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Occupational Therapy for Adults with Secondary Lymphedema: A Case Study

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

This case study was written as the culminating project of a Capstone semester spent in the area of lymphedema. The case study documents the occupational therapy treatment for a woman diagnosed with secondary lymphedema due to the removal of lymph nodes and treatment with radiation for breast cancer. The patient was assessed and treated using a combination of the biomedical model, the biomechanical model, and the Model of Human Occupation. Assessments included observation, standardized measurements, and the Occupational Self Assessment (OSA). The use of the OSA and MOHO theory was unique for this setting and this patient population. Also unique was the frequency of treatment sessions, one time per week for six weeks, which is more often than typical for this clinic. Evaluation revealed the following problem areas: edema in the left upper extremity, decreased range of motion, decreased knowledge of lymphedema specific self-care skills, difficulty in the area of physical ability, taking care of herself, and home care. Treatment centered on the three areas of deficit and was theoretically based on all three models of practice. Four long term and four short term goals were established by the client and therapists to address these areas. After six treatment sessions the patient had improvements in all problem areas. These improvements can be interpreted as improvements in the theoretical areas of the MOHO: volition, habituation, and performance capacity. In conclusion, the frequency of weekly sessions, the chosen occupations and areas of focus, and the theory guiding treatment proved to have a beneficial outcome for this patient.
Introduction

Lily is a 66-year-old woman who was diagnosed with secondary lymphedema three months after she had surgery to remove cancer in her breast. She was referred to occupational therapy after experiencing a decrease in function due to edema in her fingers, hand, forearm, and upper arm. The swelling made it difficult for her to move her fingers and upper extremity in order to complete activities of daily living. The therapist chose to treat the patient using the tenets of Complete Decongestive Therapy (CDT): skin care, wrapping, compression garments, manual lymph drainage, and exercise. This type of therapy is rooted in the biomedical model of practice as it emphasizes occupations that help enhance the physical processes or physiology of a patient. Unique to this case study is that the Model of Human Occupation (MOHO) was also used to help evaluate and determine therapy interventions, through the use of the Occupational Self Assessment (OSA) (Baron, Kielhofner, Iyenger, Goldhammer, & Wolenski, 2006). Though not typically used in this area of therapy, the model and the OSA address volition, habituation, and performance capacity, which are all important areas in the treatment of lymphedema.

Evaluation

The patient was referred to occupational therapy by her oncologist on 2/6/08. She was evaluated on February 29, 2008 through interview, observation, and standardized testing. Her medical history included a mammography on July 10, 2007, which detected breast cancer in the upper quadrant of her left breast. Magnetic Resonance imaging was performed which showed an abnormal area in the right axilla. Lily was educated on the options available for treatment and elected to have a lumpectomy and sentinel lymph node excision on 11/30/07. A biopsy of lymph nodes in the right axilla was also completed. All nodes removed were negative for cancerous cells and follow-up treatment with radiation was completed.
Lily had a family history of breast cancer; her sister was diagnosed when she was in her 70s. Lily retired from the Cleveland Board of Education one year ago and has a daughter and a son. Lily enjoys reading, watching sports on TV, and shopping. At the time of the occupational therapy evaluation Lily reported feelings of pain and swelling for approximately 6 weeks. Specifically, she stated that she would wake with her left hand slightly swollen and it would progress as the day went on. She rated her pain as 5 on a scale of 10 both while at rest and while engaging in activities. She described the pain as dull, achy, and stiff. In the area of her surgical incisions she had decreased sensation. At the initial evaluation Lily reported functioning at only 80% due to the edema, pain, and decreased range of motion.

Observation of her upper extremity showed evidence of moderate lymphedema in the fingers, hand, forearm, and upper arm. Lily had pitting on the dorsum of her hand, but her coloring and temperature were normal. She demonstrated tightness on her left at the end range of motion when asked to demonstrate shoulder flexion, abduction, external rotation and internal rotation.

Standardized measurements for upper extremity circumference and range of motion confirmed the above observations. The circumferential measurements were taken at 4 cm intervals up the length of her arm. Measurements of her left arm were 0 to 3.5 cm greater than her right arm. Range of motion was assessed according to Clarkson’s protocol (2000), and showed functional deficits. Lily lacked 35 degrees of shoulder flexion, 30 of abduction, 15 of internal rotation, and 25 of external rotation. The Occupational Self Assessment is an outcome measure based on the Model of Human Occupation and was used to assess her occupational functioning (Baron, et al, 2006). This assessment tool can be used during the initial evaluation as well as at discharge to determine the amount a patient has changed during occupational
therapy treatment (Kielhofner & Forsyth, 2001). The results of this showed that Lily was experiencing “Some difficulty” in the areas of physical abilities, taking care of herself, and home care.

**Goal Setting**

Lily’s personal goal for therapy was to decrease the swelling and to have better use of her left arm. Three goal areas were established and each broken down into short term and long term goals. The goals were based on the findings of the Occupational Self Assessment and standardized assessments. The goals and their rationale are as follows:

**Area 1: “Physically doing what I need to do.”** Decrease in functioning due to edema.

LTG 1: Pt will demonstrate a decrease in edema of left upper extremity.

STG 1: Pt will be knowledgeable of edema control techniques.

**Area 2: “Taking care of the place where I live.”** Decrease in range of motion.

LTG 2: Pt will demonstrate an increase in AROM of her left upper extremity to be able to carry out cooking and cleaning occupations.

STG 2: Pt will follow home exercise program to increase UE mobility.

**Area 3: “Taking care of myself.”** Decrease knowledge of new self-care occupations recommended for patients who have a diagnosis of lymphedema.

LTG 3: Pt will carry out Lifetime precautions for lymphedema.

STG 3: Pt will state Lifetime precautions for lymphedema.

LTG 4: Pt will carry out proper skin care for patients at risk of lymphedema.

STG 4: Pt will be able to state proper lymphedema skin care guidelines.

These goals are directly related to the three areas that the MOHO theory addresses. The first set of goals requires a great deal of commitment to the various techniques used to decrease
edema. This commitment is defined as “volition” in MOHO and refers to the motivation for occupation (Kielhofner, 2004). The second set of goals requires increased physical abilities that underlie occupational performance, which is termed “performance capacity” in MOHO. The third and fourth sets of goals deal with new ways of living every day life in order to help prevent onset of or increase in lymphedema. These recommendations need to become habitual for patients at risk of lymphedema. The MOHO theory terms this aspect of occupation as “habituation” and refers to the patterns or routines that a person uses to organize occupations in his or her life.

Interventions

The patient came to occupational therapy once a week for one hour sessions for 6 consecutive weeks. In standard practice patients who have lymphedema can be seen on a daily basis for intensive treatment that lasts 21 days. At this site it has been found that the above protocol is unrealistic given the location of the facility, the personal cost to the patient (parking, co-pays, etc.), and the availability of the therapist. This protocol also is not aligned with the philosophy of occupational therapy; it recommends that the therapist completes Manual Lymph Drainage and wrapping at the daily sessions, rather than encouraging independence in the patient’s abilities. Typically patients at this site are seen every 2 weeks to reassess functioning and edema levels. This frequency was increased to once every week for the purpose of this case study.

To address first set of goals and increased volition a treatment method known as Complete Decongestive Therapy, which incorporates specialized massage, skin care, bandaging, and exercise, was used (Brennan & Miller, 1998). In this treatment method multiple occupational forms were utilized. These included educational handouts, foam wrapping, short
stretch compression wraps, KT compression glove, and instruction in and demonstration of manual lymphatic drainage. At the initial treatment session the patient was educated on the role of occupational therapy. Lily was provided education on edema control measures of the upper extremity. She was fitted with a KT glove to control the edema and pitting in the dorsum of her hand. She was instructed in self wrapping, issued wraps, and provided a handout of step-by-step directions to complete wrapping independently. Before leaving this first session, Lily was able to independently wrap her left arm, though it did take her an increased amount of time. See Appendix A for a copy of the self-wrapping handout.

The second area of focus was addressed through demonstration of different exercises to help increase Lily’s performance capacity and upper extremity range of motion. A handout of all demonstrated exercises was provided to the patient along with specific directions on exercise frequency and duration. Exercises included:

1. Using fingers to walk up a cupboard and grab a glass on a high shelf.
2. Lying supine with head on pillow and placing hands behind head while allowing elbows to drop toward pillow to promote external rotation.
3. Washing windows or mirrors using shoulder abduction.
4. Reaching back before sitting down and holding the stretch to promote shoulder extension, and subsequent internal rotation.

Lily was also instructed in various ways to modify occupations within her home in order to simplify cooking and cleaning tasks. These included energy conservation techniques and adaptations to her environment.

The third area of focus concerned habituation, or new occupations that should become routine in Lily’s self-care. These were addressed through specific informational handouts on
skin care and lifetime precautions. The information on these handouts was based on recommendations from the National Lymphedema Network (2008) and the American Cancer Society (2006). These handouts were discussed with the patient and education regarding each precaution and guideline was reviewed. Any questions or concerns from the patient regarding these new occupations were discussed before the session was over. See Appendix B for a copy of the skin care guidelines and Appendix C for a copy of the lifetime precautions handout.

A particularly interesting session happened the second week of treatment. Though Lily did not have a substantial decrease in edema at this point, there was evidence of increased volition and habituation on her part for the newly implemented lymphedema treatment occupations in her life. Even though the patient reported disliking the occupation of wrapping, she stated that she had been wrapping consistently since the last session. She commented, “It’s easier to do, but I don’t like it.” This is evidence that she was motivated and committed to wrapping for her health. The fact that wrapping was becoming easier for her to do shows that the occupation was becoming routine, or habitual.

The treatment plan for this session included measuring Lily for a compression garment. This plan was changed after measurements revealed minor changes in the circumference of the left upper arm. The minimal progress may have been attributable to the incorrect wrapping technique that was observed during doffing of the compression wraps. After re-instruction on correct wrapping protocol, Lily demonstrated the ability to independently wrap according to the standard guidelines. Also, an alteration was made to the wrapping protocol to help ease application; Lily was advised to cease using the foam piece of wrap. This was done to decrease the bulkiness of the wrap, making it less burdensome and easier to apply independently. In light of this, the occupational form was re-synthesized to eliminate the foam wrap.
Outcomes

At the time of this writing Lily had met all of her short term goals and had partially met all of her long term goals. Circumferential measurements of her left arm were taken at each treatment session. Lily demonstrated decreased measurements ranging from 0 to 2.3 cm in the circumference of her left arm. Range of motion measurements were reassessed in a standardized fashion. She increased her range of motion 15 degrees for shoulder flexion, 20 degrees for shoulder abduction, and 10 degrees for both internal and external rotation. She consistently showed good adherence to both self-massage and self-wrapping protocols. The Occupational Self Assessment was administered again and Lily increase one level, to “I do this well,” in the areas of “Taking care of myself,” and “Taking care of the place where I live.” She rated herself as doing two levels better, or extremely well, in the area of “Physically doing what I need to do.” Her overall level of functioning increased to 95% from her initial 80%, and she stated that, “I don’t let the wraps stop me from doing anything, that is why they are so dirty.” She also reported better functioning while cooking, cleaning, and carrying out errands. This shows that she learned to adapt to the new occupations and occupational forms that were implemented in her life since being diagnosed with lymphedema.

It is inferred that although the patient was not fond of wrapping and massage protocols, she found them meaningful as demonstrated by her faithful compliance on a daily basis. Evidence for this inference includes reported frustrations with being able to wrap her arm on her own, as well as comments such as, “wrapping stinks.” In spite of this, Lily reported wrapping at least once every day, if not twice when she bathed more than once in a day.

Conclusions
At this time Lily has not been discharged from occupational therapy. It is recommended that she continues to wrap her arm with compression bandages for a further reduction in edema before purchasing a compression garment. Compression garments are costly and should be purchased once the edema has plateaued or the affected arm has similar measurements as the non-affected. Once a compression garment has been acquired, Lily should return every six months to be re-assessed and fitted for a new garment. Lily should continue her skin care and lifetime precautions every day for the rest of her life.

Using the Model of Human Occupation as a theoretical perspective, Lily made substantial changes in the areas of volition, habituation, and performance capacity. Volition deals with motivation for occupations and selecting occupations in which to participate (Kielhofner, 2004). In terms of volition, Lily was first driven to comply with the edema reduction protocol due to the value she placed on her health. The beneficial outcomes she saw and felt after wrapping further fueled her volition. It is assumed the satisfaction she felt each week when her circumferential measurements decreased also contributed to her volition and consistency in completing these new occupations.

The element of habituation refers to the patterns or routines we use to organize our daily lives (Kielhofner, 2004). Lily was able to incorporate the new, somewhat time-consuming, edema reducing, occupations into her daily schedule. By making these occupations habitual, she increased her ability to complete them effectively and reduced the amount of time that she had to consciously think about them. The end result is increased compliance with the occupations and better outcomes in terms of lymphedema treatment and recurrence.

Kielhofner defines performance capacity as the mental and physical abilities as well as the lived experience that influence actual occupation performance (2004). Lily was able to
influence her performance capacity through education to increase her mental abilities, or
knowledge, to complete edema reduction techniques, such as wrapping. She was also able to
change her physical abilities through practice of new occupations, better range of motion and
decreased edema. Her lived experience of wrapping consistently allowed her confidence in her
performance abilities. Through decreased edema and decreased pain in her body, Lily altered
her performance capacity so that she can now cope better with her diagnosis of lymphedema.

Through education and exposure to new occupations, therapy allowed Lily to make
substantial changes to her daily occupations. Though perhaps not meaningful at first, these
changes will help her to decrease the amount of edema that is currently present in her arm. The
positive changes will increase her physical capabilities to care for herself and her home. They
will also help her to prevent future recurrences of the edema. It is through this realization that
the new occupations have become very meaningful for Lily. From the positive outcomes she has
experienced thus far, Lily is able to see the importance and purpose in faithfully carrying out
these new occupations.
References


Self Wrapping

Items Required: Stockinet, Foam Finger Wrap, Tan Wraps 6, 8, & 10 cm.
Make sure that the arm to be wrapped is clean and moisturized

1. Apply stockinet
2. Wrap fingers
   a) Wrap thumb 2 to 3 times, then wrap ½ way around the wrist
   b) Repeat above step with each finger.
3. Apply foam hand piece.
4. Roll foam with light tension up the arm. Starting near the wrist.
5. Take 6 cm. of tan wrap:
   a) Spread hand wide
   b) Go around the base tree times
   c) Then go around the back of the base of the thumb
   d) Then around the base of the hand
6. Repeat step C and D one more time:
   a) Wrap remainder of the wrapping circumferentially up the wrist and forearm
7. 8 cm. wrap. Start at wrist and overlap up the arm.
8. 10 cm. wrap. Start at wrist and overlap up the arm.
9. Foam and final wrap should stop near the axilla
10. Tape end of wrap.

Therapist __________________________________________
Phone: 216/444-2623
Appendix B

The Cleveland Clinic Foundation
Occupational Therapy – Breast Center

Skin Care Guidelines

~ Daily cleansing
~ Thorough drying between skin folds and finger
~ Use a low Ph skin lotion daily (Eucerin or Nivea)
~ Use care with nail cutting and manicures
~ Protect your skin from injury (wear gloves)

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Appendix C

The Cleveland Clinic Foundation
Department of Occupational Therapy
Recommendations To Patients
with Lymphedema

1. Change limb position often rather than let it rest in one position too long.
2. Try to sleep so that your body weight is not pressing on the limb (slow circulation). If at all possible, sleep with your arm above your head as the lymph pathways from the arm will be more direct.
3. Exercise is good, but for shorter rather than longer periods so as to not over-tire the limb.
4. Use the unaffected limb for blood pressure measurements, injections, and avoid all injury to the limb (e.g. shaving a limb should be done carefully with an electric razor).
5. Have any infections and unusual redness (inflammation) attended to immediately by a medical doctor.
6. Have * MLD done immediately on recent hematoma/ bruising.
7. Keep the arm in the shade as much as possible and especially avoid sunburns.
8. Clothing should be loose and comfortable with no tight constriction on the affected side (e.g. bra straps, elasticized sock or under garments).
9. Wear a wrist watch only on the unaffected side as it may trap bacteria or pinch the skin on the affected side. Tight jewelry may have the same effect.
10. Keep the affected limb as clean and supple as possible by using cleansing lotions.
11. When taking a shower or bath, use tepid, warm water rather than hot. Heat will make the edema worse.
12. Wash the bandage or compression sleeve frequently, according to the manufactures instructions. (at least every three days) and air dry away from direct sunlight.
13. Report any chaffing, redness, indentation, looseness, or tightness of the sleeve to your therapist.
14. Wear a light prosthesis if one is used on the affected side.
15. Keep your weight down as much as possible and try to lose weight if you are over weight.
16. A low salt diet is recommended.
17. * MLD (Manual Lymphatic Drainage) Gentle skin stretching massage to help activate lymphatics and route lymphatic fluid.