

EXPLORING THE COURSE OF LYMPHEDEMA CARE:
AN OCCUPATIONAL THERAPY PERSPECTIVE

A THESIS

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Dr. Gayle Hersch
Stephanie
Marvin
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ABSTRACT

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This was a qualitative study to identify the causes behind failed lymphedema treatment and to posit practical, therapeutic strategies for occupational therapists to adopt in developing interventions for their patients. The primary methods for information gathering were face-to-face interviews and chart reviews. There were 6 participants from an original sample of 44. The results of the interview fell into five basic themes: 1) health *before* lymphedema; 2) experiences *during* treatment; 3) management *after* treatment; 4) patient perspective of how lymphedema affected areas of occupational performance; and 5) viewpoints of the emotional effects of the disease. The results showed that the educational process needs improvement, especially in the area of occupational performance. These included donning/doffing their compression garments, replacement of the garments, making lifestyle changes necessary for control of their swelling, dealing with social/psychological changes of the disease and improving problem-solving skills over the duration of the disease.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Lymphedema is an "abnormal accumulation of protein-rich fluid in the interstitium that causes chronic inflammation and reactive fibrosis of the affected tissues. It usually affects the limbs but can also be present in the abdominal cavity, chest, face and head" (Norton, 2004, p. 2). It is a chronic, progressive condition that can, however, be brought under control with proper management.

In the course of treating patients with lymphedema, a common thread of frustration to clinicians has often been the general poor condition that the patient is permitted to disintegrate into before finding treatment. Often times the person is in a dangerous and advanced state of disease before getting diagnosed. The patients frequently describe multiple efforts to obtain treatment. Even after being diagnosed and treated, patients also may experience failure in maintaining their course of treatment over a long period of time due to self-care deficiencies or psychosocial issues (Fu, 2005).

Purpose Statement

The purpose of this study was two-fold: to identify the causes behind failed lymphedema care and to posit practical, therapeutic strategies for occupational therapists to adopt in developing intervention plans for their patients.

Research Questions

1. What is the course of care for patients with lymphedema?

2. How are the patient's areas of occupational performance affected before, during, or after his or her course of care and the disease?
3. What are the implications for the therapist in planning effective educational interventions so that patients do not fail in their long term management of their disease?

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Differential Diagnosis

Lymphedema is a disease that is oftentimes difficult to differentiate from other diagnoses. Lymphedema is often misdiagnosed as vascular insufficiency, renal failure, cardiac edema, and congestive heart failure. While it is true that long-standing vascular insufficiency and other swellings can eventually result in lymphedema, the swelling and problems from this and other diagnosis do not necessarily constitute lymphedema. If the cause of the swelling is misdiagnosed, then the treatment is often not appropriate and may actually hinder progress instead of aiding it. An example is the use of diuretics. Diuretics can be helpful in the treatment of some diseases that cause swelling, but not for lymphedema. Diuretics can actually make lymphedema worse by reducing the fluid in the body and thickening the lymph fluid, thus making the system even more sluggish (Foldi et al. 2003).

Treatment of Lymphedema

The gold standard for treatment of lymphedema is actually a collection of treatments, called Complex or Complete Decongestive Therapy (CDT). The mainstay of CDT is manual lymph drainage or MLD. Manual lymph drainage was “coined” and developed by a German massage therapist and his wife, Dr. Emil and Lois Vodder, in the 1930s (Norton, 2004). Complex Decongestive Therapy (CDT) has been refined and

amended over the last fifty years to include five major components: (1) manual lymph drainage, which is a mild and gentle form of massage that seeks to both reroute and improve the drainage of the affected area; (2) compression bandaging and garments; (3) skin and wound care; (4) remedial exercise designed to enhance the drainage of fluid and improve the body's ability to cope with excess fluid; and (5) instruction to the patient in all aspects of self-management and precautions (Norton, 2004).

According to the Complex Decongestive Therapy standards of treatment, the length of treatment is determined by the severity of the disease and the patient's ability to participate in the program. The stages of severity of lymphedema are:

- Stage I: the mildest form of lymphedema, usually takes only two or three visits to complete treatment; mostly time spent in consultation and education.
- Stage II: is much more progressive and usually requires from three to six weeks of daily treatment. It is marked by the increase of fibrotic, non-pitting edematous tissue. The presence of fibrotic tissue also increases the risk of developing a serious infection such as cellulitis.
- Stage III: involves dangerous amounts of swelling, serious fibrotic changes that lead to deformity of the limb as in elephantiasis, and severe skin diseases. These skin problems include papillomas, weeping fistulas, lymphatic cysts and dry, sclerotic skin changes called keratosis. Stage III lymphedema can take months to treat and in the case of elephantiasis, years (Norton, 2004).

Review of Research on Lymphedema

A review of the current literature reveals the course of care for lymphedema is not on par with other similar or related diseases such as leg ulcers (Moffatt et al. 2003). The Moffatt study also highlighted problems in referral and insufficient treatments. Hardy (2006) reported that persons with cancer-related swellings received more attention than those with swellings from non-cancer related diagnosis both in research and treatments. Consensus among the two studies, estimated that from only one-third to one-half of persons with lymphedema received any treatment at all (Hardy, 2006; Moffatt et al. 2003).

In interviews and questionnaire surveys, patients with lymphedema revealed that many had quality of life issues (Moffatt, et al). In their journal article, Logan, Barclay, Caan, McCabe, and Reid (1996) documented that healthcare providers acknowledged psychological stress in persons with lymphedema but were unsure of what, if any, referrals or treatment was provided. According to Sneddon and Lewis (2007) and Hardy (2006) patients identified many types of distress, including poor self-esteem and feeling "different", depression and withdrawal, changes in and/or loss of employment, difficulty finding efficient treatment and lack of ongoing support. There was a general consensus that the disease was socially debilitating.

Physically, many patients faced frequent treatments for infections (Meneses & McNees, 2007; Moffatt et al. 2003) including hospitalizations. Skin problems, some of them resulting in open sores and constant leaking of lymph fluid, were described by the majority of patients. Over half reported pain with the lymphedema although historically,

medical professionals have insisted that lymphedema is not painful (Moffat et al.). Sneddon and Lewis (2007) documented difficulties in self-care, as it relates to occupational performance. These included such tasks as standing for prolonged periods of time or using the arm for repetitive motions as part of the client's employment.

Not only did lymphedema patients face debilitating problems such as open, seeping wounds or tremendously enlarged arms and legs, but they also experienced difficulty getting information about their disease from their healthcare providers. In surveying healthcare providers, Bosompra et al. (2002) and Logan et al. (1996), noted that part of the responsibility for the under treatment of lymphedema, reflected back to the medical community. Their research supported the argument that there was very little information/education transferring from the medical community to the patient. The patients were asked to rank their sources of information about lymphedema. In the Bosompra et al. study, patients named their physicians as the least likely source of information on lymphedema. Patients listed the main source of their education as coming from therapists. Their second source was identified as books and the internet (Bosompra et al.).

The researchers from both the Bosampra and the Logan studies were in agreement on the need for better care for the lymphedema patient. The estimated costs of non-treatment have been quite high, both in human suffering and in medical dollars. They called for improved empirical evidence to diagnose, stage and grade lymphedema. There was a general consensus in both studies for multidisciplinary approaches to be developed to determine effective evidence-based management of lymphedema patients.

CHAPTER III

METHODOLOGY

Research Design

This was a qualitative study that included both retrospective and descriptive portions. The retrospective portion included a review of patient charts (secondary materials). The charts were analyzed for descriptive data on lymphedema and the course of treatment. The descriptive portion included patient interviews (primary materials) from those whose charts were reviewed. John Creswell states on research design that, "These interviews involve unstructured and generally open-ended questions that are few in number and intended to elicit views and opinions from the participants" (Creswell, 2003, p. 188). These interviews were used to do just that: to characterize the participants' issues with difficulty in diagnosis, occupational performance dysfunction, and problems with integrating the care of lymphedema into their daily life.

Participants

Participants included patients diagnosed with lymphedema who were 18 and older, spoke English, and had been seen in the outpatient lymphedema clinic of a large city hospital in the last two years. The participants had previously been grouped by diagnosis codes for lymphedema through the outcome statistics kept by the mother organization. A mailing list of 43 eligible lymphedema patients was made available after IRB approval. A general flyer (Appendix A for Generic Flyer) was sent out to the 43 eligible

lymphedema patients announcing the study and inviting participation by telephoning the researcher and tentatively agreeing to be a participant. When the participant made the call, a set procedure was followed whereby they received more details of the study and could ask questions (Appendix B for Phone Explanation to Perspective Participant). Of the original group of 43, six responded to the flyer by calling the listed phone number. One of the 6 responders noted that they had had difficulty getting diagnosed with lymphedema, but after hearing that their medical record would be reviewed, declined to participate. Demographic information that represents the overall mail-out group of 43 lymphedema patients is represented in Figure 1, for gender and Figure 2, for age grouping. All of the respondents were Caucasian.

One more participant was added to the study by the *snowballing* method. When setting up one of the interviews, the researcher was told that there was a family member living in the same household that also had a diagnosis of lymphedema and had been treated in the same clinic during the same time period. That person agreed to be interviewed and to have his chart reviewed.

A time and place was arranged so that informed consent (Appendix C for Texas Woman's University Consent to Participate in Research) could be obtained. All six of the participants chose to have their interviews conducted in their homes and all six received face to face interviews of about one and one-half hours in length. They also agreed to have their medical records reviewed. The interviews focused on the incidence of poor lymphedema diagnosis and care, occupational performance dysfunction, and problems with education and instruction in the management of their disease. The chart review was

made to obtain demographics and to offer a more complete picture of referral and treatment. (See Figure 4 for a breakdown of ages for the final sample group). A more detailed discussion on the chart review is included in the Discussion section, p. 19.

Perhaps, the most difficult part of the research was finding a way to get a sample population. Originally, the study was conceived in 2006 while working in a private lymphedema clinic in a smaller city of a large metropolitan area. That clinic could have provided a much larger sample size and would have provided a broader age range and ethnicity of participants. However, due to circumstances beyond the researcher's control, those lymphedema patients could not be recruited for a sample. Instead, the sample had to be obtained from a large multi-hospital system. The umbrella organization required that an extensive IRB application be made. The hospital IRB process took over nine months to obtain permission to start the study leaving only two and one-half months to perform the study.

Data Collection Tools and Procedure

Two methods of data collection were done with six patients: chart review and qualitative interviews. All participants were asked to sign informed consent forms.

Chart review. Demographic and medical information from the participants' charts was gathered including (See Appendix G for Chart Review Criteria Form):

1. Primary and secondary diagnosis; any misdiagnosis if there were any.
2. Age and gender.
3. Referral source and process of referral if available.
4. Treatment trajectory and timelines if known.

Qualitative interview: Five participants from a list of 43 mailings chose to participate. An additional participant was added through snowballing. They were told that they would be asked to further describe their lymphedema treatment process by telling his or her story. A semi-structured interview was used by the researcher to obtain as much of the patient's perspective as possible. Open-ended questions were asked to expand upon the patient's history and detail their perspective of their occupational therapy treatment of lymphedema (See Appendix D for Interview Guide). The interview was tape recorded (Appendix F for Consent to Record) and transcribed verbatim. There was one interview per participant ranging in length from one to two hours. A journal was kept by the researcher for reflections, observations and field notes.

Data Analysis

In order to obtain the charts for review, extensive communication between the researcher and the hospital medical records department was required. Every effort was made to protect the confidentiality of the participants and their records. Each of the consent forms for all six of the participants was sent to a specific medical records person assigned to the case. She reviewed the consent forms and when all was cleared, only the lymphedema treatment portion of the medical record was made available to the researcher. No other medical records, other than the six with informed consent, were tied to the researcher's name and pin number. This was done in order to provide greater confidentiality to the participant.

For the chart review, the study used descriptive statistics. Information from the chart review data was used to answer the following questions:

1. What percentage was female/male? How many trips to one doctor were required to get a referral?
2. How many doctors were seen before getting an appropriate referral?
3. What kinds of treatments were ordered: diuretics, compression sleeves, compression pumps, "wait and see", etc.?
4. What problems were encountered in the areas of occupational performance?

The tapes of the qualitative interviews were transcribed and reviewed. Categories such as dysfunction in occupational performance, types and lengths of lymphedema treatments, identification and diagnosis of the disease, and the patients' referral processes were identified. The categories were arranged by color-codes for ease in identification. The data were reviewed and analyzed for themes or issues, and meanings and perspectives of the participants analyzed.

As a member check, the interviewee was asked to read his or her transcribed interview to verify what it was they had said. The procedure for the member check was explained in a letter (Appendix E for Transcript Check). The transcriptions were not disputed although three participants called to make corrections. All transcripts were included in the qualitative data analysis. The study was peer reviewed for structural coherence.

Findings from the Chart Reviews

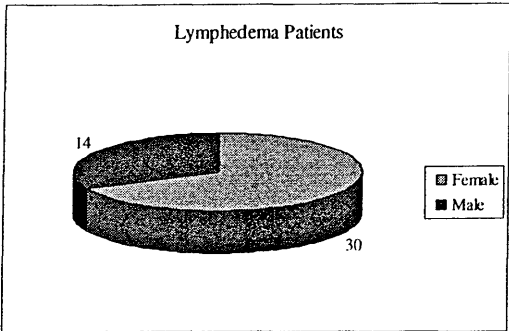


Figure 1. Gender breakdown. Demographic information that represents the overall mail-out group of 43 lymphedema patients plus the one participant added by *snowball* method for a total of 44.

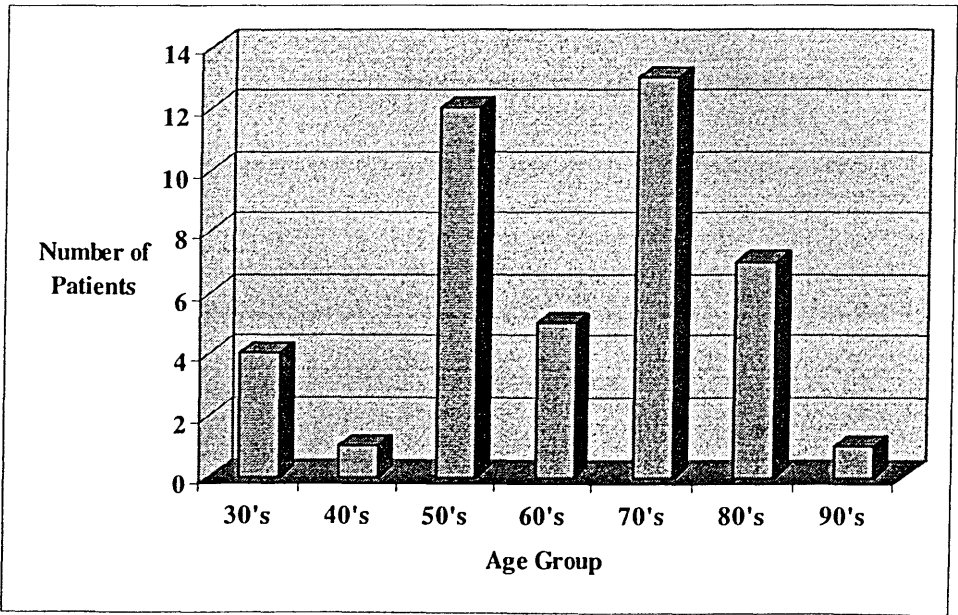


Figure 2. Group of 44 lymphedema patients broken into age groupings.

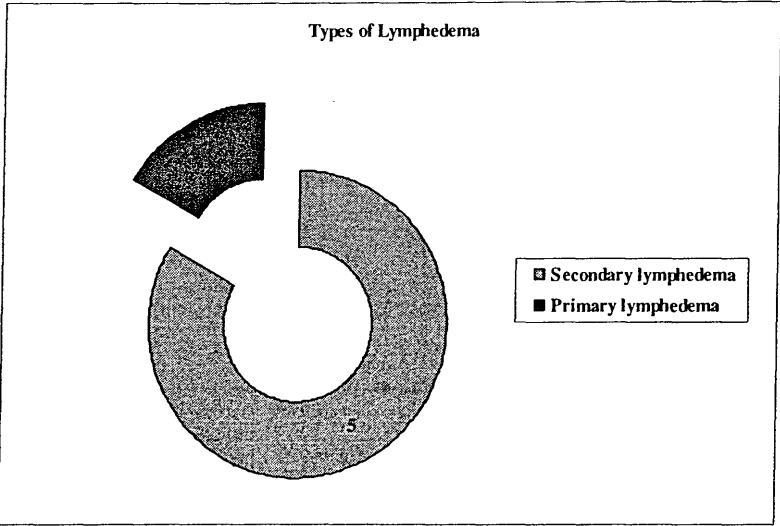


Figure 3. Ratio of types of lymphedema among the 6 participants.

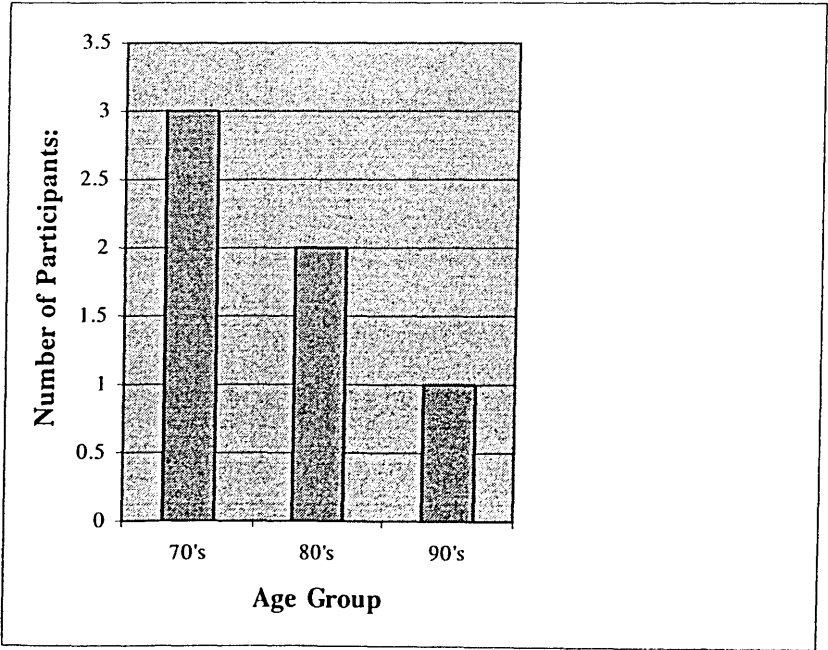


Figure 4. Age grouping of the 6 participants.

Findings from the Interviews

The results of the interviews fell into five basic themes:

1. Their state of health *before* their treatment of lymphedema.
2. Their experiences *during* treatment with Complete Decongestive Therapy (CDT).
3. Management of their swelling *after* their treatment.
4. Perspectives from patients of *how* the diagnosis of lymphedema affected their areas of occupational performance.
5. Their viewpoints of the emotional effects of having lymphedema.

Themes

General State of Health before Their Lymphedema Treatment

The first theme involved the participants' general state of health, prior to diagnosis and treatment of the lymphedema. Five had serious medical problems, many of which led either directly or indirectly to the cause of their lymphedema. Four of the six participants were obese, three morbidly so. Four had heart disease with treatments ranging from arterial stents and cardiac by-passes, to valve replacements and pacemakers/defibrillators. All of the upper extremity lymphedema cases (3 of the 5 women) were the result of their having had treatment for breast cancer. This involved mastectomies and lumpectomies coupled with lymph node removal and/or radiation of the lymph nodes.

All six of the participants had severe orthopedic problems. These ranged from multiple broken bones to joint replacements to rotator cuff repairs. Several had fractures, long in the past, that came back "to haunt them" with the swelling from lymphedema. A

common concern was their need for hip/knee replacements that could not be done due to their swelling or other major risks. (A discussion about joint replacement issues will follow later.)

Three participants reiterated that they did not either recognize their swelling or did not get diagnosed and treated speedily. Those with lower extremity swelling seemed to have the most problems obtaining a diagnosis. One participant had swelling starting in her ankles as a teenager (common in *primary* lymphedema, see Figure 3), but not diagnosed and treated until she was in her 70's. It seems that doctors and family members more readily recognized upper extremity swelling well before lower extremity swelling.

There was a difference between what two of the participants remembered about the time frame for diagnosis of their lymphedema and what their chart review revealed. The gentleman in the group noted during his interview that he had had some trouble with his legs swelling for "several years" but when the chart was reviewed it showed he had had swelling for over four years. Another had swelling that she estimated she had for 6-12 months. Her chart review noted two years of off-and-on swelling and it was a yoga instructor who first noticed it, not her physician!

Experiences during Treatment with Complex Decongestive Therapy (CDT)

The participants noted that some of their doctors were quite interested in their lymphedema and others were more distant, but all of the participants reported proper care from their physicians. Three noted that their doctors either went to training or seminars

on lymphedema, or had regular contact with the lymphedema therapists that helped keep them updated in the field.

All of the participants noted some form of capitation on their lymphedema treatment due to financial constraints. Some thought they needed more sessions but could not afford them since their insurance cut treatments off at a certain point. Others experienced difficulty with obtaining compression garments or other equipment and supplies that they really needed to manage their swelling.

Most of the participants spoke only of success with their CDT therapists. But one participant spoke of having some difficulty getting the correct therapist. She was in lymphedema treatment on two different occasions with two different therapists. The first time through the CDT treatment, she was with a therapist who the participant said used a more aggressive technique and got "wonderful results". On the second time through, she requested the same therapist. Because of scheduling difficulties she was assigned to another one who used a much lighter massage technique. The results were not as good and the participant noted she has to go back in for treatment as her legs are "worse now"

Other difficulties included transportation issues for the frequent visits during the CDT. Most could not drive themselves and had to rely on friends or family members to get them to the clinic. Two had complications from wounds and were seen for a short time in a wound care clinic.

Management of Their Swelling after Their Treatment

Once they were treated for lymphedema and managing it fairly well, three of the participants had to be hospitalized for other problems unrelated to their lymphedema.

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Management of Their Swelling after Their Treatment

Once they were treated for lymphedema and managing it fairly well, three of the participants had to be hospitalized for other problems unrelated to their lymphedema.

While hospitalized they spoke of having difficulty getting wrapped with short-stretch bandages or having access to their compression garments. Even though they all had spouses or sons and daughters, the family members did not step forward and provide an explanation to the doctors and nurses about their loved ones' lymphedema or insist that they be allowed to wear their compression garments or receive wrapping. Each hospitalized participant spoke of increased swelling that eventually required an additional round of CDT to get the swelling back under control.

The compression garments themselves were a source of frustration and annoyance to the participants. The complaints ranged from:

- Difficult to get the Velcro straps on the Farrow wraps fastened around the leg.
- Seams in the gloves not holding up and needing repair or replacement.
- The gloves getting dirty—one had a glove for everyday and a “nicer” one for Sunday church.
- Inadequate donning devices—one had put a hole in the stocking because she was using a garter-type sock aid. Others had no donning devices.

Perspectives from Patients of How the Diagnosis of Lymphedema Affected Their Areas of Occupational Performance

The participants were unanimous in voicing occupational performance issues. As mentioned in the earlier section of difficulties during CDT treatment, all had difficulties with donning their compression garments. Several had painful or injured shoulders. Others had weak hands from arthritis or diseases such as carpal tunnel syndrome. Some

were able to resolve their problems with putting on their garments with donning devices or adaptation. Two were just doing without their garments which led to diminished control of their swelling. Two could not reach their hair with the affected arm due to the heaviness in the arm and/or decreased range of motion. The lower extremity participants had trouble bending over to place their garments on their feet and legs due to arthritic hip and knee stiffness or obesity.

Another area with which the lower extremity participants had some difficulty was ambulation. The added weight, stiffness, and pain made walking much more difficult and they fatigued quickly. All three participants with lower extremity swelling used walkers and/or canes and walked very slowly and cautiously. One was in an electric wheelchair and only walked a few feet at a time with a walker. These three also needed joint replacements (knees and hips), but because of the swelling or other health risks, their doctors had told them the surgeries could not be done.

One participant described a grave loss of freedom because she could not walk or get around easily. Her friends often invited her to go places with them and go on tours, etc. But she first had to ask them if there was walking involved or many stairs. When asked what she would say to someone that had just been diagnosed with lymphedema, she succinctly said, "I would tell them it is hell!"

Participants' Viewpoints of the Emotional Effects of Having Lymphedema

None of the participants made statements that they were devastated by the effects of having lymphedema. However, half of them said that having lymphedema was: (a) irritating, (b) annoying, and (c) frustrating. One made the statement, "I guess I am

philosophical about it." Another felt that her experience with lymphedema treatment was so positive that she said, "I cried when it was all over..." "My visits to the hospital for the treatment were not bothersome for me because I enjoyed the therapists in that department so much. And so my visits there were not hard on me. Actually, it acted almost like a social outlet." Another related that after all the things that had happened to her in her life, "this would be considered a *blip*." These finding surprised the researcher. When treating lymphedema patients in the clinic, they often have seemed to struggle with the emotional aspects of managing their disease. They have frequently expressed feelings of self-pity and isolation.

In this research, it was not clear whether the participants were putting on a brave front for the researcher or if time had brought them an improved perspective, but this group definitely seemed well-balanced emotionally in spite of their lymphedema. There did seem to be some differences of opinion among the participants with some more positive and others more negative. Even though as a whole, the group emphasized a positive attitude, the comments reveal a wide range of emotion. The comment, "I would tell them it is hell!" and "This would be considered a *blip*," reveal opposite ends of a spectrum. These seemingly conflicts would make a good topic for a future study.

CHAPTER IV

DISCUSSION

Limitations of the Study

The first limitation to be noted is that the study was done from a small sample size and not intended to be all inclusive on the subject of lymphedema. However, saturation was reached on the third interview and subsequent ones, with that participant repeating almost the exact words of the two before her.

Another limitation became evident when the researcher reviewed the charts. The original criteria set up to review the charts (Appendix G) proved to be different from what was actually found. The secondary diagnoses and referral processes were not made clear in the medical record. One patient told the researcher in her interview, that she had weeping skin on her arm when she first began treatment for lymphedema. But there was no note of that in her chart. Information about misdiagnosis and the referral process also were not clearly identified in the charts. Instead, that information came from a limited extent in the interviews.

A limitation that should also be noted came from the original bias that the researcher set forth in her first proposal. At the time, a majority of patients coming into the private lymphedema clinic where the researcher was employed, were experiencing difficulties receiving a diagnosis. They were also experiencing delay in getting a referral for lymphedema therapy. The patients were often going from doctor to doctor trying to find out why they had such serious swelling. This was borne out in the literature search

confirming a fairly strong assumption. But when the study was actually completed four years later, it appeared that several things had happened to weaken that original assumption. First, in the four years that it took to complete the study, more and more of the medical community and more of the general community had become aware of lymphedema. Secondly, the actual sample group came from a clinic where the ethnicity and age of the population was very homogenous instead of diverse as it would have been if it could have been done from the original proposed sample group. In conclusion, the researcher found the lymphedema patients were receiving more prompt diagnosis and referral of lymphedema that diminished the original thinking; rather, the findings suggested other valuable information for occupational therapists wanting to increase their knowledge of lymphedema.

Summary of Research Questions

Even though this was a very small sample size, the participants were consistent and believable throughout each interview. The researcher found them to be very accommodating. Perhaps this was because no one had ever asked them to tell their story?

So how well did the participants answer the research questions with their stories? The following summary describes each research question and the participants' answers.

What was the course of care for patients with lymphedema?

The participants were all diagnosed by a physician who knew what lymphedema was and that the person should be referred to a lymphedema clinic for CDT. There were some differences in *how long* it took them to get diagnosed. One suspected that she had swelling in her arm for at least six months before going to the doctor but her daughter

thought it was more like twelve months. (The chart review revealed that she had had swelling off and on for two years). One of the lower extremity participants was unsure of how long he had had swelling. His chart review revealed that he had had venous insufficiency for over four years and that the lightweight compression hose he wore everyday were not adequate to control the swelling. His condition continually worsened until he developed cellulitis. It was at that point that he was diagnosed and brought into CDT treatment. The remaining four participants estimated that it took one to two months before receiving a referral.

Three of the referring doctors were primary care physicians and three were specialists. Once the physician recognized the lymphedema, all of the participants received a prescription to the outpatient clinic to receive the specialized care of Complex Decongestive Therapy. None of the participants appeared to be ignored or wrongly referred by their physicians.

The actual treatment time varied for each patient. The shortest length of treatment time was 8 sessions and the longest was 24. The plan of care, whether for daily times 5, or two to 3 times per week, appeared to be custom planned for each patient.

All of the participants described approximately the same course of care: (1) Manual Lymph Drainage; (2) Compression; (3) Skin and wound care; (4) Education in what lymphedema was and how to manage it; and (5) Home exercise programs.

There were varying degrees of knowledge of lymphedema before receiving their diagnosis. Those participants who had breast cancer were also the ones most likely to recognize it. Potential questions that arise from this subgroup are: Could this be due to

the attention that the news media gives breast cancer? Or, with the prevalence of breast cancer, did one or two of the participants' friends have breast cancer and either had or knew of someone who had lymphedema swelling? From the findings of this study, there appears to be a crucial need for the general community to know more about the disease. This seems to be even more the case for those with lower extremity lymphedema.

How were the patient's areas of occupational performance affected before, during, or after his or her course of care and the disease?

It would appear that all of the participants were affected in the area of occupational performance. The largeness and heaviness of their limbs made it difficult for them to use their fingers and hands or, in the case of lower extremities, they began having mobility issues. Treatment that reduced the size of their limbs resulted in improved function. However, those whose swelling was poorly managed in *post treatment* continued to have problems with ambulation and donning their compression garments. Also *during* treatment, all found the bandaging and compression wraps constraining. They all spoke of not being able to care for themselves without assistance. They could not do things such as operate their vehicles even though they still possessed driver's licenses and were still driving independently up until the time of the CDT treatments. They all noted that they had lost some of their independence to do as they pleased with the onset and diagnosis of lymphedema.

What were the implications for the therapist in planning effective educational interventions so that patients do not fail in their long term management of their disease?

Two areas stood out that were problems in the participants' treatments. The first was the lack of permanent change in lifestyle and their general inability to carry out an exercise program. As a further probe into the interview question of obtaining information about lymphedema, they were each asked if they had written exercise handouts. None of the participants had a copy of their exercises or any information about lymphedema. . The second, and most glaring of the two, was the difficulty of getting the compression garments on and then forgetting or being reluctant to spend the money in replacing the specialized garments when they became worn and inelastic. Gaps such as these imply that long term management of the disease of lymphedema is not going to be successful unless these areas are corrected or modified.

In planning a lymphedema program, it would appear that more attention needs to be paid to the educational process of the patient. The patient should not only have written copies of their exercises, but they also should be practicing them and making lifestyle changes *before* they are discharged (Sneddon & Lewis, 2007). In addition, they should possess sufficient information about the disease itself and the methods of caring for themselves. It would also seem important for the patient to have some form of reminder that their garments need to be replaced. This could be worked out in several different ways but no matter the technique, it should be done. And the most important issue for the therapists is to make sure the patient is *easily* putting on their compression garments. This would almost always involve some form of donning device(s).

Another area lacking in the educational process that became evident from the research, was family members and caretakers not understanding enough about

lymphedema and their responsibilities in the long-term management of the disease. The family members need to understand that they may have to be staunch advocates for their loved one in times of crisis or hospitalization. They should be trained and willing to step forward to take care of the swollen limb in the likelihood that their loved one should become incapacitated.

Implications for Occupational Therapy Intervention

So what are the implications for occupational therapy in the treatment of lymphedema? Besides the therapist having competency in the actual massage and compression wrapping of lymphedema treatment, it seems that the interviews with the participants indicated multiple areas of occupational performance that an occupational therapist should address. These would include but not be limited to: (a) donning/doffing of the compression garments, (b) timely replacement of the garments, (c) knowledge and acceptance of the lifestyle changes necessary for control of their swelling, (d) social/psychological changes that lymphedema and its treatment bring, and (e) improvement in the patients' understanding of lymphedema for better problem-solving skills over the duration of the disease.

Another implication is the occupational therapist's role in spreading the "gospel" of lymphedema to the general community and in educational and medical circles. Therapists should take every opportunity to share their knowledge of lymphedema to others. This might include presentations for cancer/lymphedema support groups, teaching continuing education classes, or authoring articles in therapy journals and

newspapers along with any number of other occasions. Even general practice therapists without special knowledge of lymphedema can support the educational process by showing a willingness to learn and share.

It would seem wise for educators to review their curriculums to make sure there is at least some mention of lymphedema in their coursework or invite a lymphedema therapist to lecture on the subject. This would ensure that even beginning therapists would have at least heard about lymphedema and its treatment and would hopefully recognize it if and when a person with this type of swelling came to them.

During conversations or marketing with physicians, the occupational therapist/lymphedema therapist can make sure the doctors and their office staff are comfortable with the process for referring lymphedema patients. The knowledgeable therapist can also serve as a resource for the medical community.

CHAPTER V

CONCLUSION

In conclusion, the research revealed several areas that could be topics for future research. How much education and coaching is necessary to bring actual changes to lymphedema patients' lifestyles? What methods would work best to educate lymphedema patients about their disease and by what means could you teach problem-solving skills? How much does the medical community know about lymphedema and its treatment and what processes could be used to further educate them? What would be an effective approach to reach the general community to explain and describe lymphedema? All of these and more could be used to further the knowledge of lymphedema and its treatment.

I personally learned that people still want their voices to be heard--their stories to be told. I do not think I could have found a nicer group of people. Even though I am rather shy at times, each participant went out of their way to make me feel welcome and made me feel that the work I was doing had value.

Professionally, I found that this research showed me that we need to make some changes in our lymphedema treatment program. I need to seek out and establish improved methods of education. I need to emphasize better problem-solving skills with my patients. No patient should ever leave the clinic without the donning devices they need to be fully independent in putting on their compression garments. A strategy also needs to be found that better prepares the patient for the financial output that they will need to make, both in the immediate future and farther down the road.

The results of this research could be helpful to other lymphedema therapists and occupational therapists as they seek to improve their lymphedema programs.

Lymphedema seems to be so poorly understood in the general community. Hopefully, this study can spark myself and others to continue community education, and to tirelessly work to impart knowledge of lymphedema and its treatment to those around us. A fitting quote is taken from the Lymphatic Research Foundation web page, "May this be the decade when inspired scientists, researchers and physicians reach beyond all our dreams to create a more hopeful future for all affected by lymphatic diseases!"

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APPENDICES

Appendix A
Generic Flyer

Generic Flyer

Participants needed for a research study being conducted by:

Virginia Gifford

An Occupational Therapy Student

from

Texas Woman's University

Individuals 18 years of age and older and

diagnosed with lymphedema

are invited to participate

If interested please contact Virginia Gifford at

817 681-7813

(If no answer please leave a voice message)

Appendix B

Phone Explanation to Perspective Participant

Phone Explanation to Perspective Participant

Hello _____.

This is Virginia Gifford. You must have received my flyer advertising the lymphedema research study. Let me explain in a little more detail. As part of my master's degree I must do a research project as my thesis. I have chosen the subject of lymphedema. The name of the study is, Exploring the Course of Lymphedema Care: An Occupational Therapy Perspective.

It is a study to help identify any struggles or difficulties you may have faced with day-to-day care of your lymphedema, both when you first got your swelling and later on after your treatment. It is important that your story be told so that therapists and other healthcare professionals can improve and update our level of care by looking at your unique experiences with lymphedema.

Have I answered your questions about this project? If you are agreeing to participate I will need to set up a time and place for you to sign a document that is called "Informed Consent". It gives the details of the study and asks you to sign the document indicating your full permission to use your medical record and your lymphedema story as part of the research study. If you decide you do not want to participate then you will not be contacted again. This will be the end.

When would be a good time to meet? Where would you like me to meet you?

If you need to get hold of me to change the appointment or you change your mind about

participating, please call me at 817.681-7813. You may leave a voicemail if I do not answer. Goodbye.

Appendix C

TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Exploring the Course of Lymphedema Care: An Occupational Therapy Perspective

Investigator: Virginia Gifford, OTR.....817/681-7813
Advisor: Gayle Hersch, PhD, OTR..... 713/794-2153

Explanation and Purpose of the Research

You are being asked to participate in a research study for Virginia Gifford's thesis at Texas Woman's University. The purpose of this research is to explore the care of lymphedema from an occupational therapy perspective. It will help to identify any struggles or difficulties you may have faced with day-to-day care of your lymphedema, both in the acute stage and in the long term. It will also help to identify your course of referral and treatment from your medical doctors.

Research Procedures

For this study, the investigator will review the charts of lymphedema patients who have received care over the last year at Arlington Lymphedema Center/Hand and Upper Extremity Rehabilitation. You will be mailed an introductory letter along with a consent form that will need to be signed before the chart review can take place. You will receive more details of the study and will have the opportunity to ask questions. If you decide to participate, a time and place will be decided upon to sign the consent form. Demographic information such as age, gender, source of referral and type of lymphedema will be noted. Problems getting diagnosed or difficulties learning or maintaining your lymphedema will be identified in the review. The two to three participants from the chart review that best represent these themes, will be interviewed so that a more detailed account of your experience may be told. You will decide the place and time for the interview. The interview will consist of a private face-to-face meeting between you and the investigator. You will be audiotaped during the face-to-face interview. The purpose of the audiotaping is to provide a transcription of the information discussed in the interview and to assure the accuracy of the reporting of that information. Your time commitment to the interview is estimated to be approximately one to two hours. After the interview is typed, you will be asked to read the typed transcription and confirm that the transcription is accurate. Checking the transcript may take up to thirty minutes. The estimated maximum commitment to the whole process is one and one half to two and one half hours.

Potential Risks

A potential risk to you as a result of participating in this study is the release of confidential information. Confidentiality will be protected to the extent that is allowed by law. The interview will take place in a private area of your choice and will be tape recorded by the student researcher. These tapes will be kept in a locked file cabinet in the researcher's office. Also the results of the questionnaire, the journal kept by the student researcher and the hard copies of all study information will be kept in a locked file cabinet. Upon completion of the study, the materials will be stored in the locked file cabinet for one year. The student researcher is the only one to have access to the locked filing cabinet. All confidential materials needed to complete this research will be destroyed after one year.

_____ Page 1 of 2
Participant Initials

Exploring the Course of Lymphedema Care: An Occupational Therapy Perspective cont'd.

Potential Risks Continued:

You will be given a code to conceal your identity. Only the faculty advisor and the student researcher will have access to the information.

Another potential risk, is that you may feel uncomfortable talking about the sensitive material. You are not obligated to answer any question that makes you feel uncomfortable. Those questions will be excluded without penalty. After the chart review, there is no plan to exclude any participant, however, you may withdraw without penalty anytime during the research process. Finally, the interview process may disrupt your daily routine. The time and place of interview will be scheduled at your convenience to reduce this disruption

The researcher will try to prevent any problem that could happen because of this Research. You should let the researcher know at once if there is a problem and she will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your participation in this study is voluntary and you may withdraw from the study at any time without penalty. No monetary benefit will be given for your participation. Your participation will benefit the occupational therapy knowledge base and will help evaluate the current lymphedema programs in order to assure the highest quality treatment..

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2480 or via email at IRB@twu.edu.

Signature of Participant

Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

*If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent below:

Appendix D

INTERVIEW GUIDE

INTERVIEW GUIDE

1. Please tell me how you got your diagnosis of lymphedema? Do you remember going to the doctor more than once or going to more than one doctor? Tell me about it.
2. Please give me an overview of your medical history as it relates to your swelling. Did you have cancer? Some other serious trauma or disease?
3. Can you please describe to me the approximate timeline of your first trouble(s) with swelling and how long before you were able to get treatment? About how long did your treatment take?
4. Tell me about your treatment for lymphedema. What were some of your complaints, problems? What was good about it?
5. Did you or do you still have problems taking care of your swelling? Tell me about it.
6. Do you use a caregiver or have you used a caregiver in dealing with your compression bandages, stockings, or equipment? Can you tell me how that has worked?
7. If you need information about lymphedema, where do you go for your source(s)? Tell me about any frustrations and concerns you may have in locating information.
8. Psychologically, can you describe to me how lymphedema has affected you?
9. And finally, what would you say to someone that has just been diagnosed with lymphedema? What would be your advice?
10. Do you have any advice or comments for your doctors? What would that be?

Appendix E

Transcript Check

Transcript Check

Date _____

Dear _____,

Thank you for an enjoyable and insightful interview. Attached please find a draft copy of the verbatim transcripts of the interview. Please review the transcription for accuracy of responses and reporting of information. If you have any corrections regarding the content of the interview, please contact me at 817.681-7813 within the next five days.

Thank you again for your willingness to participate in this study.

Sincerely,

Virginia Gifford

Appendix F

TEXAS WOMAN'S UNIVERSITY
CONSENT TO RECORD

TEXAS WOMAN'S UNIVERSITY
CONSENT TO RECORD

Exploring the Course of Lymphedema Care: An Occupational Therapy Perspective

You consent to have your voice be recorded by

_____, acting on this date under the authority of

Texas Woman's university with the understanding that the material recorded today may be made available for research purposes and you consent to such use.

Participant	Date
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The above consent form was read, discussed, and signed, and you signed this consent form freely and with full knowledge and understanding of its contents.

Representative of Texas Woman's University	Date
--------------------------------------------	------

Appendix G

Chart Review Criteria

Appendix G

Chart Review Criteria

Demographic and medical information from the participants' charts will be gathered including:

- A. Primary and secondary diagnosis; any misdiagnosis if there were any.
- B. Age and gender.
- C. Referral source and process of referral if available.
- D. Treatment trajectory and timelines if known.

Texas Woman's University IRB Approval Letter



Office of Research

6700 Fannin Street
Houston, TX 77030-2343
713-794-2480 Fax 713-794-2488

October 27, 2008

Ms. Virginia Gifford
School of Occupational Therapy-G. Hersch Faculty Advis
6700 Fannin Street
Houston, TX 77030

Dear Ms. Gifford:

Re: *"Exploring the Course of Lymphedema Care: An Occupational Therapy Perspective"*

Your application to the IRB has been reviewed and approved.

This approval lasts for one (1) year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

Remember to provide copies of the signed informed consent to the Office of Research, IHS 10110 when the study has been completed. Include a letter providing the name(s) of the researcher(s), the faculty advisor, and the title of the study. Graduation may be blocked unless consents are returned.

Sincerely,

Dr. John Radcliffe, Chair
Institutional Review Board - Houston

Appendix I
Texas Health Resources Approval Letter



Initial Approval Notice

To: Virginia Gifford
CC: Virginia Gifford
From: Mary Robinson, PhD, IRB Chair
on behalf of THR Institutional Review Board

Please note that the Texas Health Institutional Review Board (THR IRB) Chair, or designee, has approved you to conduct research involving human subjects. Please review the following information summarizing the approval granted:

Study No.: Pro00001079
Study Title: Exploring the Course of Lymphedema Care: An Occupational Therapy Perspective
Protocol Version: 1
Protocol Date 5/3/2009
Approval Period: 10/16/2009 through 10/15/2010

Expedited

Approved Via: Category 5 (5) Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46, 101 (b)(4). This listing refers only to research that is not exempt.)

Risk Level: Minimal Risk
Principal Investigator: Virginia Gifford
Co-Investigators: None
Other Study Staff: None

Funding
Information: Not Applicable

If applicable, informed consent is required as follows:

Written, informed consent, including a consent document signed by the subject or the subject's legally authorized representative.

To find the documents stamped with IRB approval for use in this research project, please follow the link below and click on the Documents tab (If not on this list, any documents to be used in the research must be reviewed and approved by the IRB before use in the research):

Pro00001079

The research may not continue beyond the end of the new approval period, as indicated by the expiration date above. In order for the research to continue beyond that date, the IRB must first conduct continuing review and designate a new approval period.

The IRB will send you a continuing review notice at least 30-60 days before the expiration date listed above. If not completely filled out, received, reviewed and approved by the IRB before the end of the expiration date above, enrollment of new subjects in the research must cease until IRB approval can be obtained. Continued involvement in the research of previously enrolled subjects may not continue unless explicitly approved by the IRB to prevent harm to subjects.

Based on human research regulations and THR human subject research policies, the IRB emphasizes the following requirements in granting approval for this research project:

1. Any changes, modifications, or amendments to any facet of the research must be reviewed and approved by the IRB before they can be initiated.
2. All reportable adverse events and unanticipated problems involving risks to subjects or others must be reported to the IRB according to THR IRB policy requirements. This includes reporting to this Committee any death or serious reactions(s) resulting from this study (please consult the THR IRB Policy and Procedure Manual for specific definitions and reporting time-frames and requirements).
3. It is required to submit annual and terminal progress reports to the IRB and to receive continuing review of your activity annually by the IRB.

Failure to submit the above reports may result in severe sanctions being placed on Texas Health Resources. All research-related records and documentation may be inspected by the IRB for the purposes of ensuring compliance with THR policies and procedures and federal regulations governing the protection of human subjects. The IRB has the right and authority to suspend or terminate its approval if THR and Federal requirements are not strictly adhered to by all study personnel.

The JCAHO standards related to patients taking part in research require that they be informed about the benefits, risks, alternative treatments, research procedures and refusal to participate. This information is contained in each approved research consent form. All in-patients and out-patients that are actively taking part in clinical research must have a copy of their signed consent form on their open medical records.

<https://eirb.texashealth.org/EIRB/Doc/0/KF254TFI8GMKPF1LQNQULOT348/fromString...> 1/12/2010

If you have any questions or concerns, please contact the IRB Office at (682) 682-6746 or irb@texashealth.org. The IRB thanks you for your continued commitment to the protection of human subjects in THR research.

Appendix I

Texas Health Resources Approval Letter