

Producing the CarePartners Lymphedema Information Booklet: A Valuable Resource for Improving Health

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Abstract

At CarePartners Outpatient Services, occupational therapists, speech-language pathologists, and physical therapists provide rehabilitation services to increase strength, mobility, range of motion and balance among Western North Carolina (WNC) residents. One of the rehabilitation services is treatment for lymphedema, the chronic swelling of the lymph nodes. It is important for the patients with lymphedema to have appropriate and accurate information about their diagnosis, and the steps to take to stay healthy with this condition. The goal of this public service project was to create health communication materials to educate patients who are being treated for lymphedema in WNC. The process included gathering information from professionals at CarePartners, researching lymphedema and different types of lymphedema, as well as researching different practices and procedures to help manage lymphedema. I drafted the text and formatted the materials for the patient information booklet. After it was created I solicited feedback, edited and revised the information for the needs of the patients. This project helps individuals of Western North Carolina understand their condition more fully and to continue self care. The booklet will help to promote a healthier community overall. This project has increased my understanding of the importance of health information for patients with lymphedema and how common this diagnosis is in our community. Lymphedema is not curable but it can be controlled, and controlling this illness leads to a better quality of life for residents of WNC.

Key words: Lymphedema, Health Information, Education Materials, Western North Carolina

Origins of the Project

The CarePartners organization provides post-acute care for the people of Western North Carolina. CarePartners provides therapies such as rehabilitation, home health, adult care, hospice, and palliative care. An important service offered at the outpatient facility at CarePartners is the treatment of lymphedema, the chronic swelling of the lymph nodes. My service-learning project arose from the need of health communication materials for patients at CarePartners diagnosed with lymphedema. Another primary objective of this project was to encourage lymphedema patients to become aware of their own health, and work on their lymphedema on a daily basis by creating a home management plan. This project was specifically created for the patients of the CarePartners outpatient clinic who have been diagnosed by a physician with lymphedema.

Lymphedema can occur after any surgery, removal of the lymph nodes, radiation, or chemotherapy. These procedures affect lymph node drainage. Eighty percent of patients experience onset within 3 years of surgery; the remainder develop edema at a rate of 1% per year. Upper-extremity lymphedema most often occurs after breast cancer; lower-extremity lymphedema most often occurs with uterine cancer, prostate cancer, lymphoma, or melanoma. A large population-based study supports the evidence that lower-limb lymphedema is experienced by a significant proportion of women after treatment for gynecological cancer, with the highest prevalence (36%) among vulvar cancer survivors and the lowest prevalence (5%) among ovarian cancer survivors (National Cancer Institute).

It is important for lymphedema patients to have information about their condition so that they know how to continue self-care when they return home. Lymphedema is not a curable condition, it is a manageable condition and self-care is a significant part of the treatment. Therefore, making sure that lymphedema health materials are clear, concise, contain current information, and are aesthetically pleasing to the target audience are important for initially attracting the attention of the patient, and for ensuring reader comprehension. CarePartners needed new materials and help with editing some of the older communication materials to ensure that current and accurate information were present in the materials.

My Supervisor, Susan Davis, informed me that there was a need for health communication materials for patients with lymphedema. The previous health communication materials were handouts that the therapists would print off the computer for each patient, after their first visit evaluation. This made giving the information to the patient more difficult and because it was a loose piece of paper, it is easily lost and forgotten about. It also made the therapists lose time with their patients while searching in books and through computer files to find the correct information for the individual patients type of lymphedema. Creating a booklet for patients with information about their diagnosis and how to properly care for themselves when they get home leads to better health outcomes.

Methods and Work Undertaken

The first step of my project was meeting with occupational therapist Emily Jones, physical therapist Jean Colletti, case manager Dina Peters, and my supervisor Susan Davis. Together we all brainstormed on what we wanted the lymphedema patient booklet to include, what it would look like, and how it would benefit the patients. It was important that the therapists were there to tell me exactly what they need their patients to know through this health communication material. I was given all of the materials that the therapists usually give to patients, including booklets, handouts, textbooks, websites, ect. I was asked to look over this information to get an idea of what is in lymphedema booklets for patients. I also did research on what lymphedema was, what causes lymphedema, how it is treated, the functions of the lymphatic system, functions of the lymph nodes, skin care, exercises, garments, and bandaging using credible resources.

As a group, we decided that I would take the information that was given to me by the therapists and create an outline for the patient booklet for them to look over to take sure that I include all of the important points they wanted to include in the health communication material. I created an outline of the booklet and sent it to everyone in our group to be edited, and to be given feedback. The revising of the outline led to a discussion about whether or not we should have two lymphedema patient booklets, one for upper extremity lymphedema and one for lower extremity lymphedema. The group was about half and half on the subject and we decided to create one booklet for both upper and lower extremity lymphedema.

We also decided that the most important part of the material was the actual written word information and that I would not be responsible for the layout or visual images of the health materials. The print shop at CarePartners would be responsible for the layout, visuals, etc. because of CarePartners copyright rules and regulations.

The main points of the material are:

- What is lymphedema
- What causes lymphedema
- Why some people do not get lymphedema right away
- Treatment for lymphedema
- Skin Care
- Exercise (Lower and upper extremity)
- Precautions and Prevention
- Garments and Bandaging

The booklet includes the functions of the lymphatic system, the functions of the lymph nodes, and garments and bandaging information, i.e. where to get garments and bandaging, what kind is needed for the location on the body of the lymphedema, and how severe the lymphedema is.

My first draft of the lymphedema information booklet included all of the main points listed below. I shared my draft booklet with everyone in our group. The feedback I received was that I had very accurate information, and clearly understood the process and treatment of lymphedema. The therapists also explained that the booklet used too many large words and would be difficult for patients to understand. We decided to change the lymphedema booklet to make it easier to understand by using a metaphor of a bathtub as a lymphatic system. This made the idea of lymphedema easier to understand because it related the information to something most people are familiar with.

We described lymphatic system as the overflow drain on our bathtub. We open the “valves” and let the water flow into the “tub”, or our lymph system. As long as the fluid flow is at a pace that the overflow drain can handle, everything is fine. When we really stress out lymph system, like lifting heavy objects or soaking for long periods in a hot tub, it’s like we’ve opened both valves to the maximum. The overflow drain is overwhelmed and the bathtub starts to overflow onto the floor. In the case of lymphedema, the “overflow on the floor” is our arm or leg swelling. Our lymph system simply cannot handle the extra fluid. Since our lymph nodes do not “grow back” after we have had them removed, lymphedema can appear at any time.

It is very important in health information materials to have easy to understand messages and materials. With the help of the therapists, I found an easy way to explain the complex process of the lymphatic system and lymphedema. Many of the individuals who have been referred to CarePartners for the treatment of lymphedema have not ever heard of the lymphatic system. Giving them a visual metaphor makes this complex idea easier to understand.

Ties to Academia

This project ties to my academic work as a health and wellness promotion major because it has increased my knowledge of patient-caregiver communication as well as broadened my understanding of the clinical experiences of occupational therapists, physical therapists and speech pathologists. I have learned about how clinicians communicate with their patients and about how therapists explain diagnosis to their patients in a way that is easy to comprehend. This learning directly connects with my area of academic study and course work because I am studying communicating health messages and designing and implementing an effective health promotion.

This service-learning project has enhanced my academic learning with valuable, hands-on experience. One of the required courses for Health and Wellness Promotion is Health Communications, which examines methods for communicating health messages, communication theory, and communication strategies. Being a Health and Wellness Promotion major, this project accompanied my academic learning with an important, hands-on experience, something I would not have been able to learn from a textbook or a lecture.

I contributed many of the strategies and concepts learned in health communications to creating the lymphedema patient booklet. I applied my knowledge of good health communications to this project like organized writing, and using plain language that is easy to understand.

An additional tie to my academic learning as a Health and Wellness Promotion major is that after I graduate, I plan on continuing my education and going to occupational therapy school. Having my academic experience as well as working on this community service project, I feel confident I will be able to communicate with patients in a clinical setting and help create more health communication materials in my professional career. This project gave me real world experience in health communication, which ties directly to my academic career. I have learned more about what our communities needs are in especially in the clinical setting. As a Health and Wellness Promotion major, it is part of my experience at UNC Asheville to make connections with health professionals in the community. My service-learning project has given me the opportunity to connect CarePartners and UNC Asheville.

Challenges Faced and Responses to those Challenges

The biggest challenge I faced during this project was getting my materials reviewed and edited by the professionals at CarePartners. The therapists are always, understandably, very busy, so it was difficult to find time to sit down with them and get their feedback on my outline and then, my informational patient booklet. My response to this challenge was to e-mail all of the therapists and staff who were working with me on this project regularly asking them to take a look at it and please send me edits. I also talked to some therapists in person to get their feedback on the lymphedema booklet.

Another challenge I faced with this project was setting up a meeting time with my supervisor and the print shop to talk about printing the booklet. I needed to talk to Andy Guzy, the print shop manager about the logistics of printing the booklet. I needed to talk with him about the overall layout, the size of the booklet, the color scheme, the visual aids being used, and what different types of visual aids did CarePartners approve because of copyright restrictions. I had an appointment with him but it was cancelled due to inclement weather, and since then he has been very busy with other projects at CarePartners so I have not been able to meet with him yet, but we have another meeting scheduled.

An additional challenge I faced with this project was coming to an agreement with all of the therapists and staff involved with the project on what would be included in the lymphedema patient booklet. I responded to this challenge by creating an outline in a document on Google drive and shared it with everyone involved so that they could look at it and edit it as needed. This gave them an opportunity to see what my thoughts were as well as add or take any anything they felt necessary to make the booklet what they wanted it to be.

A final challenge I faced while working on this project was the lack of research and information available on lymphedema. This made my learning about lymphedema very difficult. I got most of my information directly from the therapists who treat lymphedema patients. This is probably the best way to get information for patients because they know first hand what the patients need to know about their condition to get better and have a higher quality of life. I responded to this challenge by asking the therapists any questions I had about lymphedema to make sure I understood exactly what they wanted their patients to know when they returned home and continued their self care. I did additional research on lymphedema and the different treatments of lymphedema, though I delved deeply into the research to find the information I needed for the patient booklet.

Results

The results of this project include creating a complete lymphedema patient booklet for CarePartners outpatient clinic. This booklet offers clear, concise, accurate, easy to understand information on what lymphedema is, how the lymphatic system works, how lymphedema is treated, and exercises to do at home to continue self care and promote health. This project will greatly help the therapists that work with lymphedema patients in WNC. This booklet will hopefully improve the health outcomes of lymphedema patients referred to the outpatient clinic of CarePartners in the future.

Working with Susan Davis and the other therapists and staff at CarePartners has also helped to create a community partnership between CarePartners and UNC Asheville. I represented the Health and Wellness Department of UNC Asheville as a whole while working with CarePartners. I have done this by working with the staff at CarePartners to create this health material that they needed to better serve their patients in this community.

I have also gained important communication skills while creating this health material. I have improved on my written communication through creating a booklet that is easily understood. I have also improved on my verbal communication from working with the staff on a team to accomplish our goal of creating this lymphedema patient booklet. I have gained important experience in the health field that will help me ease into the professional world after my graduation from UNC Asheville.

Sustainability

The health communication material I have created for CarePartners is a great help to the therapists at CarePartners by saving them time and making their jobs easier by spending more time with their patients. This is also helpful to the patients being treated for lymphedema because they are spending more time with the therapists and have a concise, easy to read booklet about their condition and about how to continue their treatment in between appointments with the therapists and after they are discharged from CarePartners. This gives the patient a greater understanding of the treatments they will

receive at the outpatient clinic, and what their responsibilities are with their continued self care at home.

Additionally, this booklet is sustainable in that it has accurate, up to date information that will not need to be changed in the near future. We have made it so it is very easy to change information in the booklet for things that may change, like where to get bandages and garments, how much they cost, what brands to use, if phone numbers or addresses change for certain vendors of these products, ect. The therapists have a digital copy that will make it easy for them to change information if the need comes about.

Moreover, this project exemplifies a greater relationship between CarePartners and the UNC Asheville Department of Health and Wellness. It is likely that other Health and Wellness Promotion Majors as well as other majors at UNC Asheville working with CarePartners in the future will be able to come into CarePartners and continue to work on health communication materials for the organization. Not only could students continue working on health education materials for lymphedema patients, but it can also serve as a model on how to successfully create health information materials for community organizations that promote health.

Conclusion

Ultimately, this project has been a success in many ways, including creating health communication materials for a well-known organization in WNC, and in doing so creating understandable and useful information about lymphedema and lymphedema treatment. Hopefully this informational material will help patients at CarePartners stay on track with their treatment and continue the progress of getting healthier and having a better quality of life.

I have also improved my written and verbal communication skills through this project, as well as gained experience in the field of work I am interested in pursuing after my graduation. I feel like this project overall has benefitted everyone involved, including myself, the therapists and other staff at CarePartners, and the Department of Health and Wellness at UNC Asheville. I was able to apply what I have learned as a student to help improve the health of my community through service learning.

Appendix

Lymphedema Booklet

What is Lymphedema?

Lymphedema is the swelling of a body part as a result of damage to the lymph system through surgery, radiation therapy, or any sort of trauma. Someone with lymphedema may notice that jewelry or clothing doesn't fit as well. Fingers and toes feel full and still. The arm or leg feels heavy and swells more with use. At first the swelling can go down with elevating the arm or leg, but then, the swelling stays. It is important to note that lymphedema can occur in any part of the body where lymph nodes have been removed, not just an arm or leg. Swelling like this, after a medical history similar to the one above, is called lymphedema. It can occur during cancer treatment, or years after treatment for cancer.

What Causes Lymphedema?

Lymphedema can be caused by the removal of lymph nodes. The lymph system is a network that runs throughout our entire bodies, much like our circulatory system does. The lymph system does not carry blood- it takes fluids back to our circulatory system. Of all the fluid that is pumped into our bodies through our arteries, only 90% of it returns through our veins. The other 10% must use our lymph system.

Lymph is a clear colorless fluid. It carries fat and cell waste, as well as bacteria and viruses. It is the system through which proteins travel through our bodies, so the fluid is "protein-rich". Lymph fluid travels through a series of lymph vessels and passes through the lymph nodes which break down cell waste and makes bacteria and viruses harmless. Eventually, lymph fluid returns to our circulatory system by entering a large vein in our neck, the subclavian vein. If it didn't return to our circulatory system, we would always lose fluid we needed for our blood.

When we have lymph nodes removed, fluid can back up in the lymph vessels and stays in the arm or leg. This is when the proteins in the lymph system come into play. Proteins love water, and will draw and hold extra water in the arm or leg, making the swelling worse. Over time, the cells in the arm or leg will die off and can feel hard to the touch. Bacteria and viruses cannot be made harmless and can build up and cause infections. The arm or leg can change greatly in size, making it difficult to wear normal clothes. It also becomes difficult to use that arm or leg in our daily lives.

Some do not get lymphedema right away

Why can someone go through cancer treatment and not have lymphedema right away? The lymph system can take back much more fluid than what we usually ask it to do everyday. Our lymph system is like the overflow drain on our bathtub. We open the "valves" and let the water flow into the "tub", or our lymph system. As long as the fluid flow is at a pace that the overflow drain can handle, everything is fine. When we really stress out lymph system, like lifting heavy objects or soaking for long periods in a hot

tub, it's like we've opened both valves to the maximum. The overflow drain is overwhelmed and the bathtub starts to overflow onto the floor. In the case of lymphedema, the "overflow on the floor" is our arm or leg swelling. Our lymph system simply cannot handle the extra fluid. Since our lymph nodes do not "grow back" after we have had them removed, lymphedema can appear at any time.

Treatment for Lymphedema

Fortunately, you don't have to "just live with" the swelling. Although, once you have lymphedema, you will always have to manage it. Why would you even want to treat lymphedema? Untreated lymphedema can result in reoccurring infections, called cellulitis. Stagnant, undernourished fluid in our arm or leg sets up a great environment for bacteria to grow. Bacteria in our cell fluid would normally be taken care of by our lymph nodes, but remember, some of these have been removed. Untreated lymphedema can also cause an increase in the arm or leg size to where moving becomes difficult and stresses out our joints, causing pain. The skin can harden and dry out, making it easier to injure the skin. This can also lead to infection, since bacteria can then enter the arm or leg through the broken skin. If you have already experienced these symptoms, there is still hope to improve the health of your arm or leg.

The first step in treating this condition is a diagnosis and examination by your physician because not all swelling is caused by lymphedema. Your doctor will refer you to a therapist with specialized training in lymphedema management. Treatment consists of a special massage to move lymph fluid out of the arm or leg. The arm or leg is then wrapped with special bandages to keep the fluid out. Exercises are given to help further move the fluid out. Once the arm or leg has reduced in size, compression garments are fitted for both day and night. Someone with lymphedema will need to keep wearing compression and exercising to keep the arm or leg smaller. Treatment with a therapist can last about 4 to 8 weeks and may be daily.

Skin Care

It is easy to get skin infections when you have lymphedema, so keeping your skin healthy is very important. Here are some ways to help keep your skin healthy:

- Keep the affected area clean and dry
- Moisturize! Use lotions with low pH like Eucerin, Curel, or Johnson and Johnson Baby
- Treat small wounds with care. Clean with soap and water, then cover the wound with a thin layer of antibacterial ointment and cover with Band-Aid. Change the Band-Aid whenever it gets wet or dirty.
- Carry a small tube of antibiotic ointment, an alcohol wipe and a Band-Aid with you just in case you get a cut or scrape.
- If you are burned, run cool water or soak the area in a cool water bath for at least five minutes. Do not use ice or ice water. You may also wrap a cool compress around the burn for pain relief. If a blister forms, protect it with a Band-Aid or dry, sterile dressing. If the blister opens, follow wound care instructions above. Contact your physician if the burn is severe.
- Protect yourself from insect bites, sunburns, and animal scratches.
- Use an electric razor for shaving

Exercise

Exercising is an important part of your lymphedema treatment because when you exercise, it decreases swelling. Here are some tips on exercising with lymphedema:

- Always stretch before and after your exercise
- Do not try to lift anything heavy with your affected limbs
- Wear compression bandages or garments when exercising
- Do each exercise in a slow controlled movement
- Take time to rest in between exercises

INSERT EXERCISES HERE

Precautions and Prevention (Arm and upper torso)

Here are some suggestions to help prevent infection:

- Do not ignore increases in swelling
- Never get any shots, get your blood drawn from, or have your blood pressure taken in your affected limb
- Try not to wear tight jewelry or elastic bands on affected arms or fingers
- Avoid extreme temperature changes when bathing or washing dishes
- Do not enter into a sauna or hot tub
- Keep affected limb protected from the sun
- If traveling by airplane, you should wear a compression sleeve. Additional bandages may be required on a long flight.
- Always wear a well-fitted compression sleeve during the daytime.
- Do not wear socks or stockings with tight bands (if lymphedema is in lower body)
- Be careful when manicuring toe nails and fingernails, and do not cut your cuticles

References

1. National Cancer Institute. National Cancer Institute at the Institute of Health. 18 March 2014. 6 April 2014
<<http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/healthprofessional/page1>>.
2. Rockson, Stanley G. "Lymphedema." The American Journal of Medicine (2001).
3. BAIRD, JILL B. "REACTIVITY TO BACTERIAL, FUNGAL, AND PARASITE ANTIGENS IN PATIENTS WITH LYMPHEDEMA AND ELEPHANTIASIS." The American Society of Tropical Medicine and Hygiene (2002).
4. National Cancer Institute. National Cancer Institute at the Institute of Health. 18 March 2014. 6 April 2014
<<http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/healthprofessional/page1>>.
5. Rehana L. Ahmed, William Thomas. "Randomized Controlled Trial of Weight Training and Lymphedema in Breast Cancer Survivors." JOURNAL OF CLINICAL ONCOLOGY (2006).
6. Rockson, Stanley G. "Lymphedema." The American Journal of Medicine (2001).
Young-sup Yoon, Toshinori Murayam. "VEGF-C gene therapy augments postnatal lymphangiogenesis and ameliorates secondary lymphedema." The Journal of Clinical Investigation (2003).