from Breast Cancer program and is very confident in the positive effect it will have on participants.
The third is the Northwest Ohio Affiliate for Susan G. Komen for the Cure. Their mission is to eradicate breast cancer as a life-threatening disease by advancing research, education, screening, and treatment. The Northwest Ohio Affiliate is in full support of providing education and treatment to women with breast cancer to decrease negative side effects of the disease. They currently provide a grant annually that I had previously described. The grant supports education programs for women with breast cancer. Therefore, the Northwest Ohio Affiliate for Susan G. Komen for the Cure would be a likely supporter.

The fourth is Renee Schick. Renee is the proprietor of Renee’s Survival Shop. Renee’s Survival Shop provides quality products and information for women with breast cancer to assist them in post treatment care. Renee is knowledgeable on lymphedema and provides compression therapy products in her store. The shop has been a constant resource for therapists at the Total Rehab Lymphedema Clinic to refer patients to. Therefore, Renee Schick would be a likely supporter.
References


Appendix A

Organizational Structure
Appendix B
Systematic Field Observation Notes
Subject Observed (circle): Client  OT  OTA

Session Observed (circle): Initial Client Evaluation
    Treatment Session
    Discharge Session
    Team Meeting
    Support Group

Topics Discussed:
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________

Therapeutic Assessment/Techniques Performed:
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________
___________________________________________________________________

Patient Concerns:
___________________________________________________________________
___________________________________________________________________

Therapist Concerns:
___________________________________________________________________
___________________________________________________________________

Appendix C
Lymphedema Education and Support Survey
This survey is meant to gain important information about the lymphedema education being provided prior to surgical intervention for women with breast cancer. Select answers based upon your own perceptions and experiences. Your responses will be confidential and used only for program development purposes. Your time and assistance is greatly appreciated. Thank you!

Age: ____

Breast Cancer Diagnosis Date: ______________

Stage of Breast Cancer when diagnosed: ________________________________

What type of surgery did you have? ________________________________

How many lymph nodes did you have removed? ________________________________

Have you gone through any other treatments?
   ____ Chemotherapy
   ____ Radiation
   ____ Medications
   ____ Other treatment: ________________________________

When did you first notice the effects of lymphedema? ________________________________

Before your surgery, did you know what lymphedema was? ____
   *If yes, who/what was your first source of information?
      ____ Surgeon or other doctor
      ____ Reading Materials
      ____ Other Breast Cancer Patients
      ____ Other (please describe) ________________________________

Did you receive information on the prevention and management of lymphedema prior to surgery? ____

Could you have benefited from having an educational support group on lymphedema prior to surgery? ____

Would you have attended an education support group on lymphedema prior to surgery if one was offered? ____

What do you wish you knew about lymphedema before your surgery? ________________________________
Do you think learning about lymphedema before your surgery would be helpful, or is it better to learn about lymphedema after it has already developed? YES__ NO__

If you are currently employed, do you experience any complications from having lymphedema that affect your employment? 
_____ Yes ____ No ___ n/a

If yes, please list the complications that affect your employment? _________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Do you experience any problems performing occupations of daily living due to lymphedema (i.e. bathing, dressing, eating, etc.)?
_____ Yes ____ No

If yes, please list complications? ____________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Please list any comments you have on education and support for women who have breast cancer and have acquired lymphedema as a result of surgical intervention or other treatments for your breast cancer.
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

Thank you for you time and assistance!
Appendix D
L.E.A.P.P. to Recovery from Breast Cancer
Knowledge Questionnaire

Name: ___________________________ Pre-test Date: _________
Breast Cancer Diagnosis Date: ________ Post-Test Date: ______
Referring Physician: ______________

Please answer the following questions to the best of your ability.

What is the cause of lymphedema?
○

Please list five warning signs and symptoms of lymphedema.
1.
2.
3.
4.
5.

Please list five components of a lymphedema treatment program.
1.
2.
3.
4.
5.
Please list five factors that put you at a higher risk of developing lymphedema.

1. 
2. 
3. 
4. 
5. 

Please list five lymphedema prevention techniques.

1. 
2. 
3. 
4. 
5. 

At this time…

Could you demonstrate post-operative positioning of the potentially affected upper extremity?  
Yes ___  No ___  
* If yes, at this time please demonstrate.

Could you demonstrate therapeutic exercises that can be performed post surgery?  
Yes ___  No ___  
* If yes, at this time please demonstrate.

Thank you!
L.E.A.P.P. TO RECOVERY FROM BREAST CANCER

Lymphedema Education and Awareness for Pre-surgical Patients

The L.E.A.P.P. to Recovery from Breast Cancer Program provides pre-operative education to women with breast cancer to reduce the risk of developing lymphedema.

Total Rehab Lymphedema Clinic on the Campus of Flower Hospital
5150 Harroun Road
Ground Floor of the Flower Hospital Rehabilitation Center on the south side of the Flower campus next to Lake Park

For more information call #419-824-1116
www.promedica.org/rehab
Appendix F

Sample Brochure

L.E.A.P.P. to Recovery from Breast Cancer

Total Rehab Lymphedema Clinic on the Campus of Flower Hospital

Lymphedema is a condition that occurs when fluid accumulates in the interstitial space due to insufficiency of the lymphatic system causing swelling. Chronic inflammation results in feelings of heaviness, numbness, discomfort, and sometimes infection. Lymphedema is a frequent side effect of a mastectomy because of the removal of the lymph node for biopsy. Once an individual is diagnosed with breast cancer they then have a 25% chance of developing lymphedema following breast cancer treatment. It may appear weeks to years after the breast is removed.

WHAT IS LYMPHEDEMA?

Program Benefits:

Participants will learn:

- Warning signs and symptoms of lymphedema
- Lymphedema risk factors
- Lymphedema prevention techniques
- Lymph drainage massage techniques
- Post-operative positioning of the potentially affected arm
- Therapeutic exercises that can be performed post-surgery

Total Rehab Lymphedema Clinic on the Campus of Flower Hospital

150 North Main Street
Ground Floor of the Flower Hospital Rehabilitation
Phone: 413-824-1116
Email: lymph.patient@florihospital.com

Normal Lymph Drainage

Lymph Nodes
Appendix G

How Arm Lymphedema Happens

**How Arm Lymphedema Happens**

Lymphedema of the arm is an accumulation of lymph fluid in the soft tissues of the arm, with accompanying swelling (also called edema). To understand how it happens, you have to know a little bit about how blood and lymphatic fluid move around your body.

To keep from getting backed up, fluid has to keep moving within networks of vessels and channels. Blood travels from your heart to your arm in arteries and capillaries (the small blood vessels that connect arteries to veins). As the blood moves through the capillaries, it drops off important supplies to the cells in your arm: oxygen, nutrients, and a clear, colorless fluid called lymphatic fluid. The used blood keeps moving and travels back to the heart and lungs, where it gets refreshed. With every beat of your heart, fresh blood returns to your arm with fresh supplies.

Lymph fluid also has to keep moving through the tissues of the arm back into the bloodstream. This fluid flows in another type of vessel, called lymphatics.

**Lymph nodes in and around the breast area**

A pectoralis major muscle

B axillary lymph nodes: levels I

C axillary lymph nodes: levels II

D axillary lymph nodes: levels III

E supraclavicular lymph nodes

F internal mammary lymph node
The muscles in your arm and contractions in the walls of the lymphatic channels push lymphatic fluid up your arm. Valves in the lymph vessels keep fluid moving forward. The lymphatic channels pass through bean-shaped structures called lymph nodes, which are located under the arm, and in the neck, groin, and other areas. Lymph nodes filter out bacteria, waste products, and toxic substances from the lymphatic fluid. The trapped material is broken down and excreted from the body. Eventually, the used lymphatic fluid leaves the arm, joins the used blood within the veins, gets refreshed in the lungs, and is then pumped back to the tissues by the heart.

Lymphatic fluid contains lots of nutrients. It's an easy target for bacteria that may find their way past the protection of the skin. Bacteria can get in even through something as seemingly innocent as a torn cuticle or a splinter. If bacteria do get in, they can cause infection. Infection, in turn, results in increased blood flow to fight the bacteria—and more lymphatic fluid accumulating and needing to be drained away.

You can think of lymphedema as a plumbing problem: Veins and lymphatic channels are like pipes and drains that can handle the normal load of lymphatic fluid. If lymph nodes and channels are removed, there might not be enough pipes and drains to handle all the fluid.

This can become a real problem when blood flow to your arm increases because of an infection, a burn, overusing the muscles of the arm, or even a bug bite. In these situations, the increased amount of lymphatic fluid flowing in can sometimes be too much for the arm's lymphatic vessels. If the fluid channels can't keep up with all that extra fluid, the fluid begins to back up and gather in the spaces between the cells of your arm's soft tissues. These tissues include the skin, fat, muscle, nerves, blood and lymphatic vessels, and connective tissue. The swelling resulting from this buildup of lymphatic fluid is called arm lymphedema.

Lymphedema can affect the whole arm or only a limited portion, such as the hand, the wrist area, the area below the elbow, or, much less often, only the area above the elbow. Lymphedema can also affect the breast area, because the fluid from that area also needs to drain through the underarm to get back into circulation.

Some women have mild lymphedema, which is hardly noticeable. Some develop moderate lymphedema that may be noticeable, tends to persist, and gets worse when aggravated. Others have severe lymphedema that is very uncomfortable and even disabling. For all of these cases, there are treatments that can help ease the discomfort and lower the swelling.
Lymphedema is a type of abnormal swelling of an arm or leg. Swelling ranges from mild, hardly noticeable changes in the size of your limb to extreme swelling that can make it impossible to use the affected arm or leg.

Lymphedema symptoms include:

- Swelling, mild or severe, in the arm, leg, breast, abdomen or anywhere else, as well as in areas affected by surgery, radiation, infection or circulatory problems
- A feeling of heaviness or tightness in your arm or leg
- Restricted range of motion in your arm or leg
- Aching or discomfort in your arm or leg
- Recurring infections in your affected limb
- Hardening and thickening of the skin on your arm or leg
- Pain, with or without visible swelling
- The skin may take on the appearance of an orange peel
Appendix I

Treatment Options for Lymphedema

Lymphedema is an abnormal build up of lymph fluid. This condition may occur when an interruption in the lymphatic flow causes fluid to accumulate usually in the arms or legs.

Left untreated, patients may experience:
- Increased risk of infection
- Increased pain in affected areas
- Worsening of swelling and/or dysfunction
- Decrease and possible loss of use of affected extremity and interference with normal activities

New techniques have been developed to help you manage the symptoms of lymphedema. It is no longer something “you just have to live with.”

What is the Cause?
Lymphedema is often caused by damage to the lymphatic system leading to a disruption in the normal lymph flow. An individual may also be born with a poor functioning lymphatic system which causes lymphedema to occur.

Risk factors for developing lymphedema may include:
- Lymph node removal
- Radiation therapy
- Chronic skin infections
- Venous insufficiency

Signs and Symptoms
- Swelling, mild or severe. In the arm, leg, breast, abdomen or anywhere else, as well as in areas affected by surgery, radiation, infection or circulatory problems
- Skin thickening in swollen areas
- Pain, often described as an “ache,” with or without visible swelling
- The skin may take on the appearance of an orange peel

Treatment Options
After receiving a referral from a physician, a specially trained therapist will conduct an evaluation to develop a program that meets your needs.

- Treatment is focused on teaching the patient how to achieve and keep the condition under control.
- Treatment involves a special type of massage to re-route fluid away from problem areas.
- Instruction in use and application of special bandages.
- Instruction in specialized exercises and self-massage.
- Instruction to prevent future swelling and infection.
Lymphedema Risk Factors

Who's at Risk?

If you've had an underarm lymph node dissection (with mastectomy or lumpectomy), you are at risk for developing some degree of lymphedema. Radiation treatment to underarm lymph nodes, as well as chemotherapy treatment, can add to the risk.

Researchers disagree about how big or small the risk of lymphedema actually is. Risk is usually expressed as a percentage: how many people out of 100 will develop lymphedema following treatment for breast cancer. According to some estimates, the figure is between 10% and 15% (10 or 15 people out of 100), or as high as 35% (35 people out of 100) in certain situations. But it's clear that the more treatment you've had, the higher your risk of developing lymphedema.

The risk is the same after a mastectomy with lymph node dissection as it is after a lumpectomy with lymph node dissection. Radiation after either surgery increases the risk of lymphedema.

A relatively new technique of lymph node dissection, called sentinel node dissection, aims to identify and remove only the underarm lymph nodes most likely to contain cancer cells that could have spread beyond the breast. This technique may lower the risk of developing lymphedema because fewer lymph nodes are removed, leaving more lymph fluid drainage channels in tact.

Some women may be at a higher risk for developing arm lymphedema than others. Lymphedema can happen just weeks after surgery, or years after initial cancer treatment. Factors that may increase your risk include:

- **Being Very Overweight**: this can limit the flow of blood and lymph fluid in and around your arm
- **Being a Heavy Smoker**
- **Having Diabetes**
- **Overuse of the arm**
- **Previous Surgeries in the Armpit Area or on Your Arm**
- **Traumas to the muscles or skin of the arm that can lead to infection**. These include scratches, bug bites, sunburn, kitchen burns, garden cuts, plant rashes (poison ivy or oak), skin cracking from chronic dryness, and skin tears from nervous picking habits.
- **Gaining a lot of weight after breast cancer treatment**. Like being overweight to start with, gaining weight increases your risk for arm swelling.
- **Heat**. Because it widens blood vessels, heat allows more fluid to get into an area at risk for swelling. Very hot weather and sitting in hot tubs can bring on lymphedema.
- **Blood clots**. Occasionally, a blood clot in the axillary (underarm) vein will back up fluid in the arm.
- **Long plane flights**. Although it's rare for a long flight to bring on lymphedema for the first time, it may worsen an existing case of lymphedema because of the changes in air pressure.
- **Extensive breast cancer in the lymph nodes**. This uncommon cause of lymphedema can occur if the cancer blocks the free flow of lymph fluid trying to drain through the nodes.
Appendix K

How to Avoid Lymphedema

Current methods of breast cancer treatment lower the risk of developing lymphedema. But if you had a radical mastectomy many years ago, you may have had arm swelling, or you may still be at risk for the condition. Prevention is very much in your best interest. Even the safest and most effective therapy may only delay the condition or keep it from worsening. Immediate care is essential with any trauma or infection.

Prevention is the best tool against arm lymphedema. Learn the warning signs and the precautions to take. Make these guidelines and a heightened awareness a regular part of your life.

Skin care is your first line of defense. Since the skin acts as a barrier to infection, any disruption of the skin can spell trouble. Burns, chafing, dryness, cuticle injury (such as hangnails), cracks, cuts, splinters, and insect bites are immediate risks for infection.

Learn to recognize the signs of infection:

- fever
- redness
- swelling, warmth, or tenderness in the at-risk arm

Infection and inflammation can escalate quickly. Redness, tenderness, and warmth can spread from the injury up your arm. Call your doctor as soon as you suspect infection. You may need to start antibiotics immediately with any early sign of trouble. If you already have swelling, or if you have diabetes (whether or not you have swelling) you may need antibiotics after just the smallest of injuries—even without any sign of trouble.

If you already have significant arm edema, sometimes a dental procedure may trigger an arm infection. This is because the work a dentist does on the tissues in your mouth may increase the number of bacteria circulating in your bloodstream. Vulnerable areas in the body, like the compromised drainage of a swollen arm, may become hangouts for the bacteria. If you've already had an arm infection following dental work, talk to your doctor about whether you should take prophylactic (preventive) antibiotics before future dental procedures.
Do's and Don'ts: Preventing Lymphedema

- 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.
- 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.
- Don't go from extreme hot to cold water temperatures when you bathe or wash dishes.
- 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 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.
- 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.
- Don't permit the skin of your at-risk arm to be pierced for any reason: injections, drawing blood, or vaccinations.
Post-Operative Positioning

Right after surgery, the affected arm or breast area may swell. This swelling is usually short-term and will slowly go away over the next 6-12 weeks. The following suggestions may help relieve the swelling:

- Raise your affected arm above the level of your heart for 45 minutes, 2-3 times a day while lying down.

- Fully support your arm!
  - Put your arm on pillows so that your hand is higher than your wrist and your elbow is slightly higher than your shoulder.

- Exercise your affected arm while it is supported above the level of your heart by opening and closing your hand 15-25 times. Repeat this 2-3 times a day. This exercise helps to reduce swelling by pumping lymph fluid out of the arm through the undamaged lymph vessels.
Appropriate Post Surgery Therapeutic Exercises

ALTERNATIVE ARM EXERCISES (wearing compression)

Deep breathing.

lower chin to chest

Tilt head toward shoulder

Look to right side

Look to left side

Take arm up/down in front

Take arm up/down out to side

Sweep arm across front

Big circles from shoulder

Elbow bending

Bend wrist up/down, wrist circles, hand squeezes

march in place

Appendix N
Total Rehab Lymphedema Clinic’s Lymphedema Support Group

Please join us for the Lymphedema Support Group meetings listed below at 7 p.m. at the Total Rehab Lymphedema Clinic at Flower Hospital.

Support group activities include:
- general discussions about lymphedema.
- a review of home management techniques.
- sharing helpful information.
- question and answer sessions.

Guest speakers will also join us to help educate and share important information as it relates to lymphedema.

Most importantly, participants develop a sense of comraderie and everyone benefits from sharing similar experiences.

For more information, call 419-824-1116

Meeting dates for 2009:
- Tuesday, March 24
- Tuesday, June 23
- Tuesday, September 22
- Tuesday, November 24

The Total Rehab Lymphedema Clinic is located on the campus of Flower Hospital at 5150 Harroun Road, Ground Floor of the Flower Hospital Rehabilitation Center on the south side of the Flower campus next to Lake Park

Friends and family welcome!

Appendix O
Occupational Therapist Job Description

**Job Description:**

The Lymphedema Education and Awareness for Pre-surgical Patients (L.E.A.P.P.) to Recovery from Breast Cancer program at the Total Rehab Lymphedema Clinic on the Flower Hospital Campus will employ an occupational therapist who is a graduate of an accredited occupational therapy program. The individual must be registered and certified by the National Board for Certification of Occupational Therapists (NBCOT). The individual must also be licensed in the state of Ohio to provide occupational therapy. The occupational therapist will be scheduled to work approximately 20 hours a week. The occupational therapist will be employed by the Total Rehab Lymphedema Clinic on the Flower Hospital Campus and will report to Leslie Vassar, OTR/L, the clinical coordinator for the Total Rehab Outpatient Clinic. No prior experience with this population is required, but enthusiasm to learn about this specific population is a must.

**Position Summary:**

Responsibilities include evaluation and education of patients with breast cancer who are scheduled to undergo surgical intervention. Marketing will also be a responsibility of the occupational therapist and will include conducting in-services to local hospital’s oncology units to promote the benefit of our program. Flexibility in schedule development is possible. Effective oral and written communication skills are a must. The occupational therapist must also be able to lift/transfer a minimum of 50 pounds.

Appendix P
L.E.A.P.P. to Recovery from Breast Cancer

Lymphedema Education and Awareness for Pre-surgical Patients

Occupational Therapy Opportunity!

Seeking Part-Time Occupational Therapist

New Graduates Welcome

Flexible Schedule

The L.E.A.P.P. to Recovery from Breast Cancer Program will provide pre-operative education to women with breast cancer to reduce the risk of developing lymphedema.

Please Send Resume to:
Leslie Vassar OTR/L, Clinic Coordinator
5150 Harroun Road
Ground Floor of the Flower Hospital Rehabilitation

Appendix Q
Participant to Patient Interview

Name: __________________________  Breast Cancer Diagnosis Date: _________

L.E.A.P.P. to Recovery Participation Dates: _____________ & ______________

Date of Lymphedema Onset: _______________

Were you able to follow the recommended Do’s and Don’ts form the L.E.A.P.P. to Recovery From Breast Cancer Program?

YES  NO

If Yes, which were you able to follow?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

If No, which ones were you not able to follow?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Why do you think you developed lymphedema?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Appendix R
Stakeholder Feedback Form

Stakeholder’s Name: ____________________________  Patient: ____  Clinician: ____

Source of Feedback (i.e. verbal, written): ____________________________

Feedback:

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Therapist Signature: ____________________________  Date: ________________

Appendix S
April 17, 2008

To Whom It May Concern:

This letter is in support of the pre-operative program Kristin Pitzen is developing for her Capstone fieldwork experience scheduled to begin January 2009. This is a program the staff at the Total Rehab Lymphedema Clinic has been planning to develop for several years and it has not been organized thus far. There is a need for these women at risk for lymphedema to have proper education and training for prevention of the condition.

I am looking forward to working with Kristin on developing the program over the next months and during her fieldwork here at the Lymphedema Clinic at Flower Hospital.

Thank you,

Cindy Robertson, OT/L
Contact Information for Support Letters

**Leslie Vassar, OTR/L**  
Clinical Coordinator of Total Rehab Outpatient Clinic  
5150 Harroun Road  
Ground Floor of the Rehabilitation Center  
Sylvania, Ohio 43560  
#419-824-1116

**Denise Braden, OTR/L, CLT-LANA**  
2751 Bay Park Drive  
Oregon, Ohio 43614  
#419-690-8400

**Northwest Ohio Affiliate for Susan G. Komen for the Cure**  
3100 W. Central Ave  
Suite 206  
Toledo, OH 43606  
Phone: 419-329-2137  
Fax: 419-537-1976

**Renee Schick, Owner**  
Renee’s Survival Shop  
5401 Secor Road  
Toledo, Ohio 43623  
#1-866-625-5550  
Fax #419-725-0090
Annotative Bibliography


There is no abstract for this American Cancer Society publication. This publication attempts to summarize current scientific information about breast cancer. Information found through this publication was used as part of the social indicators analysis to aid the investigation of need for the L.E.A.P.P. to Recovery from Breast Cancer program. A social indicators analysis was performed because it is vital for any new program to obtain and utilize regularly collected data on social and health status indicators to validate the importance of developing their new program.


Abstract: Breast cancer treatment is recognized as the most common cause of secondary lymphedema (LE) in the developed countries of the world. LE occurs as both an acute and chronic health condition in which significant and persistent swelling is associated with an abnormal accumulation of protein-rich fluid. The impact of LE is significant on a wide range of daily activities and survivorship quality of life. Measurement and quantification of LE has been problematic despite the fact that various methods have been used to measure limb volume (LV). Perhaps in part because of difficulties in measurement and diagnosis, the reported incidence of LE varies greatly among persons treated with surgery and radiation for breast cancer. Through increased measurement accuracy, LE incidence and prevalence following current therapeutic approaches for breast cancer will be better understood, and more informed decisions about risk
factors, treatment interventions, and recovery will be made. Further identification of epidemiology and clinical factors associated with risk and incidence will provide the necessary foundation for preventive intervention. Bilateral measurements at pre-op and over time are necessary to assess LV changes during follow-up, as it is important as part of the differential diagnosis to note whether volume change has occurred in the affected limb alone or in both limbs. Application of rigorous measurement protocols, assessment of symptom experience, and establishment of a data base on bilateral LV at pre-op for later comparison are essential components of a solid foundation for intervention studies. Through multidisciplinary collaboration with rigorous scientific approaches feasible to be carried out in the clinic setting, we have the opportunity to better target risk factors for development of LE, design data-based interventions, and improve post-treatment quality of life.

This study was beneficial to my Capstone because it stressed the importance of proper circumferential measuring techniques. Accurate measurements of the patients’ bilateral upper extremities need to be taken pre-operative to establish a base line measurement. This article also influenced my Capstone practicum by sparking an in-depth conversation with a lymphedema therapist on the protocol for edema measurements in the clinic. The author of this article is a leader in the field of lymphedema and breast cancer, therefore making the quality of this research article very high.


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 symptom experiences. 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., >or=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.

This study was useful in the development of the L.E.A.P.P. to Recovery from Breast Cancer Program. It educated me on three common symptoms experienced by patients with breast cancer related lymphedema; heaviness and numbness in the past, and swelling now. It also reinforced the importance of educating patients on prevention and risk reduction techniques. This
research study is very reliable. It was co-authored by Armer, a leader in the field of lymphedema and breast cancer, and had reliable methodology.


There is no abstract for this reference that came from the website breastcancer.org, a non-profit organization dedicated to providing the most reliable, complete, and up-to-date information about breast cancer. This source became very useful to the development of the L.E.A.P.P. to Recovery from Breast Cancer program. It provided a very good example of how to explain lymphedema to the general population and provided links to many more reliable resources.


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Abstract: The medical records of nine women who had acquired lymphedema as a sequela to a modified radical mastectomy for breast cancer were analyzed to ascertain what factors, phenomena, or experiences in their lymphedema treatment may have influenced outcomes. The women were identified as having either successful or poor outcomes. Their conservative lymphedema treatment consisted of compression pumps, compression garments, and, in some cases, manual lymph drainage. The qualitative analysis of records implicated the following factors in the outcome of conservative lymphedema treatment for these women: (a) the amount of delay before starting compression treatment, (b) the size of the lymphedematous arm when treatment started, (c) the availability of social and financial supports, and (d) the presence of complicating health problems.

This study was not very useful to any area of my Capstone. I chose to read it because it was one of the extremely few articles written on breast cancer related lymphedema printed in *The American Journal of Occupational Therapy*. The findings of this study cannot be generalized therefore the quality of this research article is low.

There is no abstract for this reference that came from the Centers for Disease Control and Prevention website. This publication attempts to summarize current scientific information about breast cancer. Information found through this publication was used as part of the social indicators analysis to aid the investigation of need for the L.E.A.P.P. to Recovery from Breast Cancer program. A social indicators analysis was performed because it is vital for any new program to obtain and utilize regularly collected data on social and health status indicators to validate the importance of developing their new program.


Abstract: Shoulder impairments are commonly associated with surgical treatments for breast cancer. The aim of this study was to describe the physical and demographic characteristics of patients with breast cancer referred to outpatient physical and occupational therapy clinics at Memorial Sloan Kettering Cancer Center with shoulder impairments and functional deficits. The outcome of rehabilitation interventions is reported and recommendations for therapy interventions are made. Method: Information on medical diagnosis, surgical interventions, physical impairments, functional deficits, and the outcome of rehabilitation interventions were obtained by a retrospective review of 49 charts. All patients were referred to outpatient physical and occupational therapy clinics at Memorial Sloan Kettering Cancer Center from July 2001 and
January 2003. Results: Patients with breast cancer may develop shoulder impairments following treatments for breast cancer. Decreased range of motion, decreased strength, sensory impairments, and increased pain are common deficits found in this patient population. Our study did not demonstrate a significant difference between shoulder impairments in patients who had received axillary lymph node dissection as opposed to sentinel lymph node biopsy. Shoulder impairments were seen immediately postoperatively or as long as 10 years after surgery. Various rehabilitation interventions were effective in improving shoulder impairments and functional status.

This study describes the demographics, physical characteristics, and rehabilitation outcomes of patients with breast cancer and shoulder impairments. Primary treatment effects, including lymphedema, and other reasons for shoulder dysfunction are discussed. This article was used to educate myself on the types of shoulder impairments that are seen in patients with breast cancer. Many times when treating patients with breast cancer related lymphedema other shoulder impairments are simultaneously occurring. The quality of this study is rather good due to the fact that comes from a very reliable hospital that is one of the leaders in breast cancer rehabilitation. The methodology of the study isn’t flawless though. The sample size of 49 patients was too small to generalize.


There is no abstract for this publication of the National Lymph Network. This educational article influenced my lymphedema treatment sessions by informing me of the significance good
skin care plays on infection control for patients with lymphedema. Information learned from this article was integrated into all treatment sessions and passed on to patients.


Abstract: Lymphoedema is a progressive and debilitating disorder, caused by malfunction of the lymphatic system. It is characterized by chronic swelling, usually of a limb but it can also affect other parts of the body. It is not curable but can be reduced and controlled. The mainstay of management is physical decongestive treatment, of which compression therapy is one of the four elements. The simplest and most cost-effective method of applying compression is with elastic compression garments. Essential for their success are a perfect fit and appropriate selection of compression class and stocking material. Elvarex, manufactured by JOBST, is a range of custom-made compression garments for both upper and lower limbs, available in a wide variety of styles and options. The flat knitting process provides superior fit and effective long-term management of lymphoedema.

This article was very beneficial to the Practicum portion of my Capstone. When I first began working with therapists at the lymphedema clinic, I was informed that the “Cadillac” of all compression garments was the Elvarex created by Jobst. The flat knit weave used to create the fabric was what set the Elvarex apart from other compression garments. This article reinforced what I was taught at the Total Rehab Lymphedema Clinic and described in more detail the clinical benefits of having patients purchase Elvarex Compression garments over other options.

There is no abstract for this article retrieved from Medscape. Johnstone and Mondry state that the management of lymphedema should always begin with preoperative evaluation and education. Evaluation should include recording circumferential measurements of the upper extremities to form baseline measurements. Pre-operative education should include lymphedema risk factors, lymphedema prevention techniques, lymphedema treatment, long-term management techniques, and possible complications with surgery in relation to occupational performance. This article was very influential in the L.E.A.P.P. to Recovery from Breast Cancer program.


There is no abstract for this publication from Juzo. The purpose of this information booklet is to create awareness and understanding about lymphedema and educate for its prevention. The therapists at the Total Rehab Lymphedema Clinic on the campus of Flower Hospital suggested that I read this information booklet to get a better understanding of how to explain the entire lymphedema treatment process to patients. With so much information to educated patients about it is easy to overwhelm them. This source was a very useful guide for me during patient education.


There is no abstract for this publication from Jobst. The purpose of this information booklet, which is based on the latest medical and scientific knowledge, is to tell the patient more
about living with lymphedema. The therapists at the Total Rehab Lymphedema Clinic on the campus of Flower Hospital suggested that I read this information booklet to get a better understanding of how to explain the entire lymphedema treatment process to patients. With so much information to educated patients about it is easy to overwhelm them. This source was a very useful guide for me during patient education.


This source was a suggested read by Denise Braden, a LANA certified occupational therapist. It turned out to be the most comprehensive and accurate resource I found on lymphedema. This source educated me on the anatomy and physiology behind the lymphatic system, the components of a thorough evaluation, and the proper clinic skills required to manage the symptoms of an abnormal lymphatic system. I spent a good amount of my mentored studies time reading this book and outlining the chapters for future reference.


Abstract: Breast radiotherapy has a low incidence of long term complications. Lymphedema is the most commonly reported complication and adversely affects the quality of life of the breast carcinoma patient. Although its incidence is decreasing, lymphedema still remains a significant concern for patients and their physicians. With the indications for radiotherapy in breast carcinoma management broadening, current strategies to prevent radiation-related lymphedema should be applied and new strategies should be developed. A review of the literature addressing lymphedema as a complication of radiotherapy in breast carcinoma management was performed. Arm, breast, and truncal edema occur after primary breast carcinoma management. The literature
supports the view that radiotherapy contributes to arm and breast edema. Lymphedema occurs most commonly in patients who have both axillary radiotherapy and surgery, is often triggered by a soft tissue infection, and is more common in obese patients. The incidence of arm edema is decreasing due to more conservative surgical treatment of the axilla and possibly due to more conservative management of the breast. Trends in breast edema are less discernible. Single-modality treatment of the axilla is associated with a very low incidence of arm edema.

Lymphedema continues to be a problem in the care of the breast carcinoma patient. More conservative surgery combined with careful patient selection for nodal radiotherapy reduces its incidence. Radiotherapy technique, prompt treatment of soft tissue infections, and weight loss in obese patients each can contribute to prevention. The risk of lymphedema is greatly surpassed by the benefits of radiotherapy in the care of the breast carcinoma patient.

This article was very beneficial to my Capstone. I had originally thought that breast cancer related lymphedema was solely caused by the removal of lymph nodes for biopsy during surgery. When I started working with the therapists at the Lymphedema Clinic I was taught the other main risk factor for breast cancer related lymphedema was radiation treatments. This article reinforced what I was taught at the clinic. The quality of this research article is very high due to the chosen method of conducting and summarizing a review of literature.


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.

This article from the Mayo Clinic College of Medicine focuses on the importance of managing lymphedema through a multidisciplinary approach. It also provides an overview of the diagnosis, prevention techniques, and treatments for breast-cancer related lymphedema which was very helpful in the development of my program. The methodology of this study was 15 individual semi-structured interviews, therefore the quality of this research article is not good.


There is no abstract for this reference from the National Breast Cancer Coalition. The National Breast Cancer Coalition has launched a Quality Care Initiative to improve the quality of breast cancer care in the United States. This issue is the most important and challenging issue facing breast cancer activists and aims to increase access to and improve the quality of breast cancer care. This resource was used in the development of the L.E.A.P.P. to Recovery from
Breast Cancer program, and was referenced in Federal Initiatives and National Trends section of the program development plan.


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There is no abstract for this publication of the National Lymphedema Network. This position paper influenced my lymphedema treatment practice by informing me of the significance exercise plays on edema reduction and maintenance in patients with lymphedema. Information learned from this article was integrated into all treatment sessions and passed on to patients.

There is no abstract for this publication of the National Lymphedema Network. This position paper influenced my lymphedema treatment practice by informing me of the significance air travel plays on patients with lymphedema. Information learned from this article was integrated into all treatment sessions and passed on to patients.


There is no abstract for this publication of the National Lymphedema Network.

This position paper became very useful in the development of the L.E.A.P.P. to Recovery from Breast Cancer program. It served as a reliable resource for gaining risk reduction techniques for people with lymphedema. Information gained from the website was incorporated into the program.


Abstract: The author, Susan Nesbit, was diagnosed with breast cancer in March 2000, and hearing the words, "Your mammography and clinical breast exam suggest that you may have cancer," started her on a journey through the wilderness. Her wilderness included diagnostic and staging procedures and a treatment protocol of chemotherapy, surgery, radiation, and more chemotherapy. Nesbit guided herself through the wilderness using several skills and foundations of occupational therapy. She used advocacy with good communication skills, prevention of potential problems, values clarification, spirituality, psychological strategies, support with empathy, teaching, and cognitive strategies. Several contexts-the cultural (e.g., valuing her new
body without breasts and using mind-body techniques for healing), the physical (e.g., taking
attachment objects to the hospital in a special box), the social (e.g., relating to friends,
colleagues, and physicians), and the spiritual (e.g., participating in ceremonies)-influenced her
occupational performance during her journey.

This source was not useful in any part of my Capstone. It did however reinforce the need
of occupational therapists to provide holistic treatment when working with patients.


Abstract: Lymphedema is an understudied consequence of surgery for breast cancer. It is
estimated that as many as 60% of breast cancer survivors report symptoms of lymphedema. Few
studies have examined the impact of lymphedema on the lives of women with breast cancer. The
goal of this pilot study was to identify knowledge about, treatment received for, and the effect of
lymphedema among a group of breast cancer survivors and physicians. Forty women with
lymphedema and 10 physicians who treat breast cancer patients participated. Overall, women
knew little to nothing about lymphedema before they developed it. After diagnosis, the primary
source of information about lymphedema was a doctor or physical therapist. The majority of
women received compressive garment therapy (75%), 46.9% received mechanical compressive
therapy, 26% received bandaging, and 22% received physical therapy. More than half (55%)
reported that clothing and appearance were affected by their condition and 48% reported that
routine daily activities were impaired. Hot weather (58%) and regular arm use (40%) were
reported to exacerbate the swelling. Most physicians reported that they did not routinely counsel
women or provide written information on lymphedema prevention to their patients, and the
extent to which women's daily living was affected by the condition was not always recognized. These findings have implications for interventions aimed at educating women and providers about lymphedema.

This article was very beneficial to my Capstone Program Development Plan. Overall, women who participated in this study knew little to nothing about lymphedema before they developed it. Therefore, the findings of this research support the need of the L.E.A.P.P. to Recovery from Breast Cancer Program. Also, this research article found that most physicians reported they did not routinely counsel women or provide written information on lymphedema prevention to their patients, and the extent to which women's daily living was affected by the condition was not always recognized. Therefore, this article also supports the program’s marketing plan to provide educational in-services to physicians to educate them on the benefits of the program. The quality of this research article is good due to methodology used.


Abstract: Cancer treatment is the leading cause of lymphedema in developed countries. Development and severity of lymphedema have a significant impact on comfort, psychological distress, and overall quality of life. Incidence statistics have ranged from 5%-60%, with onset of symptoms ranging from immediately after treatment to 30 years after treatment. Oncology nurses caring for patients throughout the cancer trajectory have a critical role to play in early assessment of risk, prompt identification of lymphedema, and implementation of evidence-based, individualized treatment plans in collaboration with therapists. As part of an Oncology Nursing
Society (ONS) project team, the authors of this article undertook a review of current literature to identify effective interventions for the treatment of secondary lymphedema. Following the guidelines established by the ONS Evidence-Based Practice Resource Team, the authors evaluated current clinical practice guidelines, systematic reviews, and research studies conducted since 1998. The team reviewed and synthesized the literature and developed evidence tables and a Putting Evidence Into Practice(R) (PEP) card. The data were reviewed by experts in the field of lymphedema management. The lymphedema ONS PEP card, a user-friendly, succinct summary of interventions, was released at the 33rd Annual ONS Congress in May 2008.

This article from the Clinical Journal of Oncology Nursing did a good job of providing a comprehensive look at lymphedema. The content of this article was very beneficial to my overall understanding of lymphedema. Although this reference was not sited in the Program Development Plan, much was learned from reading this article and implemented in the Lymphedema Clinic during practicum hours. The quality of this article is very good to the methodological review of literature.


Abstract: PURPOSE/OBJECTIVES: To investigate chronic condition representations and treatment choices among women with post-breast cancer lymphedema (LE) to understand their receipt and use of accurate medical information. DESIGN: Qualitative, template analysis. SETTING: Midsized midwestern city and surrounding rural areas. SAMPLE: 18 Caucasian women aged 37-87 years (mean = 58.8 years) with lymphedema. METHODS: Telephone and
face-to-face interviews, lasting 45-60 minutes, were conducted by research students and graduate nursing students. Interviews were audiotaped, professionally transcribed, and verified for transcription accuracy. Self-regulation theory as a template was applied to (a) understand participants' use of health information to cope with LE and (b) evaluate the accuracy of participants' health information that may have influenced participants' abilities to make appropriate prevention or treatment choices. MAIN RESEARCH VARIABLES: Participants' illness representations and coping strategies. FINDINGS: Participants were aware of the fundamental cause of their lymphedema and breast cancer treatment. They also were conscious of other causes of symptom onset. These causes are supported by existing empirical evidence. Participants' treatment choices were consistent (e.g., use of compression treatment, massage, elevation, pumps, therapists and therapy centers, and positive attitude and faith) and inconsistent (e.g., effectiveness of exercise and medication in management of LE) with empirical evidence.

CONCLUSIONS: Future research and practice should target the role of exercise as a cause of LE and as a treatment option, investigate allergic reactions as a possible catalyst of lymphedema symptoms, work to improve diagnosis of LE and patient education, and examine the effectiveness of medications as a treatment method. IMPLICATIONS FOR NURSING: Review of lymphedema risk factors in the postoperative period and continued assessment and education are vital to a comprehensive approach to post-breast cancer LE care.

This was a very important study to refer to during my Capstone. It was very influential in the development of the L.E.A.P.P. to Recovery from Breast Cancer Program and supports the need of the program. The quality of this research study is fairly good due to the fact that the interviews were audiotaped, professionally transcribed, and verified for transcription accuracy. The quality of this research study would be even better if the sample size was larger.

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.
This is a very important study to include in my capstone because it validates the need for the development of my program. Ridner concluded with her research that pretreatment lymphedema education can help prevent lymphedema from occurring and improve breast cancer survivor’s recall of education information received about lymphedema leading to early detection. This quality of this research study is very good due to the large sample size and structured interview format.


There is no abstract for this publication of the National Lymphedema Network. This resource influenced my lymphedema treatment practice by informing me of specific diagnoses that appear similar to lymphedema but are not. Information learned from this article was integrated into all treatment sessions.


Abstract: OBJECTIVE: One distressing health problem facing breast cancer patients is breast cancer–related lymphedema (BCRL). This incurable condition can occur many years after treatment is completed and often causes pain and disability and interferes with work and activities of daily living. Patients at risk of BCRL are those who have received radiation therapy or axillary node dissection; higher incidence is reported among patients who have had both radiation and dissection. Our objective was to explore New Brunswick women's experiences of BCRL and its treatment. DESIGN: A focus group and 15 individual in-depth interviews. SETTING: Province of New Brunswick. PARTICIPANTS: A diverse sample of 22 women with BCRL was obtained using age, location, time after breast cancer diagnosis, and onset of BCRL symptoms as selection criteria. METHOD: The focus group discussion guided development of a semi-structured interview guide that was used for 15 individual interviews exploring women's experiences with BCRL. MAIN FINDINGS: Four themes emerged from the interviews. First, participants thought they were poorly informed about the possibility of developing BCRL. Eleven women reported receiving very little or no information about BCRL. Second, triggers and symptoms varied. Participants used words such as numb, heavy, tingling, aching, seeping fluid, hard, tight, limited mobility, and
burning to describe symptoms. They reported a variety of both aggravating and alleviating factors for their symptoms. Some actions, such as applying heat, were thought to both exacerbate and reduce symptoms. Third, in New Brunswick, access to treatment is poor, compression garments are costly, and accessing physiotherapists is difficult. Last, the effect of BCRL on daily life is profound: 12 of the 15 women reported that it interfered with work and day-to-day activities. CONCLUSION: Participants were unaware of the risk factors and treatment options for BCRL. Family physicians should discuss BCRL with their breast cancer patients routinely. They should be vigilant for the possible onset of BCRL and, if it is diagnosed, should manage it aggressively to minimize the severe effect it has on the lives of breast cancer patients.

This is another very important study for me to refer to because it validates the need for the development of my program. The results of this study clearly show the lack of pre-operative education women with breast cancer are receiving. Participants in this study were unaware of both the risk factors and treatment options for breast cancer related lymphedema. The quality of this research article is not perfect due to the small sample size and semi-structured interviews used as the method of gather data.


Abstract: Occupational therapists (OTs) working with patients with breast cancer provide a variety of therapeutic interventions. A survey was undertaken to record the different assessments and treatments employed by OTs in a specialist cancer centre with the type and length of interventions recorded on a log sheet by each therapist over a period of a month. A significant amount of time was spent facilitating educational programs, teaching relaxation techniques and exploring strategies for managing breathlessness and fatigue. However, documentation and report writing consumed the largest proportion of the therapists' time. Less time was spent on assessment of activities of daily living and home assessments, often perceived to be the traditional domain of OTs.
This article from the European Journal of Cancer Care was not influential in the development of the L.E.A.P.P. to Recovery from Breast Cancer Program. The article did however provide a look into the services that some occupational therapists provide to patients with breast cancer.