

THE USE OF THE REMOTIVATION PROCESS IN AN OCCUPATIONAL  
THERAPY PROGRAM FOR BREAST CANCER-RELATED LYMPHEDEMA:  
A FEASIBILITY STUDY

A DISSERTATION  
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
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BY  
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## DEDICATION

For my husband, Emmanuel San Gabriel, thank you for your love that sustains me and keeps me motivated in this journey.

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## ABSTRACT

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### THE USE OF THE REMOTIVATION PROCESS IN AN OCCUPATIONAL THERAPY PROGRAM FOR BREAST CANCER-RELATED LYMPHEDEMA: A FEASIBILITY STUDY

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**BACKGROUND:** Lymphedema affects a significant number of women with breast cancer. It affects a woman's occupational performance and adaptation, and quality of life. Self-Management Programs (SMP) have been utilized for the long-term management of breast cancer-related lymphedema. Motivation is a key element in the daily performance of the SMP. The Remotivation Process is an occupational therapy intervention that can be used to facilitate motivation. It is grounded in the model of human occupation practice framework.

**OBJECTIVE:** This dissertation research explored the effect of the Remotivation Process on the motivation of women with breast cancer-related lymphedema to incorporate the SMP in their daily routine, the manifestation of lymphedema, occupational participation, and quality of life.

**METHOD:** The study utilized a concurrent triangulation design that involved six participants ( $n = 6$ ) from a large metropolitan hospital. The Remotivation Process was used as an occupational therapy intervention for four weeks. A follow-up session was completed after eight weeks.

**RESULTS:** The quantitative analysis showed significant differences in the pretest and posttest scores in the Model of Human Occupation Screening Tool, Volitional Questionnaire, and the girth of the affected upper extremity. The qualitative findings also reflected these improvements in occupational performance, motivation, and physical manifestation of lymphedema. The quantitative analysis did not show a statistically significant difference in the daily performance of the SMP and scores on the Lymphedema Quality of Life Inventory. However qualitative findings suggested that the participants became more aware of their adherence to the SMP and experienced improved quality of life after the intervention.

**CONCLUSION:** This dissertation research found that the Remotivation Process is a potentially useful occupational therapy intervention that addresses the motivational needs of women with breast cancer-related lymphedema. Though this dissertation research was a feasibility study with a small sample size, the study is a first step in investigating the effect of the Remotivation Process upon a larger and more diverse group of women with breast cancer-related lymphedema.

## TABLE OF CONTENTS

	Page
DEDICATION .....	i
ACKNOWLEDGEMENTS .....	ii
ABSTRACT .....	iii
TABLE OF CONTENTS .....	v
LIST OF TABLES .....	xii
LIST OF FIGURES .....	xiii
 Chapter	
I. INTRODUCTION .....	1
Background on Lymphedema .....	1
Incidence and Prevalence .....	1
Pathology .....	2
The lymphatic system .....	2
Lymph formation .....	3
Lymphedema.....	4
Breast cancer treatment.....	5
Effects of BCRL .....	6
The effects of lymphedema on activities of daily living.....	6
Effects on quality of life .....	8

Lymphedema is a chronic condition that impacts daily life .....	8
Treatment for Lymphedema .....	9
Background on Self Management Program (SMP) for Lymphedema.....	11
Definition of SMP.....	11
Difference between self-care, patient education, and SMP .....	12
The benefits of self-management.....	13
Adherence to SMP is Important in Patients with BCRL .....	14
Sources of dissatisfaction.....	15
Conflict in roles.....	16
Self-sacrificing behaviors .....	17
Statement of the Problem and Aims .....	18
The research questions of the study .....	19
Significance of research in occupational therapy and outside discipline ...	20
II. REVIEW OF LITERATURE.....	21
Theories and approaches Used in Healthcare to Improve Adherence .....	21
Supportive-Educative System.....	22
Social Learning Theory and Self-Efficacy .....	23
Motivation.....	24
Theories of motivation.....	25
Transtheoretical model of change .....	27
Motivational interviewing.....	28
Theories in motivation and adherence to SMP .....	29

MOHO .....	30
The MOHO concept of Volition and BCRL.....	33
Comparison of the Theories of Motivation and MOHO Concept .....	36
Personal Causation.....	37
Values .....	38
Interest.....	39
The Unique Contribution of the MOHO Concept of Volition.....	39
Self-efficacy and volition.....	40
Volition as a gateway for change.....	41
The process of change and adaptation .....	44
The Role of Occupational Therapy in BCRL .....	46
Adherence and Occupational Therapy .....	46
Occupational therapy's role in motivation.....	48
Occupational therapy's role in adaptation through MOHO.....	49
The use of the remotivation process in clients with BCRL .....	50
The Remotivation Process .....	51
III. METHODS .....	56
Research Design.....	56
Quantitative Study Design.....	56
Qualitative Study Design .....	56
Descriptive Phenomenology .....	58
Hermeneutic Phenomenology .....	59



The researcher's perspective.....	59
Setting .....	60
The Collaborating Institution.....	60
Onsite Collaborator.....	61
Treating Therapists .....	61
Institutional Review Board .....	62
Sampling .....	66
Sampling method of the quantitative study .....	66
Power analysis .....	66
Inclusion and exclusion criteria .....	66
Participant recruitment.....	66
Sampling method of the qualitative study .....	68
Description of the intervention .....	68
The Remotivation Process .....	68
The Volitional Questionnaire.....	69
Treatment implementation using the Remotivation Process .....	71
Exploration stage .....	74
Competence stage .....	78
Achievement stage.....	80
Data Collection Tools .....	81
Circumferential Measurement .....	81
Model of Human Occupation Screening Tool .....	82

Lymphedema Quality of Life Inventory .....	83
Data Collection Procedures.....	84
Quantitative Study .....	86
Qualitative Study .....	90
Data Analysis .....	92
Quantitative Data Analysis .....	92
Qualitative Data Analysis .....	96
Integration of Data from Quantitative and Qualitative Studies .....	102
IV. RESULTS .....	106
Participant Demographics .....	106
Participant Drop-Outs .....	106
Results of the Quantitative Study .....	108
Research question 1 .....	110
Research question 2 .....	111
Research question 3 .....	113
Comparison of participants and those who dropped-out .....	117
Volitional Questionnaire .....	119
Results of the Qualitative Study .....	120
Step 1 .....	121
Step 2 .....	121
Step 3 .....	122
Step 4 .....	125

Exploration of the Nodes and NMUs.....	129
Volition .....	129
Participant's Response to BCRL .....	141
Family's Response to BCRL .....	149
Impact on Human Occupation .....	153
Perception of Occupational Therapy .....	158
Perception of the SMP .....	166
Negative Factors .....	170
Support for SMP .....	176
Triangulation of Qualitative Data .....	181
Integration of the Qualitative and Quantitative Studies.....	189
The Remotivation Process and VQ.....	189
Integration of research question 1 .....	199
Integration of research question 2.....	201
Integration of research question 3.....	202
V. DISCUSSION .....	205
Translating the Nodes from the Qualitative Study into MOHO Concepts .....	205
Impact of the Remotivation Process .....	217
Comparing the Study with Literature Review .....	224
Summary of Findings.....	228
Implications.....	230
Limitations .....	231

Future Directions .....	232
Conclusion .....	235
REFERENCES .....	236
APPENDICES	
A. CITI Certificate of the Onsite Collaborator.....	253
B. The Collaborating Institution's Study Protocol.....	256
C. Recruitment Brochure.....	328
D. The Collaborating Institution's Informed Consent.....	331
E. Recruitment Script .....	345
F. Remotivation Process Interview Questions and Stages.....	347
G. Participant Handout of the Remotivation Process .....	362
H. Girth Measurement Chart in the Data Collection Form .....	364
I. Model of Human Occupation Screening Tool.....	366
J. Lymphedema Quality of Life Inventory .....	368
K. Researcher's Journal Template .....	373
L. The Collaborating Institution's Data Collection Form.....	375
M. Field Notes of Participant 1 .....	378
N. Field Notes of Participant 2 .....	387
O. Field Notes of Participant 3 .....	394
P. Field Notes of Participant 4 .....	401
Q. Field Notes of Participant 5 .....	405
R. Field Notes of Participant 6 .....	413
S. Field Notes of Participant 7 .....	421
T. Interview Guide for Qualitative Data Collection.....	428
U. Researcher's journal entries .....	433
V. Example of a Completed Data Collection Form .....	472
W. TWU IRB Approval and NIH Certificate of Second Coder .....	474
X. Chronbach's Alpha of MOHOST at Pretest .....	478

## LIST OF TABLES

Table	Page
1. Recruitment of Additional Participants After the 2-Week Period .....	67
2. Data Gathering Process to Answer the Research Questions.....	84
3. Planned Data Analysis .....	92
4. Demographics .....	107
5. Implemented Data Analysis.....	109
6. Reduction in Volume .....	113
7. Child/Nodes that were Identified in Step 2.....	121
8. Central Themes that were Identified in Step 3.....	123
9. Parent Node and Child Nodes that were Identified in Step 3.....	124
10. Nodes in the Thematic Index .....	126
11. Statements that Answer the Research Questions .....	128
12. Translating the Nodes into MOHO Concepts .....	206

## LIST OF FIGURES

Figure	Page
1. Configuration of MOHO Intervention Protocols .....	51
2. Study Design Schema Approved by the Dissertation Committee .....	64
3. Study Design Schema Approved by the Collaborating Institution.....	65
4. The Volitional Continuum .....	71
5. The Application of the Remotivation Process to BCRL.....	73
6. Integration of Quantitative and Qualitative Data.....	104
7. Volitional Questionnaire of Participant 1 .....	191
8. Volitional Questionnaire of Participant 2 .....	192
9. Volitional Questionnaire of Participant 3 .....	194
10. Volitional Questionnaire of Participant 5 .....	195
11. Volitional Questionnaire of Participant 6 .....	196
12. Volitional Questionnaire of Participant 7 .....	198

## CHAPTER I

### INTRODUCTION

#### **Background on Lymphedema**

Breast cancer-related lymphedema (BCRL) is the swelling of the upper extremity, a side effect of cancer surgery and treatment. Swelling may be experienced in the chest wall, axilla, shoulder, arm, or hand. Lymphedema is a lifelong condition and treatment involves the daily performance of a self-management program (SMP). Women need to adapt to the chronic and lifelong nature of BCRL in order to adhere to the SMP.

However, research on the adherence to SMP revealed that not all of the women are able to perform the SMP every day (Kulesza-Bronczyk et al., 2014; Ridner, Dietrich, & Kidd, 2011). One of the reasons may be a decrease in the woman's motivation. This study investigated the impact of motivation on a woman's adherence to SMP.

#### **Incidence and Prevalence**

There are more than 3.5 million women with a history of breast cancer in the United States as of January 2020 (breastcancer.org, 2020). These numbers include those currently being treated and those who have completed breast cancer treatment. It is estimated that 276,480 new cases of invasive breast cancer will be diagnosed in women in 2020, with an average risk of 13% among women in the United States (breastcancer.org, 2020). The 5-year survival rate for breast cancer varies by stage. The rate is close to 100% for women with stage 0 or stage 1, 93% for women with stage 2, 72% for stage 3, and 22% for those with metastatic or stage 4 breast cancer (American

Cancer Society, 2016a). The 5-year survival rate for breast cancer in the United States has improved from 63% in the 1960s to 90% in 2011 (Loh & Musa, 2015) and continues to improve. The overall death rate from breast cancer has decreased by 1.3% each year since 2013 as a result of advances in treatment and earlier detection (breastcancer.org, 2020). However, the increased survival rate has also led to more women living with the side effects of cancer surgery and treatment. Physical impairments, such as BCRL, are among the most debilitating complications after surgery (Loh & Musa, 2015). The risk of BCRL depends on the type of treatment (Burckhardt, Belzner, Berg, & Fleischer, 2014). There is a 2 - 4.9% risk of developing BCRL following lumpectomy, 95% after mastectomy, 65% among those who underwent more extensive surgery or radiation therapy, 5-20% after sentinel lymph node biopsy (SLNB), and 10-56% after axillary lymph node dissection (ALND; Bojinovic-Rodic, Popovic-Petrovic, Tomic, Markez, & Zivanic, 2016; breastcancer.org, 2020; Burckhardt et al., 2014). The risk can increase up to 66% in patients who underwent both ALND and radiation (Cal & Bahar, 2016). BCRL also has a significant impact on health care expenses. A study found that women with BCRL have significantly higher medical costs per year than breast cancer survivors who do not develop the condition. Additional services for lymphedema, such as outpatient care, mental health services, and diagnostic imaging account for the majority of the difference (Shih et al., 2009).

## **Pathology**

**The lymphatic system.** The lymphatic system has 3 main functions. It maintains homeostasis, transports nutrients to the tissues, and plays a role in the body's immune



system (Foldi, 2006; Mortimer & Rockson, 2014). It consists of the lymphatic organs and lymph vessels. Lymphatic organs include the bone marrow, thymus, spleen, lymph nodes, and mucosa-associated lymphatic tissue. The lymph vessels are networks of endothelial tubes, which are formed by overlapping endothelial cells held in place by anchoring filaments. The lymph vessels follow the pathway of blood capillaries and are involved in the formation of lymph fluid (Foldi, 2006). It functions in partnership with the cardiovascular system to maintain tissue volume homeostasis. It also serves as the main pathways for the removal of inorganic materials and mutant cells (Mortimer & Rockson, 2014). Lymph vessels transport lymph fluid to the lymph nodes. Lymph nodes form small clusters or chains and are embedded in adipose tissue. Examples of these node clusters and chains are located in the axilla, inguinal area, neck, and abdomen. Lymph is conducted from the nodes through a series of larger lymph vessels and reaches the lymphatic trunks where it enters the venous circulation. The axillary lymph nodes receive lymph from the upper extremity, the shoulder region, mammary glands, and anterior and posterior chest wall above the umbilicus. Excised lymph nodes do not regenerate and nodes that undergo partial resection do not regain their original capacity. Lymphatic flow is impeded in the areas that empty into the damaged lymph nodes (Foldi, 2006).

**Lymph formation.** Water and other molecules flow between the blood circulation and interstitium at the blood capillaries. Water, plasma protein molecules, vitamins, hormones, fatty acids, and metals diffuse through the capillary membrane into the interstitium to nourish the tissues (Foldi, 2006). The diffusion of water and molecules

occurs at the arterial end of the blood capillary. Water is reabsorbed back into the blood capillary to remove waste. Reabsorption happens at the venous end of the blood capillary; however, protein molecules and other larger molecules are not reabsorbed and remain in the interstitium (Foldi, 2006). The oncotic pull of the protein molecules causes water to remain in the interstitium. It is estimated that 10% of the water that diffuses at the arterial end is not reabsorbed at the venous end of the blood capillary (Foldi, 2006). However, the current research found that diffusion of water and molecules occur along the entire length of the blood capillaries. This means that the lymphatic system transports a larger volume of water and molecules from the interstitium (Mortimer & Rockson, 2014). The accumulation of water and other molecules in the interstitium causes the anchoring filaments to pull the overlapping endothelial cells apart, which opens the lymph vessels. Water and molecules enter the lymph vessels, forming the lymph or lymphatic fluid (Foldi, 2006). The endothelial cells return to their overlapping position once the vessel has reached its capacity. Lymph then travels toward the lymph nodes and through the lymphatic system (Foldi, 2006).

**Lymphedema.** The lymphatic system, as mentioned in the previous section, is responsible for the maintenance of fluid homeostasis. Lymphedema is a chronic, progressive condition where lymph fluid accumulates in the interstitium as a result of the failure of the lymphatic system to maintain fluid homeostasis (Foldi, 2006). It develops when the diffusion of fluid from the blood capillaries into the interstitium exceeds the transport capacity of the lymphatic system (Foldi, 2006). Lymphedema progresses through four stages. The first is the latency stage, or stage 0, where obstruction of the

lymphatic flow and reduction of lymph transport occur as a result of trauma or surgery. Focal changes in the tissues occur, but the person does not experience signs or symptoms of lymphedema. Patients who undergo breast cancer treatment may remain at this stage and not develop BCRL (Foldi, 2006). Stage 1 is the reversible stage. The person develops pitting edema, which subsides with elevation. It progresses to stage 2, or spontaneously irreversible stage. The person develops fibrotic changes in the skin and non-pitting edema. The final stage is stage 3, or elephantiasis, where the formation of scar tissue and the proliferation of adipose tissue occur in the limb (Foldi, 2006).

Lymphedema is a chronic medical condition that is classified as primary or secondary based on the cause of lymphatic insufficiency. Primary lymphedema is caused by the abnormal development of the lymphatic system in utero (Bogan, Powell, & Dudgeon, 2007). Secondary lymphedema is caused by damage to the lymph vessels following trauma, infection, immobility, or cancer treatment (Bogan et al., 2007; Foldi, 2006).

**Breast cancer treatment.** The lymphatic system serves as a pathway for inorganic material and mutant cells, which makes it the preferred route for cancer metastasis (Mortimer & Rockson, 2014). Women with breast cancer may undergo surgery to remove the affected lymph nodes to stop the spread of breast cancer. Surgical procedures include mastectomy and lymph node resection. Two main types of surgery that involve the lymph nodes include sentinel lymph node biopsy and axillary lymph node dissection. Sentinel lymph node biopsy involves the removal of the lymph nodes where the cancer is likely to spread. Axillary lymph node dissection involves the removal of 5 to 40 lymph nodes in the axilla (breastcancer.org, 2020; American Cancer

Society, 2016b). Women with breast cancer may also undergo radiation therapy following mastectomy or when cancer has metastasized to the lymph nodes or other parts of the body. These procedures may damage the lymph nodes and vessels, impede lymph flow, and reduce the transport capacity of the lymphatic system. Lymph nodes may be damaged or removed during surgery. Radiation can cause scar tissue formation and damage to the lymph nodes and vessels, which impede lymphatic flow. In some cases, the tumor may block the flow of fluid in the lymphatic system (American Cancer Society, 2016b; Campbell & Munoz, 2016). Individual studies have estimated that 10% up to 90% of breast cancer survivors develop BCRL while experts estimate a range of 20-30% (breastcancer.org, 2020).

### **Effects of BCRL**

Lymphedema has a negative impact on body image, daily living, sexual participation, and leisure participation (Armer et al., 2011; Meiklejohn, Heesch, Janda, & Hayes, 2013; Radina, 2009; Ridner, Dietrich, & Kidd, 2011; Radina, 2009). Quantitative and qualitative research reported that women with BCRL have statistically significant decreased mental well-being, increased psychological distress, and more severe physical discomfort than those without BCRL (Cuevas et al., 2014; Loh & Musa, 2015; Ridner et al., 2012b).

**The effects of lymphedema on activities of daily living.** Occupational therapy defines Activities of Daily Living (ADLs) as those activities oriented towards taking care of one's self that enables basic survival and well-being (American Occupational Therapy Association, 2014). Literature in oncology and nursing refers to ADLs as self-care. Self-

care is the acquired ability to perform daily requirements that regulate life, support the human body, maintain function, and promote well-being (Armer et al., 2011). Women with BCRL reported that physical changes led to limitations in self-care (Armer et al., 2011; Bloomquist et al., 2018; Bulley et al., 2014; Cohen, 2011; Devoogdt, Van Kampen, Geraerts, Coremans, & Christiaens, 2011; Lindquist, Enblom, & Bergmark, 2015; Meiklejohn et al., 2013; Radina, Armer, & Stewart, 2014; Upton & Solowiej, 2011). These physical changes included swelling of the hand, pain, sense of heaviness and tightness, cramping, paresthesia, decreased range of motion and strength, compromised fine motor coordination, reduced sensation, and fatigue (Bojinovic-Rodic et al., 2016; Davies, Ryans, Levenhagen, & Pardomo, 2014; Grada & Phillips, 2017; Hidding, Beurskens, van der Wees, van Laarhoven, & Nijhuis-van der Sanden, 2014; Kulesza-Bronczyk et al., 2014; Martinez & Martinez, 2018; McGrath, 2013; Meiklejohn et al., 2013). Increased limb girth and impaired skin integrity led to difficulty in finding clothes that will fit and cover the affected extremity. BCRL also affected participation in Instrumental Activities of Daily Living (IADLs). Occupational therapy defines IADLs as more complex activities that support daily life in the home and community (American Occupational Therapy Association, 2014). Women with BCRL are also limited in IADLs such as writing, opening bottles, carrying items, shopping, gardening, cleaning the house, ironing, cooking, caring for pets, and caring for others. Patients either have to change the way these tasks are performed, set aside more time for task completion, or avoid doing the task completely.

**Effects on quality of life.** Women also experienced psychological impacts such as negative self-identity and emotional distress. Lymphedema can be a constant reminder of breast cancer (Radina et al., 2014; Taghian et al., 2014). Women with BCRL struggled with their current situation, appearance, activity restrictions, self-confidence, and self-efficacy (Fu, 2005; Kulesza-Bronczyk et al., 2014; Fangel, Panobianco, Kebbe, de Almeida, & Gozzo, 2013). Women may perceive life as overshadowed by the demands of the SMP, which is time-consuming and often leads to frustration, depression, or anger. The decline in ADLs also has psychological effects. Women with lymphedema experienced a change in roles, work participation, and a change in family dynamics as a result of limitations in self-care. Women experience loss of independence and inability to perform the activities related to their roles. They may abandon their roles, which will be assumed by other members of the family (Fangel et al., 2013; McGrath, 2013; Radina et al., 2014). Quality of life is affected by lymphedema due to changes in body image, the decline in function, and required lifestyle change associated with lymphedema management. Psychological consequences included depression, embarrassment, anxiety, frustration, reduced body image, and social avoidance (Abou-Elenein, Makar, Abdel-Azim, 2016; Bloomquist et al., 2018; Bogan et al., 2007; Bojinovic-Rodic et al., 2016; Bulley et al., 2014; De Brucker et al., 2016; Meiklejohn et al., 2013; Upton & Solowiej, 2011).

**Lymphedema is a chronic condition that impacts daily life.** Chronic medical conditions are long-term diseases that affect people of all ages, social class, and ethnic groups. The Centers for Disease Control and Prevention estimates that 6 out of 10 adults

in the United States have a chronic condition. Examples of chronic conditions include heart disease, diabetes, arthritis, and chronic obstructive pulmonary disease (Connors, McGlamery, & Stern, 2019; National Institutes of Health, 2020). Patients with chronic conditions face common challenges. These include dealing with the symptoms and disability, managing complex medication regimens, maintaining proper levels of nutrition, diet, and exercise, recognizing and managing symptoms, managing emotions, managing stress, adjusting to the psychological and social demands, making lifestyle adjustments, and adapting to work. Patients also have difficulty communicating with health care providers and seeking necessary health information to manage the condition (Grady & Gough, 2014; Lorig & Holman, 2003; Ryan & Sawin, 2009). BCRL is a chronic condition and current treatment methods do not cure lymphedema; rather, treatment is directed towards symptom management and reduction of complications (Cal & Bahar, 2016).

### **Treatment for Lymphedema**

The executive committee of the International Society of Lymphology advocates complete decongestive therapy (CDT) as the treatment of choice for lymphedema because of its effectiveness without the side effects associated with pharmacologic or surgical treatments (Bogan et al., 2007; Cohen, 2011; De Brucker et al., 2016). It has four components: (1) manual lymphatic drainage, (2) compression therapy, (3) exercise, and (4) skincare. Manual lymphatic drainage is a specialized technique designed to improve fluid removal from congested areas where the lymph vessels are impaired. Compression therapy prevents the re-accumulation of evacuated edema fluid.

Compression is provided through compression bandaging or garments. These are designed to provide compression that will facilitate lymphatic flow back to the lymph nodes in the axilla of the arm. Serial compression bandaging is the use of multiple layers of bandages to create a gradient where compression is greater around the hand and lower arm and less toward the axilla. Compression garments are made from a blend of fabric that provides a compression gradient similar to serial compression bandaging. Two common compression garments for the upper extremity are the sleeve and gauntlet. Resistive exercise, aerobic activity, gentle stretching, and deep breathing exercise were found to improve lymphatic flow, increase oxygenation, and promote tissue repair. A meticulous skincare routine keeps the skin clean and moisturized to avoid further complications from skin tears and wounds (National Lymphedema Network, 2011b).

CDT has two phases. CDT Phase I is a daily program consisting of manual lymphatic drainage, exercise, skincare, and serial compression bandaging. A certified lymphedema therapist provides therapy during this phase. Limb volume or girth is taken during each session to measure girth reduction, monitor change in the limb, and document treatment outcomes. The patient is seen three times a week to provide manual lymphatic drainage and serial compression bandaging. The patient performs an SMP in between sessions. The SMP includes self-administered manual lymphatic drainage, exercises, bandaging, and skincare routine. These components are vital to control the manifestation of lymphedema. Compression alone was found to reduce swelling by 60% (Grada & Phillips, 2017). CDT Phase II begins when there is no further reduction in measurements. Phase II is a daily SMP that is completed by the patient at home. It



consists of self-massage, exercise, skincare, an inspection of the limb, wearing of compression garments and nighttime compression either through self-bandaging or custom garments. The patient must complete the daily SMP in order to avoid the recurrence of lymphedema. Early treatment is necessary to achieve the goal of lymphedema treatment. BCRL is a chronic condition and requires an SMP. The goal of treatment is to improve quality of life (QOL) and reduce morbidity through the control of swelling, improve function, and prevent complications (Bogan et al., 2007; Grada & Phillips, 2017; Radina et al., 2014).

### **Background on Self-Management Program for Lymphedema**

#### **Definition of SMP**

The National Institutes of Health define self-management as an approach to managing chronic health conditions by empowering patients to understand their conditions and take responsibility for their health (National Institutes of Health, 2020). The American Occupational Therapy Association defined self-management as the development, management, and maintenance of routines for health and wellness promotion, such as physical fitness, nutrition, decreasing health risk behaviors, and medication routines (American Occupational Therapy Association, 2014). Self-management focuses on strategies that enable patients to deal with the challenges related to the condition. It is about being in charge of one's life and managing one's condition, instead of being managed by that condition. Self-management is broadly defined as the tasks that a person must perform to live with one or more chronic conditions. This

includes having the confidence to deal with medical management, role management, and emotional management (Grady & Gough, 2014; Lorig & Holman, 2003).

**Difference between self-care, patient education, and self-management.** Self-care refers to ADLs such as bathing and toileting. These are routine activities that are independent of the activities and behaviors related to the chronic condition. Patient education refers to the provision of information by a health care provider with the intent to increase the person's knowledge about the condition. Self-management involves the facilitation of skills and health behavior change with the intent to increase the quality of life of the person. Self-management is a lifelong task that requires the person to take responsibility for day-to-day performance. It is the core target for the improvement of health and management of chronic conditions. Self-management is a process of actively engaging in activities designed to improve well-being. The person has to actively address the consequences of developing the condition, which includes the symptoms, emotions, and functional limitations (Carpenter, DiChiacchio, & Barker, 2019; Connors et al., 2019; Leland, Fogelberg, Hale, & Mroz, 2017; National Institutes of Health, 2020). The literature presented specific definitions of self-management. Ryan and Sawin (2009) defined self-management as a complex phenomenon that occurs through the interaction between the person with the condition and her family. Self-management included the risk and protective factors specific to the condition, components of the physical and social environment, and characteristics of the person and family members. Grady and Gough (2014) considered self-management integral to the maintenance of health and management of illness. It can be a process, a program or an outcome. Self-management

is a process where the person undergoes health behavior changes through goal-setting; self-monitoring and reflective thinking; decision-making; planning, resource utilization, and self-evaluation. Self-management is an intervention program designed by a health care provider to enable the patient to assume responsibility for managing their chronic illness. Self-management is also an outcome measured to determine the extent of success of the process and program. (Grady & Gough, 2014; Ryan & Sawin, 2009). Examples of self-management as an outcome include the Hemoglobin A1C levels of a person with diabetes or limb girth in the case of lymphedema.

**The benefits of self-management.** Self-management a method for improving the health status of patients with conditions in 2020. Self-management is one of the approaches that shift the responsibility of disease management from the health care provider to the patient (National Institutes of Health, 2020). It promotes a partnership between the person with the chronic condition and the healthcare provider. Programs that involve SMP are tailored specifically to the needs of the intended patient population; examples are the Arthritis Self-Management Program, Diabetes Self-Management Program, Community Aging in Place, and Advancing Better Living for Elders (Grady & Gough, 2014). Interventions that support SMPs have demonstrated improvements in chronic conditions such as diabetes (Carpenter et al., 2019).

A systematic review of research involving older individuals with chronic conditions explored the value of a Chronic Disease Self-Management Program. The review found strong evidence that demonstrates the effectiveness of using the SMP in the improvement of occupational performance. The SMP focused on increasing the client's

confidence in managing multiple chronic conditions through mastery of skills, problem-solving, action planning, coping skills, opportunities for practice, and decision making (Berger, Escher, Mengle, & Sullivan, 2018). Self-management will continue to become a crucial approach to managing chronic conditions, preventing illness, and promoting wellness. Self-management is an approach in chronic conditions since the disease process is often slow in progression and may last a lifetime. Patients who adhered to the SMP were found to have better health status and developed a sense of self-efficacy and enhanced engagement in self-management behaviors (Ryan & Sawin, 2009; Trudeau et al., 2015). They developed confidence in their ability in managing their health (Trudeau et al., 2015) and experienced an increase in quality of life (QOL; Ryan & Sawin, 2009). Patients who adhered to the SMP also saw a decrease in health care expenses (Ryan & Sawin, 2009; Turner, Allison, Wallace, & Bourne, 2015).

### **Adherence to SMP is Important in Patients with BCRL**

Lymphedema is a chronic condition that involves self-management to control the symptoms or prevent re-occurrence. Adherence to SMP is vital in the management of chronic conditions (Holmes, Hughes, & Morrison, 2014; National Institutes of Health, 2020). Self-management involves an SMP for lymphedema performed by the person. This phase is critical to reduce exacerbations of swelling, prevent infections, and manage symptoms. Adherence to SMP is critical. Adherence is enhanced when the person with BCRL sees the visible and satisfactory outcome of the SMP. The SMP should also be compatible with the pattern of personal and family life. The health care professional should help women with BCRL build a satisfying support network and help her

incorporate the SMP in her daily routine (Dennis, 1993). A study of women with BCRL found that awareness of the consequence of non-adherence to SMP increased their decision to perform SMP (Kulesza-Broczyk et al., 2014). However, instead of passive acceptance of the recommendation from the health care provider, women selected their own strategies that they believed to be more effective and less time-consuming. Those who adhered to all 4 components of the SMP maintained 90% of their upper limb girth upon discharge, reported a positive effect on QOL and reduced symptoms of BCRL (Lashinski et al., 2012; Loh & Musa, 2015). Women who did not maintain the SMP protocol over time experienced the progression of lymphedema along with its physical, functional, and psychological impact (McGrath, 2013; Lashinski et al., 2012). However, only 45- 49% of breast cancer survivors with lymphedema adhere to the SMP for lymphedema (Dominick et al., 2014; Kulesza-Bronczyk et al., 2014; Ridner et al., 2011). This level of compliance is similar to that of individuals with other chronic medical conditions (Kulesza-Bronczyk et al., 2014; Ridner et al., 2011). Non-adherence to the SMP is a challenge in health care (Carpenter et al., 2019; National Institutes of Health, 2020). There are several reasons for non-adherence and some of these reasons will be explored in the next section.

**Sources of dissatisfaction.** Women experienced dissatisfaction while adjusting to the new experience of living with BCRL. Some sources of dissatisfaction included financial difficulties, problems with insurance, limited social supports, no interests, no engagement in pleasurable activities, and disenchantment with the treatment for BCRL (Armer et al., 2011; Davies et al., 2014; Dennis, 1993; Fu, 2005; McGrath, 2013;

Meiklejohn et al., 2013; Radina et al., 2014; Ridner et al., 2014). Perceived barriers in the environment may also negatively affect the women's adherence to the SMP for lymphedema (Dennis, 1993). A qualitative study showed that women with BCRL have strong ambivalence towards BCRL and SMP (McGrath, 2013). Six participants with BCRL were interviewed. They experienced the limited use of the affected arm while performing valued activities such as child care, home management, and participating in leisure. Their sense of occupational identity was threatened since they could no longer perform activities related to their occupational roles. The participants chose to ignore self-management protocols “in order to experience the familiar self that was connected with occupational identity [sic]” (McGrath, 2013, p. 48) The experience of disruption in the sense of normalcy, constancy, and continuity led them to choose to participate in activities related to their valued roles prior to breast cancer and BCRL instead of adhering to the SMP. The participants resisted lifestyle change related to BCRL “because to stop or change their performance would mean that the sense of constancy and continuity that signaled the personally normal was broken” (McGrath, 2013, p. 48). Their strong desire and deep concern with preserving occupational participation negatively affected adherence to SMP.

**Conflict in roles.** Literature has found that women tend to decide not to adhere to SMP due to conflict with their valued roles and strong desire to maintain the current roles, habits, values, and interests (Radina et al.2014; McGrath, 2013). Lymphedema management requires some degree of prioritizing the self over the needs of others. Women with BCRL need to perform daily lymphedema management techniques that are

“time-consuming and cumbersome” (Radina, 2009, p. 454). It added 30 minutes to 2 hours to their time for self-care. It has a negative impact on the time for family and restricted participation in both self-management and other personal responsibilities (Radina, 2009). Some survivors have a lack of interest in SMP or do not value the importance of SMP (Armer et al., 2011). Several researchers have examined reasons for low adherence, most of which revolved around the decision between the significant amount of time needed to engage in SMP and other occupational roles (McGrath, 2013). These occupational roles included time with family, personal life, and social responsibilities (Radina et al., 2014; Radina, 2009).

**Self-sacrificing behaviors.** Women are also found to engage in self-sacrificing behaviors. Women are responsible for housework and childcare aside from work outside the home. Women tend to neglect their own needs as they attend to the needs of the family first; these behaviors are referred to as self-sacrifice (Fangel et al., 2013; Radina et al., 2014). Social and political forces led them to self-sacrificing behaviors in order to ensure their connection with the family (Radina et al., 2014). Women also engaged in this behavior because of the value of their role in relation to others (Fu, 2005; McGrath, 2013; Meiklejohn et al., 2013; Palmadottir, 2010; Ridner et al., 2014). Self-sacrificing behaviors may cause women to neglect self-care. Lymphedema management requires some degree of prioritizing the self over self-sacrifice. There is a need to address women's own needs, desires and abilities in order to facilitate behavior change needed to adapt to life with BCRL (Armer et al., 2011; Fangel et al., 2013).

## **Statement of the Problem and Aims**

BCRL affects a significant number of women with breast cancer. It is a chronic condition, which is a potential side effect of breast cancer treatment. Women with this condition experience physical changes such as increased girth in the arm and hand. These affect occupational performance, occupational adaptation, and QOL. SMPs are necessary for the long-term management of BCRL. However, most women with lymphedema do not perform SMP on a daily basis. A woman's motivation may have an impact on the incorporation of the program in her daily routine (Muraca, Leung, Clark, Beduz & Goodwin, 2011; Riegel, et al., 2006; Teo, Fingeret, Liu, & Chang, 2015; Trinh, Mutrie, Campbell, Crawford & Courneya, 2014). This study explored the use of the Remotivation Process (de las Heras, Llerena, & Kielhofner, 2003) to increase a woman's daily performance of the SMP for lymphedema. The Remotivation Process is a continuum of interventions based on the Model of Human Occupation (MOHO) concept of volition. (de las Heras et al., 2003). The authors of the process state that motivation is affected by illness or life events (de las Heras et al., 2003). The Remotivation Process can be used as an occupational therapy program to facilitate the return of motivation in clients with motivational problems. This was a feasibility study of an occupational therapy intervention involving one group of participants, using a mixed-methods concurrent triangulation design. It aimed to explore whether or not the Remotivation Process leads to an improvement in the adherence to the SMP, girth reduction, occupational performance, self-perception, and quality of life when added to a customary occupational therapy program for BCRL.



## **The Research Questions of the Study**

The research questions for the quantitative study were:

1. How does Remotivation Process, as an occupational therapy intervention, change the daily performance of the lymphedema management techniques?
2. How does the Remotivation Process affect the client's manifestation of BCRL?
3. How does the Remotivation Process affect the client's occupational participation and quality of life?

The research questions for the qualitative study were:

1. What are the perspectives of patients with BCRL about the self-management program after participating in an occupational therapy program using the Remotivation Process?
2. What are the perspectives of patients with BCRL about the physical appearance of their arm after the occupational therapy program?
3. How do patients with BCRL describe their daily life after receiving occupational therapy?

These questions need to be addressed since research has found that women who do not continue to perform the SMP after lymphedema therapy experience a reoccurrence of the condition (Loh & Musa, 2015; Lashinski et al., 2012). Furthermore, while the effectiveness of the Remotivation Process has been demonstrated with the homeless population (Parmenter, Fieldhouse, & Barham, 2013), clients with dementia (Raber, Purdin, Hupp, & Stephenson, 2016), and clients with depression (Pepin, Guerette,

Lefebvre, & Jaques, 2008); research on the effectiveness of the Remotivation Process in conjunction with SMP and a diagnosis of lymphedema has not been conducted.

**Significance of research in occupational therapy and outside discipline.**

Advances in medical technology will lead to a continued increase in breast cancer survivors. Still, survivors will experience the lasting side effects of breast cancer, affecting their occupational participation in occupation and adaptation to life after cancer. Occupational therapy has a role in responding to the needs of this growing population. The study aimed to provide evidence for the possible use of the Remotivation Process in BCRL to enhance motivation and engagement in SMP. The Remotivation Process is based on the MOHO, which is one of the models of practice in occupational therapy. The study aims to present an occupation-based, evidence-based and practical intervention process for BCRL. This study attempted to address the problems of adherence to SMP that have been identified by other disciplines and provide a program to improve adherence to the SMP through an approach based on occupational therapy. The study also aimed to investigate the practical use of the Remotivation Process in oncology, specifically with BCRL. Kielhofner (2005) proposed the concept of the scholarship of practice where clinicians and researchers work collaboratively to cultivate the science of occupation. This research was based on the situations faced by clinicians in their practice. This study aimed to provide an intervention process that is both practical and evidence-based. The study explored the application of the Remotivation Process to facilitate adherence to SMP and its effect on upper extremity girth, occupational participation, and QOL

## CHAPTER II

### REVIEW OF LITERATURE

#### **Theories and Approaches Used in Healthcare to Improve Adherence**

Healthcare professionals must address non-adherence to SMP. There is an increased awareness of the importance of self-management in improving health outcomes and decreasing health care costs. Health care providers need to participate in the government's efforts to shift the responsibility of care. The literature on self-management showed the need for individualized intervention programs specific to the person with the chronic condition and at the same time considers the impact of the environment (Grady & Gough, 2014; Ryan & Sawin, 2009; Turner et al., 2015). Client activation is a key element in SMP. The National Institutes of Health defined client activation as having the knowledge, skills, abilities, and willingness to manage one's own health. There is evidence to support that clients who are more activated are more likely to participate in SMPs, and those who are not activated have a greater risk of developing new chronic conditions. The National Institutes of Health also recognized that the importance of client activation is largely ignored. The organization took an initiative to look into client activation, which closely resembles the importance of motivation in the adherence to the SMP. (Carpenter et al., 2019; Leland et al., 2017; National Institutes of Health, 2020). Occupational therapy can play an important role in self-management. The profession focuses on improving and maintaining performance in all areas of occupation when participation suffers as a result of a decline in health. Occupational therapy focuses on IADLs, which include health management and maintenance, aimed at developing

routines that enhance self-efficacy for disease management. Occupational therapists play a vital role when working with clients with multiple chronic conditions to help them engage in self-management activities. Occupational therapy focuses on habits, routines, and self-direction, which support the client's efforts to improve their own health. The occupational therapist can assess the client's knowledge of the SMP, willingness, and ability to engage in the SMP within the client's context while taking into account the client's habits, roles, and routines. The occupational therapist can also develop interventions appropriate to the client's cognitive, physical, and social components. These interventions optimize adherence and establish a routine that aligns with the health regimen and client's daily routine (Berger et al., 2018; Leland et al., 2017). The development of healthy routines incorporates learning and adopting appropriate strategies and utilizing the support available in the environment, which includes the family (American Occupational Therapy Association, 2014). Self-management is more complex than self-care or patient education. Literature proposed several theories to explain the complexity of self-management.

### **Supportive-Educative System**

Patient education is not enough to increase adherence to SMP. There is a need for a supportive-educative system to enhance a person's capabilities to include SMP into their daily routine. The supportive-educative system also uses empathy, active listening, and reflection to affirm patients and acknowledge their fears and concerns (Armer et al., 2011; Riegel et al., 2006). The supportive-educative system aims to facilitate the person's engagement by strengthening her decision-making and motivation towards

SMP. Decision-making is “a sequential process whereby decision rules are used to match a context-specific problem with a decision and an action” (Riegel et al., 2006, p. 233-234). The person makes a daily decision to adhere to the SMP as well as follow lifestyle choices and treatment options. The decision to engage in the SMP depends on the person's unique situation and context. It is influenced by the person's knowledge of the SMP, past experience with treatment, skill to perform components of the SMP, and perceived contextual barriers and facilitators (Armer et al., 2011; Reigel et al., 2006). The SMP should also be compatible with the person's values since values also have a strong influence on decision-making (Reigel et al., 2006). A study of breast cancer patients found that participants' values were influenced by the realization of the benefits of exercises on their health and function, which also affected their decision to perform the exercise program (Sander, Hajer, Hemenway, & Miller, 2012).

### **Social Learning Theory and Self-Efficacy**

The social learning theory/social cognitive theory emphasizes the importance of self-efficacy in self-management. It takes into account the impact of the person's emotional and cognitive state as well as the social and physical environment (Ryan & Sawin, 2009). Self-efficacy involves acquiring task-specific knowledge and skills and developing confidence in the ability to accomplish these tasks. Self-efficacy is learned through personal experience. Those who developed more self-efficacy were more likely to participate in decision-making to adhere to the SMP (Turner et al., 2015). Engagement in self-management that resulted in a positive effect on the person's health and positive feedback from the environment increases self-efficacy, which then led to further

engagement in self-management (Carpenter et al., 2019; Chang, Choi, Kim, & Song, 2014; Holmes et al., 2014; Lorig & Holman, 2003; Ryan & Sawin, 2009; Trudeau et al., 2015).

## **Motivation**

A literature search was completed using Medical Subject Headings (MeSH) terms “volition,” “will,” and “motivation”. These were combined with the terms “quality of life,” and “breast cancer”. The literature search retrieved 152 articles. These were filtered using the terms “quality of life,” “motivation,” “decision making,” “breast cancer,” and “depression” in the subject box. The publication date was also limited from 2000 to 2016. Out of the articles that were retrieved, 56 articles were retrieved for abstract review and 15 articles were selected for a full article review. Six articles were selected for the literature review on the relevance of motivation in BCRL. Of the six, one article was a survey that studied the coping and QOL of breast cancer survivors with lymphedema (Teo et al., 2015). The behaviors of breast cancer survivors toward physical activity and the impact of these behaviors on QOL were explored in three articles: one was a survey (Cuevas et al., 2014), one before and after research design (Muraca et al., 2011), and one randomized control trial (Trinh et al., 2014) that involved a 12-week program with 5-year follow up. The remaining two articles were similar studies on emotional well-being, QOL, and adaptation through a survey design (Matthews & Cook, 2009; Friedman et al., 2006).

**Theories of motivation.** The six studies listed above focused on survivors' behavior toward physical activity aimed to determine the effectiveness of programs that

target change in behavior towards exercise (Cuevas et al., 2014; Friedman et al., 2006; Matthews & Cook, 2009; Muraca et al., 2011; Teo et al., 2015; Trinh et al., 2014). Physical activity was found to increase QOL. The target behaviors were labeled as “motivation,” “intention,” “decision-making,” “willingness,” and “change”. The survey by Cuevas et al. (2014) used the reversal theory (RT), which focused on the person's motivation and readiness to change or “reverse” an existing behavior for the target behavior. The study found that most of the participants were motivated by personal goals, the need to abide by the rules or norms and the drive to care for others. The study by Trinh, Mutrie, Campbell, and Courneya in 2014 used the theory of planned behavior (TPB), which focused on the person's plan to engage in favorable behavior. The study found that intention is affected by the person's perceived benefits of the behavior change. The person is most likely to engage in a change to respond to the expectation of others. The person's belief that she has the ability to successfully engage in the new behavior also increases the person's intention to change (Trinh et al., 2014).

The studies of Matthews and Cook (2009) and Friedman et al. (2006) found that optimism and transcendence significantly predict well-being that positively influences QOL. Self-transcendence referred to the drive to find meaning and purpose in life. Optimism is the tendency to have positive expectations, which is an important mechanism in adaptation to breast cancer. Optimism enhanced perceived social support and sustains problem-focused coping. Optimism allowed the person to transcend difficult situations (Matthews & Cook, 2009; Friedman et al., 2006). The person is able to

integrate her past with a favorable outlook for the future in order to cope with a difficult present situation.

Patients with lymphedema engage in new behaviors to adapt to the condition. Teo, Fingeret, Liu, and Chang (2015) completed a survey of 75 women who underwent microsurgical treatment for BCRL. The participants received a study packet containing three self-report surveys through the mail. The self-report surveys include Functional Assessment of Chronic Illness Therapy, Breast Cancer (FACT-B) to assess QOL. The Brief COPE inventory to examine coping skills, and the Appearance subscale and Symptoms subscale of Lymphoedema Quality of Life Tool for the Arm (LYMQOL-Arm) to obtain information about the symptoms of BCRL experienced by the participants. The study aimed to investigate the effect of lymphedema on 4 domains of QOL. The domains included physical, functional, emotional and social well-being. Participants utilized coping strategies to manage stress. Adaptive coping strategies included acceptance, cognitive reframing, and utilization of available support. Maladaptive coping strategies included avoidance, disengagement, self-blame, and venting. Theo et al. (2015) reported a significant relationship between lymphedema and the domains of QOL. There was a large effect size between lymphedema and physical and functional well-being. There was a medium effect size between lymphedema and social well-being. There was a negative association between maladaptive coping strategies and physical, social, emotional and functional well-being. There was a positive correlation between adaptive coping strategies and the 4 aspects of QOL. The maladaptive strategies identified were disengagement and denial. Disengagement was seen in the person's tendency to avoid



the situation through self-distraction. Denial was seen when the patient refused to acknowledge the situation. Participants who used these strategies tended to perform activities that are potentially harmful, such as not wearing compression garments or performing strenuous activities.

**Transtheoretical model of change.** Transtheoretical model of change (TTM) focuses on a person's intention to change (Muraca et al., 2011; Prochaska et al., 1994). Change occurs in stages. The person's self-efficacy and confidence increase as she progresses through each change. The person undergoes a decision-making process that enables her to progress through the stages of change. Each stage motivates the person to progress to the next. The stages of readiness to change are hypothesized to predict treatment participation, dropout, efficacy, and long-term maintenance of improvement. The key assumption is that interventions need to be matched to the person's specific stage of change to be effective (Muraca et al., 2011). Intervention should incorporate constructs of self-efficacy and perceived benefits and costs of change. Decision-making in TTM involves weighing the pros and cons. It considers the potential gains and losses to self and significant others to assist in arriving at and maintaining a decision that incorporates the values and concerns of the individual. The TTM aims to facilitate a person's self-efficacy (Muraca et al., 2011; Prochaska et al., 1994). Self-efficacy is the confidence that she can change, which increases with each experience of success in similar situations (Muraca et al., 2011). The importance of self-efficacy in readiness to change is also supported by the social learning theory and supportive-educative system, which were discussed earlier.

**Motivational interviewing.** Motivational interviewing (MI) is described as “a client-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence” (Miller & Rollnick, 2013, p. 25). It states that readiness to change and motivation fluctuates. It emphasizes the humanistic proposition that people are naturally motivated for growth and self-direction. MI states that the greater the intrinsic motivation, the increased likelihood to change. The person has to realize she needs to change and the advantage of change. Motivation is facilitated as the person thinks through the relative pros and cons of changing or remaining at the current status, and considers the advantages and disadvantages of behavior change. MI is an approach used by a healthcare provider to facilitate behavior change by helping the patient become aware of the discrepancy between the current maladaptive state and a more adaptive alternative along with the advantages and disadvantages of the new behavior. MI has been used to facilitate a person's progression through the stages of change outlined by TTM.

The goal of MI and TTM is to support self-efficacy (Carpenter et al., 2019; Connors et al., 2019). A study by Muraca, Leung, Clark, Beduz, and Goodwin (2011) utilized the TTM and MI to explore behavior changes that promote health, such as exercise and weight management in breast cancer survivors after treatment. The study involved a lifestyle program designed to promote healthy eating habits and exercise in women with early-stage breast cancer who have completed active cancer treatment. The participants attended five 2-hour sessions over a 10 to 12-week period. Each participant completed a diet and exercise log. A dietician also monitored their BMI and weight

during the study. A social worker facilitated group discussions where the participants shared their breast cancer experience. A nurse used the TTM and MI to assist the participants to learn about their readiness to change. The study focused on a person's intention to change. The person undergoes a decision-making process to progress from a precontemplative stage when she is not ready to change to a state of contemplation and preparation where she intends to change, then a stage of action where she is actively making the change, and finally a maintenance stage where the person makes the commitment to continue the new behavior. Forty-two women completed the 12-week program. The study found that breast cancer survivors were at the action and maintenance stage at the end of the 12-week program. Participants in the action and maintenance phases experienced increased self-efficacy, as they felt more empowered to change their behaviors. The completion of each change seems to further motivate the participants to continue with the target behavior.

**Theories in motivation and adherence to SMP.** These theories and approaches to improve adherence seem to support the positive impact of self-efficacy on readiness to change. The decision to engage in new behavior and adhere to the change is influenced by the person's awareness of her capability to perform the target behavior, her perceived barriers, and personal values (Armer, et al., 2011; Riegel et al., 2006). Behavior change is important to facilitate adherence to recommended treatment in clients with chronic conditions. Multiple theories have provided frameworks for testing self-management interventions, many of which have shown effectiveness for chronic conditions (Chang et al., 2014; National Institutes of Health, 2020). Self-efficacy reflects the person's

confidence in her ability to accomplish a goal. The person should acquire the knowledge and skills needed to perform the new behavior in order to be confident (Ryan & Sawin, 2009; Turner et al., 2015).

There is a need to support patients and educate them on how to engage in new behaviors in order to facilitate self-efficacy that leads to change (Armer et al., 2011; Riegel et al., 2006). A decrease in self-efficacy has been observed in patients who demonstrate decreased intention to change. Patients with decreased self-efficacy show a lack of belief in the ability to change, passive inaction, lack of interest to change (Armer et al., 2011), and tend to focus on the barriers that hinder change (Cal & Bahar, 2016). These behaviors also indicate a decrease in motivation (Cal & Bahar, 2016). These studies indicate that motivation to engage in new behaviors as part of lifestyle change due to lymphedema is influenced by perceived benefits of the behavior, the person's belief in the ability to engage in the new behavior, purpose in life, and optimism. These new behaviors can be adaptive or maladaptive. BCRL is a chronic condition that necessitates a change in behaviors in order to adhere to the SMP. The literature that was presented in this section discussed the different theories and approaches to promote adherence to SMP. The literature identified the need to address a woman's motivation to engage in an adaptive behavior when faced with BCRL (Cuevas et al., 2014; Fu, 2005; Muraca et al., 2011; Teo et al., 2015; Trinh et al., 2014).

### **MOHO**

The previously discussed theories on motivation and approaches emphasized the importance of the person's values, self-efficacy, context, roles, and beliefs. These theories

and approaches come from the fields of nursing, psychology, and oncology. The person's values, self-efficacy, context, roles, and beliefs are included in the domains of practice of occupational therapy. Occupational therapists have an established body of knowledge and expertise in client factors that include values and beliefs, performance patterns, which include roles, and context (American Occupational Therapy Association, 2014). Occupational therapy, as mentioned earlier, can facilitate adherence to SMP and promote adaptation to life with BCRL.

MOHO is a practice model in occupational therapy. It views the person as a dynamic system, where the person and her environment change each other (Kielhofner, 2008; Taylor, 2017). The person has the urge to explore and master the environment. She is able to do so through three interrelated components of volition, habituation, and performance. Volition provides the motivation to act. It is further divided into (1) personal causation, which is the person's awareness of what she can do and the effectiveness of her actions; (2) valued goals, which gives a unique meaning to occupation; and (3) interest, which directs occupation toward a productive and satisfying end (Lee & Kielhofner, 2017; Taylor, 2017).

Habituation is the readiness to perform a pattern of behavior that reflects a person's habits, roles, values, interests, and context. Habituation organizes occupation into patterns. One important concept of MOHO in the study is the person's roles. Roles pertain to the person's pattern of action, shaped by her perceived social status or identity. Habits are formed around these roles (Yamada, Taylor, & Kielhofner, 2017).

Performance capacity emphasizes the interplay between objective and subjective performance capacities. The objective performance capacity refers to a person's physical and mental capabilities. The subjective performance capacities, or the lived body, are the thoughts and feelings she experiences as she uses these capabilities to perform an action. The interplay between the person's objective ability to perform a task and her subjective experience of the performance has a significant effect on volition patterns (Yamada et al., 2017).

The environment is the physical and socio-cultural context the surrounds the person as she engages in occupations. The environment has three dimensions, which are the physical environment, social environment, and occupational environment. Each dimension provides environmental qualities that either support or hinder occupational performance. The physical environment includes the space in which the person performs the occupation and the objects that she uses to complete the occupation. Some of the environmental qualities that affect performance include accessibility, safety, adequacy of space, availability of objects, visual and cognitive supports, and adequacy of objects (Fisher, Parkinson, & Haglund, 2017). The social environment involves a person's relationships and the type of interactions with other people. Some of the environmental qualities that can impact performance include the availability of people and relationships, emotional support, empowerment, physical and cognitive support, form of interaction, and adequacy of communication (Fisher et al., 2017). The occupational environment includes the occupations and activities that the person engages in; including the culture, economic, and political forces within the context. Some of the environmental qualities

that may affect performance include the nature of the occupation or activity itself, the appeal of the occupation or activity to the person, available support, opportunities for participation, time elements, the structure of the occupation or activity, and the cultural preferences involved in the occupation or activity (Fisher et al., 2017).

MOHO states that the environment is intricately connected with the person and any of the three components of volition, habituation, and performance capacity. The environment influences and gives meaning to occupations. However, the person's engagement in occupations also influences the environment in return (Fisher et al., 2017; O'Brien & Kielhofner, 2017; Yamada et al., 2017). This intricate and dynamic integration of volition, habituation, and performance capacity with the environment is referred to as environmental impact (de las Heras de Pablos, Fan, & Kielhofner, 2017). The environment influences the person's motivation, patterns of behavior, capacities acquired, and her subjective experience when she uses these capacities. The environment provides opportunities to perform, support, demand for action, as well as barriers to performance. Healthcare professionals who use the MOHO practice model look into the person's volition, habituation, performance capacities, and the environment during patient interaction (Taylor, 2017).

### **The MOHO Concept of Volition and BCRL**

Volition is a woman's thoughts and feelings about herself, which is shaped by experiences, her interpretation of the present situation, and her anticipation of the future as a breast cancer survivor. These thoughts and feelings guide her decision-making process as she adjusts to life after breast cancer and life with BCRL. Volition is also

influenced by the woman's environment. The social and physical contexts affect her volition through the supports and opportunities the contexts provide, as well as the imposed demands and restrictions (Taylor, 2017). Volition is further divided into 3 essential concepts: personal causation, values, and interests. Personal causation refers to a person's sense of capacity and efficacy. Sense of capacity is the person's awareness of her capabilities. Self-efficacy allows the person to determine if her efforts are sufficient to accomplish her goals. Personal causation influences volition, or the motivation for occupation. It makes the person aware of her ability or inability to control herself and her surroundings. The awareness of limitations can lead to denial and avoidance, which may be an effort to protect oneself from psychological pain when limitations are acknowledged (Kielhofner, 2008).

Values reflect the person's conviction and sense of obligation, define what is important for the person to do, and the perceived “right way” to act. Culture exerts a strong influence on a person's values. A person's values may be a source of disappointment if she is unable to perform according to her beliefs and contextual demands. There might be a need to form new values and adjust or modify existing values during times of change. Interests refer to the person's tendency to prefer actions and decisions that lead to something she finds enjoyable. A person's interest patterns reflect her preferred occupations and actions that usually parallel routines. A person's interests may also be a source of disappointment if she is unable to engage in these patterns of activities. Volition reflects a person's history and circumstance (Lee & Kielhofner, 2017; Taylor, 2017).



MOHO forwards the concept of the volitional cycle, where the person experiences the present and interprets it according to past experience. This leads to anticipation for the future. The person makes activity and occupational choices based on her anticipation. A person makes these choices based on her appraisal of her action or behavior, personal convictions, sense of obligation, and interest (de las Heras de Pablo et al., 2017; Lee & Kielhofner, 2017; Pepin, 2017; Taylor, 2017). For example, a woman with BCRL might find that she is unable to finish decorating a cake on time given the time constraints that the SMP added to her morning routine. She realizes that she is no longer capable and effective (personal causation) in decorating a cake, which is an activity that she enjoys doing (interest). Being able to bake is important (value) to her because she is the owner of a bakeshop. Volition allows the person to decide to make new patterns of behavior when impairment occurs. In this case, the woman makes a choice to modify how she performs the actions involved in baking (activity choice) or decide to give up her role as a hands-on cake decorator and focus on creating designs for a cake and have an apprentice apply the design (occupational choice). The woman constantly evaluates these choices. She may decide to continue with the new activity or occupational choice if she finds it satisfying. She may also decide to change these choices when necessary. Therapeutic transformation occurs when the person is able to find harmony between the components of volition and what she can do at the time of the impairment in order to regain satisfaction (Kielhofner, 2008). The volitional cycle determines how the person experiences and interprets the life event.

As previously discussed, women with BCRL experience change, which includes their ability to use the affected arm (objective performance capacity), their feelings toward their body (subjective performance capacity), their roles and routines (habits), and self-efficacy (volition). Readiness to change and self-efficacy are important in adjusting to life with BCRL. While the other components of MOHO can be an initial pathway for change, volition is a starting point for change in most cases (Taylor, 2017). Volition provides the person with a positive experience of accomplishment, pleasure, and interest. A person will continue to engage in actions and behaviors that lead to a positive experience. Habits are formed when a person repeatedly engages in actions as part of a routine. This repeated engagement is driven by volition. She develops capacities by repeating these actions and behaviors. These capacities are practiced so that she becomes more proficient and effective, which leads to a positive experience.

### **Comparison of the Theories of Motivation and the MOHO Concept of Volition**

Literature from psychology, nursing, and oncology on breast cancer used terms such as “motivation,” “intention,” “decision-making,” or “willingness” to describe a woman’s readiness to change in order to adjust to the impact of BCRL on her life (Cuevas et al., 2014; Fu, 2005; Muraca et al., 2011; Teo et al., 2015). Breast cancer survivors are motivated by personal goals, the need to abide by the rules or norms, and the drive to care for others (Cuevas et al., 2014). They have the intention to change, which occurs in stages (Fu, 2005). The concepts introduced by these studies seem to parallel the concept of volition discussed by MOHO. The components of the MOHO concept of volition seem to parallel the definition of self-efficacy and motivation as

discussed in literature from other disciplines. A person has an inherent desire to be competent in the activities that she values. She enjoys those activities that give her a sense of competence, which keeps her interested and motivates her to keep doing these activities. Volition has three components: personal causation, values, and interests (Lee & Kielhofner, 2017; Taylor, 2017).

**Personal causation.** MOHO defines personal causation as the person's perceived self-efficacy and sense of personal capacity. Self-efficacy refers to the perceived effectiveness of using one's own abilities to achieve the desired goal. The sense of personal capacity is a person's assessment of one's own physical, intellectual, and social abilities (Kielhofner, 2008; Lee & Kielhofner, 2017; Taylor, 2017). The theories from other disciplines have a similar description of personal causation. The transtheoretical model of change states that change occurs in stages. The person's self-efficacy and confidence increase as she progresses through the stages (Muraca et al., 2011). The transtheoretical model of change's concepts of self-efficacy and confidence seem to parallel the MOHO concept of personal causation. The theory of planned behavior presented perceived behavioral control as a construct of intention. It refers to the person's perceived self-control and efficacy (Trinh et al., 2014). The construct of intention described by the theory of planned behavior also reflects the concept of personal causation. Personal causation is affected as the person discovers new inabilities as a result of breast cancer and lymphedema. The tendency to engage or avoid a task is influenced by her sense of self-control and efficacy. However, not all descriptions of personal causation from other disciplines reflect the MOHO concept of volition.

Teo et al. (2015) found that clients with breast cancer chose strategies that can either be adaptive or maladaptive and that the selection of strategies is influenced by personal causation. Participants who choose adaptive strategies engage in cognitive reframing, acceptance, and utilization of social support. Those who choose maladaptive strategies tend to show denial and disengagement. The dichotomous classification of strategies as maladaptive or adaptive does not parallel with the MOHO concept of volition. Volition is a process or a dynamic cycle (Lee & Kielhofner, 2017; Taylor, 2017). The Volitional Process will be discussed in the next section.

**Values.** MOHO defines values as the person's beliefs and commitment to what she perceives as good, right, and important to do. The person's culture has a strong influence on the development of values. Values determine what is important to the person and what drives her emotional disposition to act (Lee & Kielhofner, 2017; Taylor, 2017). The theories from other disciplines have a similar description of values. The reversal theory of motivation has 4 motivational states, which determine the source of the person's motivation (Cuevas et al., 2014). A person is motivated either by (1) the process or end goal, (2) the need to follow rules or break free, (3) the desire to dominate or to care for others, and (4) the need to benefit the self or others. According to the theory of planned behavior, the subjective norm is another construct of intention. This refers to the perceived social pressure to perform a behavior. It includes behaviors that the person thinks others expect her to do (Trinh et al., 2014). These constructs are similar to the MOHO concept of values.

**Interest.** The MOHO concept of interest refers to the things and activities that the person finds enjoyable. A person engages in activities that she finds rewarding and enjoyable. She then develops a pattern of interest, which is a configuration of preferred activities. A person's daily routine is usually parallel with the person's pattern of interest (Lee & Kielhofner, 2017; Taylor, 2017; Kielhofner, 2008). A person intends to engage in activities and behavior that she finds enjoyable. Interest patterns are formed based on what the person finds rewarding. The theories from other disciplines have a similar description of interests. The theory of planned behavior considers attitude as a construct of intention. Intention is the attitude that reflects the person's belief that the target behavior will lead to a positive or rewarding experience. The person engages in a behavior that has both instrumental and affective benefits (Trinh et al., 2014).

### **The Unique Contribution of the MOHO Concept of Volition**

A person has an inherent need to act. This need to do things is expressed through occupation, which includes the doing of work, play, and ADL. Volition is the motivation for occupation (Lee & Kielhofner, 2017; Taylor, 2017). MOHO states that while a person has an innate drive for action, she selects activities that she finds important, meaningful, enjoyable, and feels competent in doing. The confluence of values, interests, and personal causation reflect the concept of volition. Volition also influences the person's selection of what capacities and abilities need to be developed. Her decision to learn skills and acquire knowledge is driven by the desire to be competent in doing things that she considers valuable, meaningful, and important. Volition plays a key role in

learning new skills and behaviors necessary in making lifestyle changes related to a condition such as BCRL.

**Self-efficacy and volition.** Literature from other disciplines identified the importance of self-efficacy in the decision to change (Cuevas et al., 2014; Muraca et al., 2011; Trinh et al., 2014). Self-efficacy is a component of personal causation, which is one of the three components of the MOHO concept of volition. Self-efficacy refers to the person's perceived effectiveness in using her physical and mental capabilities to achieve the desired outcome. Sense of capacity, on the other hand, is the person's own assessment of her physical, social, and mental abilities. The interplay of self-efficacy and sense of capacity forms a person's personal causation. A person will be motivated to engage in occupations if she feels capable and effective. Personal causation influences whether or not a person will continue to engage in behaviors, and persevere if she feels capable and effective (Lee & Kielhofner, 2017; Taylor, 2017). A person may need to re-assess her own capabilities and efficacy after the onset of a condition such as BCRL. She realizes her effectiveness through experience. Therefore, it is necessary for her to engage in occupations. This process of appraising oneself may be difficult since she will discover aspects of daily living that she can no longer control or life roles that she cannot fulfill. It is important for the person to also identify aspects of her life that she is able to control or still successfully perform in order to regain a sense of self-efficacy and a sense of capacity while she adjusts to her condition.

**Volition as a gateway for change through the volitional process.** Literature from other disciplines identified the importance of readiness and intention to change; this

was discussed in the previous section. The transtheoretical model of change states that a person progresses through the stages of change through a decision-making process. A positive experience motivates the person to progress through the stages (Muraca et al., 2011). The volitional cycle involves anticipation, interpretation, experience, and choice. The person goes through the stages of exploration, competency, and achievement. The studies by Matthews and Cook (2009) and Friedman et al. (2006) focused on optimism and self-regulation. Matthews and Cook (2009) examined the relationship between optimism, self-regulation, and emotional well being of breast cancer survivors. The study surveyed 93 women who underwent radiation therapy. Friedman et al. (2006) examined the relationship between optimism, self-regulation, and health-related quality of life of breast cancer survivors. The study surveyed 81 women. Both studies described optimism as the anticipation of a positive outcome in the future. The person utilizes “filters” as she interprets the present. These filters are based on past experiences. Self-regulation is important in optimism so that the person sets realistic goals and expectations. Self-regulation guides the person's goal-directed activities. It allows goal-directed activity when a routine is interrupted or when the intended goal is not achieved. The belief that a goal is achievable despite interruptions or challenges leads to continued engagement in the activity. A belief that a goal is unachievable can lead to denial, withdrawal and decreased motivation.

Self-regulation and optimism, as described in these studies, parallel to the volitional process of MOHO. According to MOHO, the person experiences the present and interprets it according to past experience (de las Heras de Pablo et al., 2017; Taylor,

2017). This leads to anticipation for the future. The person chooses an activity and occupational choices based on her anticipation. Previous literature also stated that women engage in either adaptive or maladaptive behaviors as they cope with BCRL. This is different from the Volitional Process, which states that a person undergoes a dynamic cycle. This process is a cycle of anticipation, making choices, experience while doing, and interpretation. Anticipation refers to the person's understanding of the expectations and possibilities. Choices are the decisions the person makes based on anticipation. The experience involves the thoughts and feelings of the person while performing an action or behavior. Interpretation is the person's reflection of her experience, which influences her anticipation of both the near and distant future. These four components shape and influence each other (de las Heras de Pablo et al., 2017; Lee & Kielhofner, 2017; Pepin, 2017; Taylor, 2017). The person also undergoes change as she goes through the different stages in life.

A person's experience of adjusting to life with BCRL may differ depending on her life stage, such as adulthood or late adulthood. The person's environment can also initiate change through new opportunities or constraints. This sets the process of change in motion and has a profound impact on the person's volitional process. The environment can provide support or opportunities that lead to a positive experience. It can also place barriers and challenges that lead to a negative experience (Taylor, Pan, & Kielhofner, 2017). In the example of the cake decorator, she experienced being rushed as she tries to finish decorating a cake. She reflected on this experience and realized that she does not have time to do her work at her usual pace since she has to make time to



perform her SMP in the morning. She knows that she needs to perform the SMP in order to keep her arm from swelling again. She also knows that she needs to be able to finish the cake orders on time in order to keep her customers satisfied. She anticipates that she will continue to have this problem of not having enough time to perform the SMP and meet the demands of her customers. She then makes a choice to either modify her morning routine or hire an apprentice to help her decorate. The volitional process does not end when she makes the choice since she needs to reflect on the experience of the new morning routine or having to work with an apprentice. The reflection moves the cycle once again. In this example, the person underwent a process of change, which was made possible by the volitional process. MOHO states that change can occur through the components of volition, habituation, performance capacity, or environment. The change process begins either when there is an alteration in something internal to the person or something in the person's environment or both.

As previously discussed, women with BCRL experience change, which includes their ability to use the affected arm (objective performance capacity), their feelings toward their body (subjective performance capacity), their roles and routines (habits), and self-efficacy (volition). Readiness to change and self-efficacy are important in adjusting to life with BCRL. While the other components of MOHO can be an initial pathway for change, volition is a starting point for change in most cases (Taylor, 2017). Volition provides the person with a positive experience of accomplishment, pleasure, and interest. A person will continue to engage in actions and behaviors that lead to a positive experience. Habits are formed when a person repeatedly engages in actions as part of a

routine. This repeated engagement is driven by volition. She develops capacities by repeating these actions and behaviors. These capacities are practiced so that she becomes more proficient and effective, which leads to a positive experience.

**The process of change and adaptation.** The previous literature indicated that BCRL is a condition that leads to change in a person's life. Women with BCRL need to make lifestyle changes to adapt to life with BCRL. MOHO defines occupational adaptation as being able to make the changes needed to continue to engage in valued activities or develop new activities. Adaptation is “the development of a positive occupational identity, coupled with the experience of occupational competence over time within the context of one's environment” (de las Heras de Pablo et al., 2017, p. 116). A person is defined by her actions, thoughts, and her perception of her own actions. MOHO defines occupational identity as a combination of the person's sense of capacity and effectiveness, the things that she finds interesting, aspects of her life that she considers important, her routines, her perceived support from her environment, her perceived expectations from her environment, anticipated goals for her future, and decisions about her present life (Taylor, 2017). Occupational identity is formed as the person experiences life and interprets her experience. She uses her occupational identity to form her anticipation for the future. The volitional cycle, therefore, has a significant effect on a person's occupational identity. The person expresses her occupational identity as she participates in occupations; engagement in these occupations shapes her identity. MOHO defines occupational competence as “the degree to which one sustains a successful pattern of occupational participation that reflects one's occupational identity”

(de las Heras de Pablo et al., 2017, p. 117). Competence is achieved when the person is able to meet her roles and responsibilities, meet her basic needs, and maintain a satisfying lifestyle. Adaptation is achieved when she experiences competence as she moves within and interacts with her environment. When a person is able to develop an occupational identity in response to a change in her life and sustains a pattern of competence in her participation, she is said to have achieved adaptation. Therefore, adaptation is not only the adjustment to life after the onset of a condition such as BCRL but an ongoing expression of one's occupational identity.

MOHO also states that a change in the component of volition, habituation, performance capacity, or environment will result in a change in occupation (Taylor, 2017). Women with BCRL undergo a change in one or more of these components. Women may experience a change in the ability to participate in occupations. The volitional cycle is one way a person engages in a change in order to regain her occupational identity and achieve occupational adaptation.

## **The Role of Occupational Therapy in BCRL**

Women are referred to occupational therapy for lymphedema prevention, routine post-operative care, and management of symptoms (Dominick et al., 2014; McGrath, 2013). The goal of therapy is to prevent the recurrence of BCRL, assist the women in the management of current symptoms, and improve arm use (Kulesza-Bronczysk et al., 2014). Occupational therapy programs enable women to manage symptoms, improve upper extremity function, adjust to BCRL, and perform their occupational roles (Dennis, 1993; McGrath, 2013; Palmadottir, 2010).

### **Adherence and Occupational Therapy**

Radomski, in her article in *The American Journal in Occupational Therapy*, defined adherence as “the degree to which patients and research participants act in accord with the advice of the clinician or researcher” (Radomski, 2011 p. 471). It is different from “compliance,” which connotes patient passivity and obedience, suggesting external behavior change without acceptance.

People with chronic conditions experience everyday changes associated with the condition and onset of disability. These changes include adherence to therapy recommendations. It was found that adherence to therapy recommendations have a positive association with occupational therapy outcomes for BCRL (Johnstone, Hawkins, & Hood, 2006). However, lifestyle change related to adherence to therapy recommendations may be difficult for some since these changes are not necessarily brought about by their own choosing. There is a 30-60% rate of non-adherence to chronic illness regimens (Christensen, 2004). People with chronic conditions may

experience treatment fatigue, have little confidence that the treatment program will make a difference or experience sequelae associated with the condition. These factors may also affect adherence to therapy recommendations. There is a need to address the issue of non-adherence in occupational therapy.

Adherence is an ecological enterprise since it is a function of the patient, care provider, intervention factors, and context. Support from the environment, including support from the family and shared support from others, improve adherence. The interaction between the patient, care provider, intervention, and context is synthesized, shaped and actuated through self-determination (personal choice) and learning (skill acquisition and employment or utilization). Occupational therapists can improve adherence through strategies such as tailoring recommendations to the needs and abilities of the patient, facilitate self-determination and learning, and support the formation of habits. The occupational therapist can facilitate habit formation since the patient must routinely perform the behavior or activity after discharge from occupational therapy. Adherence may be better sustained if therapists provide feedback that is measurable, such as limb girth in the case of lymphedema. It will continue if the patient determines that the behavior or activity leads to a desired impact or outcome, which provides a positive experience and increase her sense of self-efficacy.

Adherence is optimized when the recommended activity or behavior is in harmony with the woman's priorities, preexisting routines, and available supports and enablers. It is also optimized if she can link the recommended activity or behavior with an existing routine, especially morning routines. The woman's insight into the chronic

condition and readiness to change are prerequisites to adherence to treatment recommendations. A collaborative relationship between the occupational therapist and the woman with BCRL will help the patient come to terms with the new diagnosis, condition or limitation (Radomski, 2011). As discussed earlier, motivation plays a key role in behavior change that leads to adherence. The occupational therapist can use motivational strategies to identify the woman's priorities and routines and help the patient's transition toward these change stages.

**Occupational therapy's role in motivation.** A literature review found that women with BCRL try to cope in different ways. Some become motivated to stay active and healthy and refused to let lymphedema control their lives, while others were unable to do so (Ridner et al., 2011; Taghian, Miller, Jammallo, O'Toole & Skolny, 2014). The researcher completed a single case study of a client with upper extremity lymphedema following breast cancer (Rubio, 2016). The study found that commitment and motivation are needed in order to incorporate the SMP for lymphedema into a woman's daily life. The client in the study found a way to remain motivated and take control of her well being despite the condition (Rubio, 2016). It revealed that breast cancer survivors with BCRL experienced limitations in daily life due to the signs and symptoms of the condition. The personal value of independence provided the motivation to commit to the long-term daily self-management of BCRL. Women with BCRL need to have the knowledge and skills to commit to SMP. Occupational therapy programs for BCRL must provide patient education and skills training in a manner specific to the woman's roles, daily occupations and performance skills.

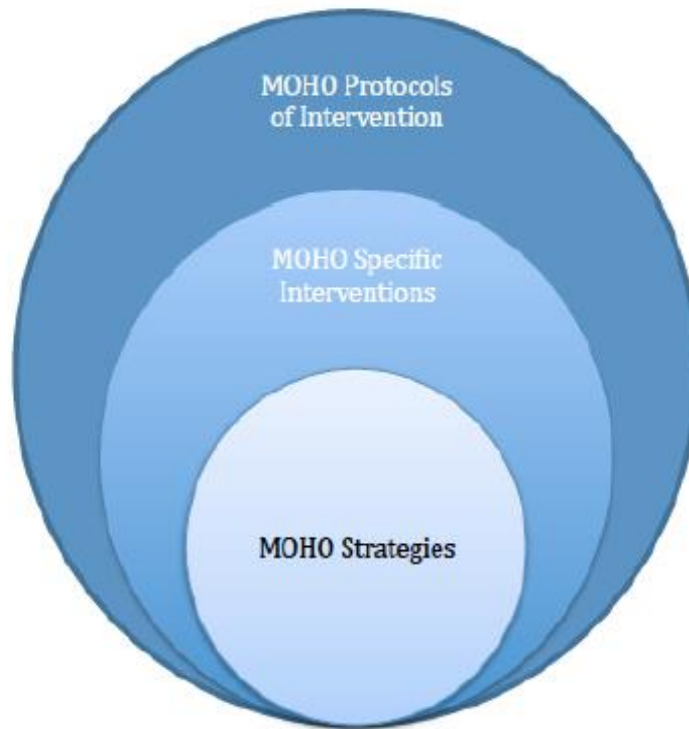
**Occupational therapy's role in adaptation through MOHO.** It is important for women with BCRL to incorporate the SMP into their daily routine to prevent the reoccurrence or exacerbation of BCRL. According to the literature presented in the previous sections, SMP involve strategies and skills that the person needs to learn. The person uses goal-setting, self-reflection, reflective thinking, resource utilization, and self-evaluation in order to learn each component of the SMP and incorporate the program, in her daily routine. The person must adhere to the SMP in order to manage BCRL. Adherence leads to a sense of self-efficacy and confidence. Non-adherence is caused by feeling several reasons, which include feelings of dissatisfaction, awareness of limitations, feelings of disappointment, inability to fulfill roles, and lack of interest. These reasons seem to reflect the impact of disability on a person's personal causation, values, and interests. There is a need to increase adherence to SMP. In order to do this, healthcare professionals should address the person's needs, desires, and abilities to facilitate change, motivate the person to engage in adaptive behaviors and adapt to life with BCRL. The theories and approaches used in the literature from psychology focused on increasing self-efficacy and improving motivation in order to facilitate a change in behavior that leads to adherence.

Motivation occurs in stages, with the person changing her behavior from maladaptive to adaptive. The incorporation of SMP in a woman's daily routine is essential to adapt to life with BCRL. Adaptation is observed when the woman is able to control lymphedema and not allow lymphedema to control her life (Tahan, Johnson, Mager, & Soran, 2010). Adaptation, in this sense, is the ability to cope or adjust to life

after the onset of BCRL. However, MOHO has presented that adaptation is a complex phenomenon. Occupational adaptation is a combination of occupational identity and occupational competence. Occupational therapy, through MOHO, can facilitate occupational adaptation. The study used volition as an initial pathway for change. The volitional process presents a cycle of change, instead of a linear change from maladaptive to maladaptive behavior. The volitional process was used to restructure a person's occupational identity and facilitate occupational competence. MOHO provides occupational therapists with methods to use volition as a pathway for change. One of these methods is the Remotivation Process.

**The use of the remotivation process in clients with BCRL.** MOHO enables the occupational therapist to provide client-centered practice. It guides the occupational therapist to understand the person's volition, habits, performance capacities, and environment. The components are specific to the person instead of the condition. MOHO promotes the active participation of the client during occupational therapy through intervention methods that guide the therapists to support the client's participation in occupations (see Figure 1). These methods are organized into three categories: (1) MOHO strategies, which are the occupational therapist's actions that facilitate the client's stages of change; (2) MOHO specific interventions, which are types of procedures that foster occupational adaptation; and (3) MOHO protocols of intervention, which are systematized procedures that guide client-therapist interactions. The Remotivation Process is one type of MOHO protocols of intervention.





*Figure 1.* Configuration of MOHO intervention methods. Adapted from “Intervention process: Enabling occupational change” by C.G. delas Heras de Pablo, S. Parkinson, Pepin, and G. Kielhofner, 2017, *Kielhofner’s model of human occupation 5<sup>th</sup> ed*, p. 197. Copyright 2017 Lippincott Williams & Wilkins.

### **The Remotivation Process**

The Remotivation Process (de las Heras et al., 2003) is an intervention based on the MOHO concept of volition. It states that low volition is reflected in a decrease in motivation (de las Heras et al., 2003). The researcher reviewed the Remotivation Process Manual (de las Heras et al., 2003), three articles on the use of the Remotivation Process in occupational therapy (Parmenter et al., 2013; Pepin et al., 2008; Raber et al., 2016), one article from the field of nursing (Pullinger, 1960), and one article from the field of education (Falout, 2012).

The article from the field of nursing discussed the application of the concept of Remotivation in a mental hospital (Pullinger, 1960). The Remotivation techniques were used in a group program to provide structure to the patients' daily lives to stimulate interaction with reality and the present world. The study found that Remotivation techniques improved the interaction between the nurses aides and patients (Pullinger, 1960). The article from the field of education discussed the use the Remotivation process to facilitate learning. The study found that learners with positive coping strategies reacted to demotivation through negotiation, self-reliance, support-seeking, problem-solving and flexibility (Falout, 2012). They used multiple strategies to adapt. Learners with negative coping strategies experience self-blame, helplessness and tend to escape the present task. Those with negative strategies began to cultivate self-reliance, although they still did not use existing support in the environment. They need a chance to reflect, a supportive environment that promotes evidence of their abilities, cognitive restructuring, and an environment that provides praise in an effective way to promote positive self-concepts and satisfying social exchange (Falout, 2012).

There were three studies from the field of occupational therapy studied the use of the Remotivation Process in clients with dementia (Raber et al., 2016), the homeless (Parmenter et al., 2013), and clients with depression (Pepin et al., 2008). Raber, Purdin, Hupp, and Stephenson (2016) completed a qualitative study of occupational therapists who were involved in the care for clients with dementia. In the study, 33 occupational therapists completed an online survey, which consisted of nine closed-ended questions. The 10th question invited the survey respondent to participate in an interview. Eight

occupational therapists participated in an in-depth interview, which lasted 36-60 minutes. The study examined the experience of occupational therapists when they used the Remotivation Process in their clients with dementia. Thematic analysis revealed that the Remotivation Process requires commitment from the occupational therapist and everyone involved in the client's care. The Remotivation Process requires the occupational therapist to set aside time and energy to become familiar with MOHO, MOHO-related assessment methods, and the Remotivation Process. Raber, Purdin, Hupp, and Stephenson (2016) also stated that the study had a small sample size. Further research should use qualitative and quantitative methods to evaluate Remotivation Process as an intervention for clients with dementia.

Parmenter, Fieldhouse, and Burham (2013) evaluated an occupational therapy program for the homeless population over a period of 7 months. The study involved 16 clients, each were provided with an individualized occupational therapy program to facilitate motivation, acquire life skills, and engage in the environment. The occupational therapists used the Remotivation Process as an intervention. The Model of Human Occupation Screening Tools (MOHOST) was used as an outcome measure. The study found that creating a *microenvironment* within the homeless shelter allowed the clients to have a positive experience and contemplate the possibility of change.

Pepin, Guerette, Lefebvre, and Jacques (2008) gathered and analyzed the narratives of four occupational therapists who work in mental health. The therapists used the Remotivation Process in clients who did not respond to the usual treatment methods for depression. Data were gathered over a two-year period and themes were identified

through descriptive analysis. The occupational therapists found that the Remotivation Process provided a detailed structure that was flexible. This characteristic allowed them to adjust their approach with each client. The Remotivation Process allowed them to focus on the client's strengths, which made the client feel respected and acknowledged. The intervention enabled the client to actively participate in their intervention. The therapists also reported that the Remotivation Process improved their cohesiveness as a team. However, therapists need to invest additional time and energy to become comfortable in using the Remotivation Process. This finding was similar to the findings of Raber et al. (2016).

These studies found that the Remotivation Process enabled the therapists to gain a deeper understanding of volition, and how it manifests in practice. They became more sensitive to the subtle signs of change in motivation, which may seem meaningless to others. It provides therapists with a flexible structure and concrete strategies that they can tailor according to the needs of their clients. The Remotivation Process involves an ongoing assessment, which gave the occupational therapist a chance to adjust the program according to the client's needs. It provided them with cohesiveness as a team and facilitates communication with other professionals. The Remotivation Process focuses on the person's strengths, enables them to make choices about their occupational therapy program, and compares their current function with their own function at the start of the program instead of pre-established norms. The participants in the studies reported that they felt secure with their current function and gained a positive feeling about their future performance in occupational therapy. Intervention is collaborative and individualized so

that the client feels acknowledged, respected and valued. It recognized their lived experience. Therapy is implemented in a meaningful environment, which promotes the transfer of skill for sustained change (Pepin et al., 2008; Raber et al., 2016).

Chronic conditions may alter volition (de las Heras et al., 2003). BCRL is a chronic condition that interrupts daily occupations and role performance. Demotivation is a mentally stagnant state in which the person loses interest in taking care of themselves and interacting with the outside world. If a person loses her self-respect, she no longer considers herself a valuable member of society (Pullinger, 1960). A positive, adaptive change starts with the volitional process. Volition is a dynamic process where the person experiences occupation in her current environment, which she interprets through a reflection of past experiences. She anticipates the future based on this reflection. Activities and occupations are chosen based on this anticipation. According to MOHO (Kielhofner, 2008), a person chooses to participate in activities that she has access to and feels that she is able to perform successfully. A positive change in a person's volition occurs when she gains a new interpretation of herself and the environment through new experiences and new choices made (de las Heras et al., 2003). However, the application of the Remotivation Process to women with breast cancer-related lymphedema has not been studied. Raber et al. (2016) also identified the need for qualitative and quantitative studies to investigate the impact of the Remotivation Process. This study attempted to address this important research focus.

## CHAPTER III

### METHODS

#### **Research Design**

The research questions were answered through a mixed-methods study using a concurrent triangulation design. Quantitative and qualitative data were collected, analyzed, and compared (Creswell, 2009). A mixed-methods design was used to provide an in-depth understanding of the impact of the Remotivation Process when included in an occupational therapy program for BCRL. This kind of design expanded the explanation and interpretation of the quantitative data. The statistical findings combined with the qualitative research findings allowed the primary investigator (PI) to reach an interpretation of the participants' experience of lymphedema, occupational therapy, and the self-management program.

#### **Quantitative Study Design**

The study followed a pretest-posttest single-subject design. The Remotivation Process was the intervention administered by the PI once a week for 4 weeks with a follow-up during the eighth week of study. The quantitative design provided objective data that measured the effect of the Remotivation Process on the participants' ability to perform the SMP and participate in daily occupations.

#### **Qualitative Study Design**

This study followed the tradition of phenomenology to provide insight into the participants' own interpretation of the effect of the Remotivation Process. Phenomenological research begins with a description of the phenomenon experienced in

the participant's daily life. Data were obtained through first-person accounts, usually in the form of one-to-one interviews, in order to obtain vivid descriptions of the experience (Mapp, 2008). Interview questions facilitate the emergence of narrative data in the form of stories shared by the participant. The interview begins with a social conversation to establish a relaxed atmosphere. The qualitative portion of the study involved a 60-minute interview, which occurred during the fourth week of the intervention. The participants were invited to participate in the 60-minute interview during the third week of the intervention. The length of time depends on the time needed for data saturation. Data saturation is reached when no new information is obtained and participant responses are similar or redundant (Patton, 2015). Previous studies have reported that saturation was reached between 30 to 120 minutes (Mapp, 2008).

Qualitative research expands a clinician's perspective of the therapy services he or she provides (Tomlin & Borgetto, 2011). Phenomenology investigates the meaning, structure, and essence of the lived experience to gain new insight into a particular phenomenon. It aims to capture the thoughts and feelings of the person who has experienced or currently experiencing the phenomenon of interest. It seeks to understand the lived -hand experience of the research participants. The data gathered were in the form of narratives, which provide descriptions of the lived, subjective experience of the participants. Phenomenology states that human experience provides valuable information that will understand human motivation. Two main phenomenological approaches were reviewed for the study. Descriptive phenomenology is based on Husserl's tradition of scientific inquiry. Hermeneutic phenomenology is based on the work of Heidegger, a

student of Husserl who adapted and modified Husserl's approach (Corby et al., 2015; Flood, 2010). Both descriptive and hermeneutic phenomenology use qualitative, in-depth interviews as the traditional data collection strategy. However, descriptive phenomenology and hermeneutic phenomenology differ in the approach to data analysis. The following section briefly discusses the difference between descriptive and hermeneutic phenomenology and the rationale for selecting descriptive phenomenology.

**Descriptive phenomenology.** Descriptive phenomenology is based on Husserl's assumption that the experience perceived by the person's consciousness is able to generate valuable data and needs to be studied objectively. Humans, according to Husserl, generally do not take time to critically reflect on their experiences. There is a need for a scientific approach to gather and analyze the lived experience of a group of people specific to the phenomenon of interest. Husserl believes that the PI must suspend, or abstract themselves from all prior personal knowledge and biases related to the phenomenon of interest during data collection and analysis (Corby et al., 2015; Flood, 2010). This is referred to as bracketing. Bracketing is necessary to maintain a scientific approach and it reflects Husserl's attempt to provide rigor and establish phenomenology as a scientific inquiry. Husserl also believed that there are common features in the experiences of those individuals who live through the phenomenon of interest. Therefore, the purpose of descriptive phenomenology as a scientific inquiry is to identify these commonalities, or what he called eidetic structures (Corby et al., 2015; Giorgi, 2009). Husserl's approach is aimed at describing how a phenomenon presents its self at that given moment. It seeks to use language to articulate or describe the phenomenon in the



present rather than interpret or analyze based on past knowledge and experience. The study followed the tradition of phenomenology by Edmund Husserl as outlined by Giorgi (Giorgi, 2009). Giorgi outlined scientific methods to provide rigor in the psychologist's effort to study the participant's subjective experience and behavior (Corby et al., 2015; Flood, 2010; Giorgi, 2009).

**Hermeneutic phenomenology.** Hermeneutic phenomenology, on the other hand, aims to interpret the experience instead of identifying commonalities (Corby et al., 2015; Flood, 2010). It forwards that humans are deeply embedded in their social, political, and cultural contexts. A person's interpretation of a lived experience is strongly influenced by the environment. Therefore, it is impossible for a PI to abstract himself or herself from prior knowledge of the phenomenon of interest. The PI's prior knowledge and experience, according to Heidegger, led him or her to investigate the phenomenon. However, the study aimed to explore the meaning of living with BCRL through the experience of the participants. The PI has no prior experience with living with BCRL. The PI is an occupational therapist and lymphedema therapist who provides services to the population of interest. It is important for the PI to abstract herself from the phenomenon to reach an in-depth understanding of the impact of BCRL on the person's life.

**The researcher's perspective.** Lymphedema has been a topic of interest of the PI, who is an occupational therapist and certified lymphedema therapist. BCRL affects ADLs, IADLS, work, leisure and sleep, which are the domains of practice of occupational therapy. Occupational therapists can teach the client ways to prevent the occurrence of BCRL, monitor for symptoms and create an SMP as needed. Occupational

therapists can also enable the client to make the lymphedema self-management program a part of their routine. Adherence to the SMP is part of a lifestyle change that lymphedema therapists aim to facilitate in their clients. Motivation is a key component of lifestyle change and therapy interventions need to address motivational problems in clients. The PI aimed to understand the experience of living with BCRL and the motivational needs of the participants in order to effectively facilitate lifestyle change aimed at incorporating the SMP. The PI aimed to understand BCRL and SMP from the perspective of a provider of therapy to the perspective of a person receiving therapy. The outcomes of this study aimed to explore the potential use of the Remotivation Process in an occupational therapy program that is unique to women with BCRL.

## **Setting**

### **The Collaborating Institution**

The collaborating institution was a National Cancer Institute-designated comprehensive cancer care center based in California. It has multiple locations within the state and the study was based at the location in Duarte, California, which is the main campus for medical, research and education activities. The location in Duarte also provides in-patient and outpatient physical, occupational, and speech therapy as well as specialized services including lymphedema therapy and orthotics and prosthetics. The study involved three occupational therapists from the Department of Rehabilitation Services consisting of one onsite collaborator and two treating therapists.

### **Onsite Collaborator**

The onsite collaborator is the manager of the rehabilitation department and an occupational therapist who is trained in MOHO. The onsite collaborator was not involved in the occupational therapy program for lymphedema. The onsite collaborator recruited participants, obtained the study forms and informed consent, and sent these forms to the PI. The onsite collaborator also scheduled the webinar between the PI and treating therapists prior to the start of the study to discuss the study. The PI and onsite collaborator discussed participant progress at the end of each week through encrypted email, which was relayed to the treating therapists. A debriefing was completed at the end of data analysis through video conference.

### **Treating Therapists**

Two occupational therapists who were employed by the participating facility provided the occupational therapy treatment. The therapists were trained in MOHO and certified in lymphedema therapy. The therapists met with the PI through a webinar to discuss the study, roles of the treating occupational therapist and PI, a review of the MOHO concepts, overview of the Remotivation Process, discussion of the three outcome measures that were used in the study, and practice administration of the outcome measures. The treating therapists were provided with a brief overview of the Remotivation Process to facilitate the exchange of information with the PI. The webinar lasted for an hour and completed through the Zoom video conferencing platform. They did not administer the Remotivation Process, did not collect data, and were not actively involved in the study. The treating therapists provided the customary treatment session

for lymphedema, which included manual lymphatic drainage, exercises, compression, and patient education. The treating occupational therapist and onsite collaborator also completed the initial evaluation, treatment session, and re-evaluation at the end of the study. These are also customary to the plan of care for lymphedema therapy. The PI administered the Remotivation Process to the participant. The treating therapists did not implement the Remotivation Process. However, they were given a brief overview of the Remotivation Process to facilitate communication between the therapists and PI during the weekly discussions. Details are provided in the next section.

### **Institutional Review Board**

Institutional Review Board (IRB) approval was obtained from Texas Woman's University. The PI then collaborated with the onsite collaborator, who is an occupational therapist employed by the collaborating institution, and completed CITI certification (see Appendix A). The collaborating facility required the university's IRB approval prior to the concept review by the Breast Cancer Disease Team. The concept review determined that the study has scientific merit. The study was then allowed to create a study protocol. The onsite collaborator and PI submitted a proposal to the breast cancer disease team, who then reviewed and endorsed the study protocol (see Appendix B). The PI and onsite collaborator then submitted an IRB application to the collaborating institution, which was approved.

The original study planned to use a two-group pretest-posttest study design, which involved a treatment and control group (see Figure 2). This design was approved by the dissertation committee in February 2018. However, the research design was changed

based on the recommendation of the breast cancer disease team of the collaborating institution. The institution approved the protocol and allowed it to be implemented with a one-group pretest-posttest research design (see Figure 3).

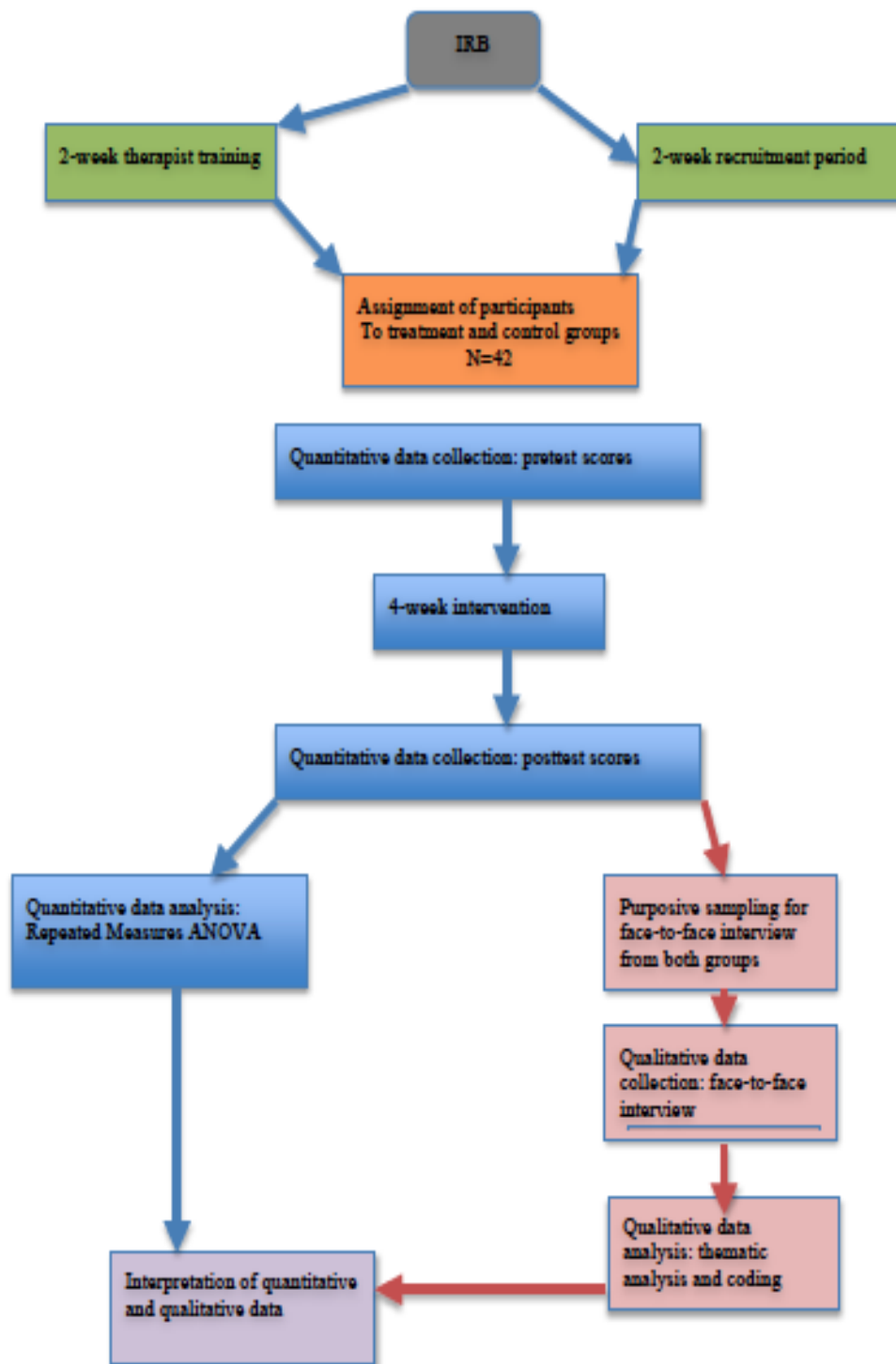


Figure 2. The Study Design Schema Approved by the Dissertation Committee.



Figure 3. Study Design Schema Approved by the Collaborating Institution.

## **Sampling**

### **Sampling Method of the Quantitative Study**

**Power analysis.** G\*Power 3.1 software was used for a priori power analysis to determine the sample size (Faul et al., 2007). The desired sample size to obtain an alpha of 0.05 and power of 0.8 with medium effect size ( $f = 0.25$ ) was at least 34. The study aimed to recruit a sample of 42 participants to account for possible attrition.

**Inclusion and exclusion criteria.** Adult females, ages 18 and older, with BCRL who were referred to the participating facility for occupational therapy were included in the study. Inclusion criteria were females with unilateral upper extremity lymphedema following mastectomy, able to communicate in English and able to participate in a discussion session with the PI once a week for 4 weeks. Factors such as the number of lymph nodes removed, the time of the initial surgery, and the initial recurrence of BCRL were not considered during the recruitment process.

**Participant recruitment.** Clients referred to the occupational therapy department of the collaborating institution were invited to participate. The potential participant was provided with a brochure as an invitation to participate in the study (see Appendix C). Participants were informed that they should be able and willing to participate in a 15-minute discussion once a week for 4 weeks with the PI and were asked to participate in a 60-minute individual interview during the fourth week of the study. Informed consent was obtained from participants prior to the commencement of the study (see Appendix D). Recruitment began as soon as IRB approval from Texas Women's University and hospital setting were obtained, concurrent with the training sessions of the treating



therapists. Participants were recruited through convenience sampling. The onsite collaborator reviews the daily referrals received by the department to identify potential participants. She then meets with the potential participants during the occupational therapy session. The PI and onsite collaborator created a recruitment script, which is included in the IRB (see Appendix E). The participant received information about the study and was asked to sign the informed consent. The consent was obtained prior to the commencement of the study (see Appendix D). The study began after the 2-week recruitment period with only four participants, which is a very small sample size and did not meet the assumptions of the parametric analysis. Recruitment continued on an on-going basis in an attempt to obtain the targeted sample size of 42 (see Table 1).

Table 1

*Recruitment of Additional Participants After the 2-Week Period*

Month 1	Week 1	Recruitment of cohort 1		
	Week 2			
	Week 3	Intervention of Cohort 1	Recruitment	
	Week 4			Recruitment
Month 2	Week 5	Intervention of Cohort 2	Intervention of Cohort 2	Intervention of Cohort 3
	Week 6			
	Week 7	Qualitative Data Analysis		
	Week 8			

The on-going recruitment resulted in participants starting the study at different times. Participants were then grouped and labeled as cohort 1 ( $n = 4$ ), cohort 2 ( $n = 3$ ), and cohort 3 ( $n = 2$ ) to easily monitor their progression in the study. Quantitative data from the subsequent cohorts were included in the final data interpretation and analysis. Participants in the subsequent cohorts were included in the qualitative data gathering.

The study addressed loss to follow up or withdrawal bias by using the outcome of the participants who were unable to complete the study and compare it with those who completed the study. The PI attempted to follow up with participants who did not complete the study. The PI also determined the reasons for dropping out. Baseline data of those who dropped out were also compared with those who completed the study to determine important differences (Kielhofner, 2006), which may also have some implications on factors that affect a client's adherence to therapy and SMP.

### **Sampling Method of the Qualitative Study**

The study participants were included if they agreed to participate in a 60-minute interview with the PI. The onsite collaborator was informed of the date and time of the interview to help schedule the session via Zoom. All of the participants were invited to participate in the interview due to the small sample size.

### **Description of the Intervention**

The study used the Remotivation Process in combination with a Complete Decongestive Therapy program. Two treating therapists provided Complete Decongestive Therapy to the study participants, however, this is customary to the occupational therapy services provided at the collaborating facility and not part of the study. The PI implemented the Remotivation Process to the participants and used the Volitional Questionnaire (VQ) to help tailor the Remotivation Process intervention.

### **The Remotivation Process**

The Remotivation Process is a continuum of intervention based on the volitional process centered on the MOHO practice model. It has three stages: exploration,

competence, and achievement. The first stage is exploration, which is an informal stage to establish rapport and provide the opportunity to experience the self successfully. The competency stage focuses on developing specific skills and working towards goals identified by the person. The person reaches the achievement stage when she spontaneously participates in a skill, challenge or task. In BCRL, the volitional process involves the person's ability to incorporate the self-management program for lymphedema in her daily life. Habits are formed during the competency stage following exploration. Achievement is observed when she integrates the program into her daily life so that roles and routines are altered to accommodate the new pattern of life with lymphedema.

### **The Volitional Questionnaire**

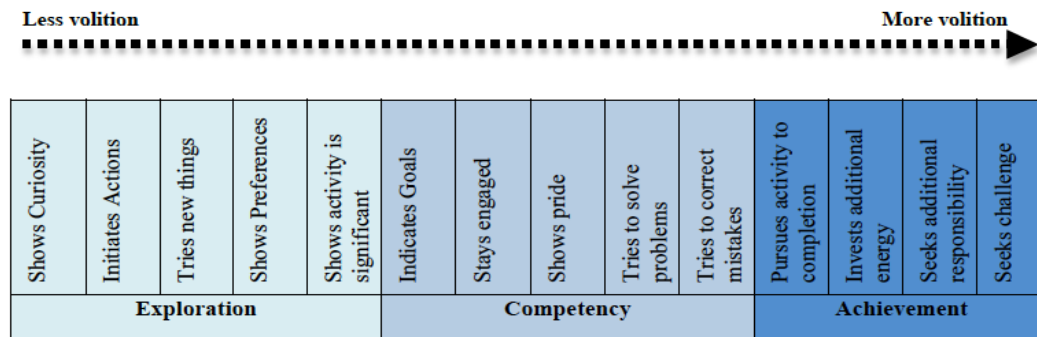
The VQ is a structured method to gather information on the client's volition based on the MOHO practice model (de las Heras, Geist, Kielhofner, & Li, 2007). It is used to monitor volitional change over time. The VQ enables the occupational therapist to document the amount of environmental support, encouragement, and structure needed by the client to exhibit volitional behaviors. The items on the scale are ordered in a sequence from less to more volition, where a client with higher volition demonstrates the behavior more readily and with less need for environmental support, encouragement, or structure. The VQ is implemented as an observational tool and can be administered during the occupational therapy session. It can also be used as a self-assessment tool. Observation periods may last from 15-30 minutes and the VQ form can be completed in 10 minutes (Kielhofner, 2008). A study by Dahmer and du Reitz in 2000 of therapists' perception of

the VQ found that the instrument was effective in providing insight into the client's volition (Agren & Kjellberg, 2008). The VQ demonstrated acceptable construct validity, content validity, and interrater validity (Chern, Kielhofner, de las Heras, & Magalhaes, 1996).

Rasch analysis by Li and Kielhofner (2004) reported a participant separation index of above 3.0, which suggests that the VQ can detect a difference between participants. Rater's fit statistics indicated that raters validly used the VQ. However, it noted that the rater's separation ratio was 4.8, which suggests a difference in the scoring of those who used the VQ in the study. The rater's separation index shows the spread of ratings between the persons assigning a score. Rater leniency is the tendency to give a higher score, while rater severity is the tendency to give a lower score. A rater's separation index of zero is most desirable since the instrument is able to promote a more consistent score between two or more raters. A high rater's separation index indicates that there maybe a significant difference between the scores given by 2 or more raters on the same item (Myford & Wolfe, 2004). De las Heras et al. (2007) noted that a high raters' separation ratio might have been caused by insufficient information provided in the instrument manual. The VQ was only administered by the PI in this study to avoid the potential confounding effect from the instrument's high raters separation ratio. The study mitigated the potential effect of the rater's separation index by having only one rater.

The PI studied the manual of the Remotivation Process and the Volitional Questionnaire to prepare for the intervention and data collection. The VQ is the central

assessment tool of the Remotivation Process. It is used to determine the client's stages of volition, which corresponds to the three stages of motivation outlined in the Remotivation Process (see Figure 4). The ordering of the items of the VQ corresponds to the three stages of motivation, which are exploration, competence, and achievement. The stages of the Remotivation Process can be interrelated and overlap at any given moment (de las Heras et al., 2003). Repeated use of the VQ is necessary to continuously determine the client's level and volitional needs (de las Heras et al., 2003).



*Figure 4. The three stages of volitional development and corresponding VQ items. Adapted from “A User's Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p. 23.*

### **Treatment Implementation Using the Remotivation Process**

The PI implemented the Remotivation Process to each of the participants in a one-on-one session either through Zoom or phone call, depending on the preference. Appendix F presents the possible questions the PI might ask during each stage. Each participant was provided with a handout that briefly explains the Remotivation Process during the first week. The handout also included guide questions to help the participant reflect on her weekly progress in the program and facilitate the weekly discussion with the PI (see Appendix G). The PI used guide questions, which reflected each stage of the

Remotivation Process (see Appendix F). The guide questions along with the expected behaviors (see Appendix F) allowed the PI to determine the participant's stage of Remotivation.

Input from the treating occupational therapist is important in the determination of the participant's level in the Remotivation Process since they may capture behaviors that did not manifest during the participant's 15-minute session with the PI. The onsite collaborator relayed the input from the treating therapists to the PI. The PI and onsite collaborator met at the end of each week to discuss each participant's progress. The PI shared her observations with the onsite collaborator each week through encrypted email. The feedback from the onsite collaborator was considered when assigning a stage on the VQ. The PI's interaction with each participant varied based on the stage. The following section describes the implementation of the Remotivation Process in women with BCRL:



*Figure 5.* The researcher’s conceptualization of the progression of a client with BCRL through the stages of the Remotivation Process.

As mentioned earlier, the Remotivation Process is an intervention based on the volitional process. It has three levels (see Figure 5). The exploration stage provides the person with the opportunity for a positive experience. The competency stage develops specific skills and goals identified by the person. The person reaches the achievement stage when she spontaneously participates in a challenge or task. The volitional process is involved when the person's ability to incorporate the SMP occurs in daily life. Habits are formed during the competence level following exploration. Achievement is observed when she alters roles and routines to integrate the program into her daily life (see Appendix F).

**Exploration stage.** The goal of this stage is for the client to discover her capacities, values, and preferences given the change in her life after the onset of BCRL. She develops personal meaning and pleasure in engaging in her environment once again. The PI aimed to establish trust, make the participant feel accepted, and increase the person's curiosity in the program during this stage. The goal of the PI was to elicit curiosity in the client's options for lymphedema treatment. It was hypothesized that patients with BCRL at this stage may show interest in the components of lymphedema therapy. Curiosity in lymphedema treatment may also be present since the person was already scheduled for an occupational therapy evaluation and attended the session.

This stage has four discrete stages. The first is validation, which begins with the initial evaluation. The PI uses four validation strategies. The first is significant greeting. The PI built trust by providing a detailed explanation of lymphedema and CDT. The participant may feel more empowered if she understands lymphedema and the rationale for CDT. In the clinical setting, a therapist needs to build trust since CDT involves hands-on treatment. The participant allows the treating occupational therapist to administer manual lymphatic drainage and shows interest in the self-administered manual lymphatic drainage program. In this study, however, the PI did not provide hands-on treatment. The PI obtained this information from the treating therapists.

The second strategy is the introduction of meaningful elements into the client's personal space. It was hypothesized that clients at this stage will at least show interest in the compression garments. The PI asked general questions such as “What do you think of the information provided?” , “Do you have any questions about lymphedema?” and



“How do you feel about the lymphedema program?”, to encourage the client to reflect on her condition and current behavior (see Appendix F). The participant may also identify components of the SMP that she might try at home or initiates ordering compression garments. These behaviors show that the person is now allowing a component of the SMP into her activities at home, or personal space.

The third strategy facilitates the participant's participation in activities of interest. It was hypothesized that the participant will state a plan to perform at least one component of the SMP at home. She might identify the task that she may delegate to others in order to make time for the SMP. The PI also asked the participant to perform some components of CDT during the session, such as deep breathing, upper body exercises, or roll the bandages in preparation for serial compression bandaging. The goal is for the participant to actively participate in the CDT.

The fourth strategy involves generating interaction. The PI still validates the participant's effort despite not being able to follow through with the plans she had verbalized during the past session. The PI also facilitated a discussion on the possible reason for her inability to perform at least one component of the SMP or follow through with her plans. It is important for the PI to be flexible, maintain an accepting environment, with no expectation and allow the participant space and time.

The PI still tries to help the participant become aware of the benefits of CDT and adherence to SMP. For example, the PI can point out that arm girth decreased significantly because the participant was able to adhere to one or more components of the SMP such as leaving her compression bandages intact since the last session or

performing her deep breathing exercise at home. It is also important for the PI to provide positive feedback regarding the outcome of each session. For example, the PI can point out that girth decreased, although minimal. The PI can also state that a more significant girth reduction can be expected if the participant performed at least one component of the SMP. The PI can ask the participant to share the progress she made during the week. The PI based her comments and feedback on the information shared by the treating therapists during the weekly discussions on each participant's progress; however, the client's attendance to sessions may be inconsistent. The treating occupational therapist recorded any missed sessions and the reason for the missed session on the participant's chart. The onsite collaborator relayed this information to the PI since the PI was not granted access to the medical records of the collaborating institution. The information is relayed through encrypted email.

The second stage is disposition for exploration. It is hypothesized that the participant attempts to perform one or more components of the SMP at home. She might be able to identify aspects of her home environment that facilitate or hinder her performance of SMP. The participant may also be able to identify daily routines and activities that may or may not be compatible with the SMP. The participant may also invite a family member or caregiver to attend the session in an attempt to ask for assistance in performing the SMP at home or initiate a conversation with the family regarding new roles in the presence of the PI. The participant may require significant support from the PI to initiate the discussion with the participant's family or caregiver.

The PI forwarded this information to the onsite collaborator if this need arises during the session. The information was then relayed to the treating therapists.

The third exploration stage is choice making. It was hypothesized that the participant, during this stage, will identify modifications in her routine and roles that she is comfortable with. She continues to keep her appointments and involves significant others in her appointments. The participant chose to attend the occupational therapy sessions and set aside time for one or more components of the SMP.

The fourth exploration stage is pleasure and efficacy in action. The participant continues to regularly attend the sessions. It was hypothesized that the participant at this stage will verbalize satisfaction in the program, the outcomes observed, and her new knowledge of BCRL, Complete Decongestive Therapy and SMP. The participant may also share some of her success at home, challenges she encountered as she attempts to change her routines, and ask for suggestions from the PI. The participant may begin to share her thoughts and concerns regarding the long-term management of BCRL following discharge from occupational therapy. For example, the participant may ask how many outpatient occupational therapy sessions she has left. However, the participant has not yet assumed full responsibility for SMP and still relies on the PI and therapists. The treating occupational therapist continues to measure girth during this stage to provide the participant with a tangible measure of success in order to maintain the participant's interest in SMP, demonstrate the value of behavior change, and contribute to her personal causation that she is able to do something about the condition.

**Competence stage.** The participant builds new routines and continues to make activity choices with the assistance of the treating therapists and PI during this stage. However, the new routines revolve around the occupational therapy sessions, which may have a frequency of 3-5x/week. The PI and treating therapists have a strong presence during the participant-therapist collaboration. The participant engages in spontaneous decision-making, realizes the value of the SMP, initiates SMP-related activities and indicates her goals without the assistance of the PI as she transitions from exploration to competency stage. The participant's micro-reality, or the world outside of therapy which includes the home, becomes the focus of the interaction between the participant and PI. The PI increased expectations for the participant to perform all components of SMP. Discussions focus on the participant's perception of meeting new challenges. The goals of this stage are the internalization of self-efficacy and facilitate skill learning through repeated practice and habit formation.

The PI provided accompaniment in new and challenging situations to develop self-efficacy. For example, the PI discussed possible discharge plans. The treating occupational therapist continues with girth measurements to demonstrate the positive outcomes of the treatment. Skill learning includes competency in performing components of the SMP and an understanding of the side effects of cancer treatment, which includes cancer-related pain and cancer-related chronic fatigue. The PI reassessed the participant's performance of the components of the SMP and identifies skills that may need to be addressed. Discussions also focused on the participant's initial plans to incorporate the SMP into the routine. The PI guided the participant in evaluating her typical day and

identifies goals, potential change in the participant's previous routine, and possible methods to implement and incorporate it into her current daily routine. The PI then asked the participant to describe her experience during the next session.

The PI provided feedback and facilitated reflection of the experience (see Appendix F). The PI used the frequency table to record the days that she was unable to perform the SMP and initiated a discussion on the possible reasons why she was unable to do so. The PI also addressed the participant's concerns regarding performance and assure the participant that moments of doubt and failure are part of the process of change. Responses include the participant's identification of reasons for not performing the SMP, the effect of non-adherence to the SMP, and changes in behavior that she might be willing to try instead. It was hypothesized that the participant will share what she did on her own, ask the PI opinions and suggestions, and how she was able to follow through with her plans. These behaviors indicate spontaneity and continued engagement in the SMP. However, performance is still inconsistent since she is still in the trial period of assuming the role of long-term management of BCRL, in addition to other roles. The PI used the participant's volitional narrative to show the participant her past success, the difference in her behavior and her potential as she anticipates the future. The PI also examined the effectiveness of different strategies the participant incorporated in her attempts to perform the SMP at home and her feelings regarding her attempts. The PI also facilitated role reflection and asked about how she interacts with her family, her attempts to delegate tasks, and how her family responds. The PI also provided other resources available in the participant's environment, such as breast cancer support group or online

support group. It was hypothesized that the participant at this stage will identify goals that lead to the incorporation of SMP in the routine.

**Achievement stage.** The exploration stage provided the participant with a positive experience that moved her volitional process forward. The competency stage allowed the participant to be comfortable with the new normal, form habits, gain self-efficacy, and participate in her chosen activities. She reshapes her occupational identity, which she attempts to express by extending her patterns of participation in other aspects of her life, such as the home and community. In the study, the PI shifted the focus on discharge plans where the participant is expected to continue with the new routine even after she is discharged from occupational therapy, provided advice, gave feedback and provided resources and strategies for self-management and self-evaluation. In the clinical setting, the occupational therapist should step back by decreasing the frequency of the sessions and focuses on the monitoring of symptoms. The PI also facilitated self-monitoring and self-evaluation.

It was hypothesized that a participant during this stage will be able to use her knowledge and past experience in occupational therapy to overcome challenges, doubt or setbacks. The Remotivation Process acknowledges that participants move back and forth between exploration, competency, and achievement. The PI tailored the responses according to the participant's stage during the session. The participant is still able to continue with SMP despite changes in personal life and family, such as becoming a grandparent, traveling, volunteering and return to work. During the stage, the participant uses both new and modified habits, routines, and skills as well as her awareness of her

capabilities as she faces new challenges in the environment outside of the occupational therapy setting. She modifies roles and routines as she participates in occupations through the volitional process of experiencing, reflecting, choice-making, and anticipating. The continued participation in occupation allows her to experience occupational competence that leads to occupational adaptation.

### **Data Collection Tools**

There are no occupational therapy assessment instruments developed specifically for BCRL. The study used circumferential measurement to measure upper extremity girth, the Model of Human Occupation Screening Tool (MOHOST; Parkinson, Forsyth, & Kielhofner, 2006), and the Lymphedema Quality of Life Inventory (LyQoLI; Klernas, Johnsson, Horstmann, Kristjanson, & Johansson, 2015).

### **Circumferential Measurement**

The National Lymphedema Network considers circumferential tape measurement as an acceptable and objective measure of lymphedema. Measurement methods for lymphedema must be consistent at pre- and post-treatment to facilitate comparison (National Lymphedema Network, 2011a). A systematic review by Hidding et al. (2016) of clinical instruments used to measure lymphedema focused on its psychometric and practical properties. The review found that girth measurement using a circumferential tape measure had high reliability and excellent validity. The studies included in the review reported a pooled ICC intra of 0.99 (95% CI = .99) and ICC inter value of 0.98 (95% CI = .98). Circumferential tape measurement also showed excellent concurrent and convergent validity with perometry and water volumetry, two clinical instruments also

used in lymphedema with high reliability and excellent validity. The review also found that a girth difference of two centimeters showed high sensitivity (Hidding et al., 2016). The girth was obtained by measuring seven fixed measurement points, which start at the palm of the hand going through the thumb web space, followed by the wrist at the ulnar styloid then every 10 centimeters from this point until the axilla (see Appendix H). Both affected and unaffected extremities are measured. A difference of two centimeters between the affected and non-affected extremity is significant and indicative of lymphedema (Hidding et al., 2016; McGrath, 2013, National Lymphedema Network, 2011a; Taghian et al, 2014). A girth difference of two centimeters in the affected extremity before and after treatment is also considered significant (Taghian et al., 2014).

### **Model of Human Occupation Screening Tool**

The MOHOST is based on the MOHO practice model (Parkinson et al., 2006), which is also the practice model that guided this study. It provides a broad view of the client's occupational performance through 24 items that assess volition, habituation, skills, and environment (Kielhofner, 2008) (see Appendix I). The MOHOST was found to have good psychometric properties (Kramer, Kielhofner, Lee, Ashpole, & Castle, 2009). The MOHOST is able to discriminate between clients with varying degrees of difficulty in occupational participation. Psychometric studies demonstrated good construct validity, item separation, reliability, and concurrent validity (Lee et al., 2013; Forsyth et al., 2011; Kielhofner et al., 2010). It was found to have high utility in the inpatient rehabilitation facility (Kramer et al., 2009). It is also valuable as an outcome measure for clinical practice and research. The Remotivation Process utilizes the



Volitional Questionnaire as the main assessment instrument. However, Parmenter et al. (2013) used the MOHOST in their study on the efficacy of the Remotivation Process in an occupational therapy program for homeless people. Although it was intended to be used as a screening tool, the MOHOST “may also be used alone” (Parkinson et al., 2006, p. 15) to provide a comprehensive evaluation and enables the occupational therapist to “systematically record baseline assessment and changes in occupational participation” (Parkinson et al., 2006, p. 16).

### **Lymphedema Quality of Life Inventory**

The Lymphedema Quality of Life Inventory (LyQoLI) is a 45-item questionnaire that gathered data on the effect of lymphedema on the participant's QOL and performance of daily activities (see Appendix J). The LyQoLI was selected for this study due to its psychometric and practical properties. The questionnaire consists of three sections that cover the physical, psychosocial, and practical aspects of the client's life. The LyQoLI is a shortened version of the Swedish Lymphedema Quality of Life Inventory (SLQOLI). The SLQOLI is the only health-related quality of life assessment designed for lymphedema with good psychometric properties; however, it consists of 188 items and takes 30 minutes to administer. Klernas et al. (2015) used correlation analysis, factor analysis, content validity assessment and expert panel to reduce the 188 items of the SLQOLI to 45 items. The LyQoLI takes 6 minutes to administer compared to the 30 minutes required for SLQOLI.

A psychometric study of the LyQoLI found that it has significant validity with the SLQOLI, good reliability, and significant correlation with the SF-36. Reliability using

ICC for the physical and psychosocial domains were 0.88 ( $p < 0.01$ ) for the physical section of the LyQoLI, 0.87 ( $p < 0.01$ ) for the psychosocial section, and 0.87 ( $p < 0.01$ ) for the practical section. Cronbach's alpha coefficients for the three sections were 0.88, 0.92 and 0.88, respectively. The physical section of the LyQoLI correlated highly significantly with the physical health section of the SF-36, while the psychosocial section correlated highly significantly with the mental health section. The practical section of the LyQoLI correlated highly significantly with both physical and mental health sections of the SF-36 (Klernas et al., 2015).

### Data Collection Procedures

The research questions were answered through data gathering and analysis of quantitative and qualitative data (see Table 2).

Table 2

#### *Data Gathering Process to Answer the Research Questions*

Quantitative Data Gathering	
Research Question	Outcome Measures
How does the Remotivation Process change the daily performance of lymphedema management techniques?	Average number of days each participant completed the SMP during the first week and fourth week ( $x/7$ days) as reported by the participant
How does the Remotivation Process affect the client's manifestation of upper extremity lymphedema?	<ul style="list-style-type: none"> <li>• Girth measurement</li> </ul>
How does the Remotivation Process affect the client's occupational participation and quality of life?	<ul style="list-style-type: none"> <li>• MOHOST</li> <li>• LyQoLI</li> </ul>

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Qualitative Data Gathering

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Qualitative Research Question	Interview Question
What are the perspectives of participants with BCRL about the self-management program after participating in an occupational therapy program using the Remotivation Process?	<p><i>What are your thoughts on the lymphedema home program?</i></p> <p><i>Sample questions:</i></p> <ol style="list-style-type: none"> <li>1. <i>What do you understand about lymphedema?</i></li> <li>2. <i>If there were challenges in doing the home program, how were these problems handled?</i></li> <li>3. <i>What has helped you do the home program?</i></li> </ol>
What are the perspectives of participants with BCRL about physical appearance in their arm after the occupational therapy program?	<p><i>How do you feel about your body after spending some time with occupational therapy?</i></p> <p><i>Sample questions:</i></p> <ol style="list-style-type: none"> <li>1. <i>What have you noticed in your arm in the past four weeks?</i></li> <li>2. <i>How do you feel about lymphedema when you first noticed changes in your arm?</i></li> <li>3. <i>How do you feel about lymphedema after receiving occupational therapy?</i></li> </ol>
How do participants with BCRL describe their daily life after occupational therapy?	<p><i>How do you feel about your everyday life given what you understand about lymphedema?</i></p> <p><i>Sample questions:</i></p> <ol style="list-style-type: none"> <li>1. <i>What are some of the things that you engaged in before lymphedema?</i></li> <li>2. <i>What are some of the things that you engage in at this point after occupational therapy?</i></li> </ol>

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- 
3. *What are some of the activities that you were doing before lymphedema?*
  4. *What are some of the activities that you were doing after lymphedema?*
  5. *What are some activity limitations, if any, have you experienced?*
- 

### **Quantitative Study**

A systematic review by Lashinski et al. (2012) found that certified lymphedema therapists spend an average of 60 minutes each session. Each participant received lymphedema therapy consistent with the plan of care designed by their respective occupational therapists and followed the existing lymphedema therapy program of the facility. The occupational therapists provided evaluation and intervention services that are customary for BCRL and were involved in the study. Participants spent an additional 15 minutes each week for 4 weeks to allow time for interaction with the PI. The PI used this time to implement the Remotivation Process. Each participant met with the PI once a week through a video and audio conferencing platform.. Participants who were not comfortable with the platform or preferred phone calls were reached through a private line in the PI's private office. The PI and onsite collaborator met at the end of each week to discuss the progress of each participant through encrypted email. The PI shared the self-report on the frequency of performing SMP, verbalizations of each participant relevant to their individual occupational therapy sessions, and problems that the PI encountered during the weekly discussions. The onsite collaborator then shared any

concerns that were identified by the treating therapists during the participants' occupational therapy sessions. The discussions between the PI and onsite collaborator were recorded in the PI's researcher journal (see Appendix K) to capture data, which might be useful in data triangulation in the qualitative study. The PI also shared her observation of each participant's place on the VQ with the onsite collaborator to be verified with the treating occupational therapist. The information was used in the VQ scoring once it was is verified.

**Study week 1.** The participants were either evaluated or received customary lymphedema therapy intervention from the treating occupational therapist, whichever was scheduled for the week. The evaluation or treatment session was part of the treating occupational therapists' role in the department and not a part of the study. The collaborating facility used the MOHOST and girth measurements as routine assessments for patients with lymphedema. It is administered regardless of the patient's involvement in the study. The following section clarifies the role of the onsite collaborator and The PI.

***The onsite collaborator.*** The onsite collaborator gathered the signed consent forms and pretest data. Pretest data included girth measurement of the affected and unaffected extremities, MOHOST, and LyQoLI. The onsite collaborator completed the collaborating institute's Data Collection Form (see Appendix L) based on the treating occupational therapist's initial evaluation, which also included the MOHOST. The onsite collaborator also administered LyQoLI to participants during the first week. The onsite collaborator also reminded the participants of the scheduled 15-minute session with the

PI. The onsite collaborator met with the PI at the end of the week to discuss any issues that occurred during the sessions.

***The PI.*** The PI received an electronic copy of the collaborating institute's Data Collection Form, MOHOST, and LyQoLI through encrypted email. She then met with the participants individually for 15 minutes through Zoom or phone, whichever was preferred by the participant. The PI asked each participant how often she performed the SMP to gather pretest frequency of performance of the SMP. The PI then proceeded to implement the planned discussion sessions, which followed the Remotivation Process (see Appendix F). The PI documented these weekly discussions using field notes for each participant (see Appendices M through S). Audio or video recording was not used during this time.

**Study week 2 and 3.** The participants continued with their occupational therapy program with their respective therapists following their individual plan of care. These sessions are not part of the study. The following section once again clarifies the role of the onsite collaborator and The PI.

***The onsite collaborator.*** The onsite collaborator communicated with the PI of any issues that may have occurred during the week. She also reminded the participants of the 15-minute discussion session with The PI. The onsite collaborator communicated with the PI any issues regarding the study via encrypted email or through Zoom.

***The PI.*** The PI continued to implement the individual 15-minute sessions to each participant through Zoom or phone call. The outcomes of the discussions were documented using field notes. Audio or video recording was not used during this time.

The PI invited the six selected participants to complete a 60-minute interview for the qualitative study at the end of the intervention.

**Study week 4.** The participants continued with their occupational therapy program with their respective therapists following their individual plan of care. These sessions are not part of the study. The following section once again clarifies the role of the onsite collaborator and the PI.

***The onsite collaborator.*** The onsite collaborator gathered posttest data. She completed the collaborating institute's Data Collection Form to obtain girth measurements and MOHOST scores and administered the LyQoLI to participants. Posttest data were sent to the PI through encrypted email. The onsite collaborator also discussed the outcome of the study with the PI at the end of the week through email correspondence or Zoom meeting

***The PI.*** The PI received an electronic copy of the collaborating institute's Data Collection Form, MOHOST, and LyQoLI through encrypted email. She then met with the participants individually for 15 minutes to administer the Remotivation Process, followed by the 60-minute interview for those who agreed to participate. This will be discussed in the section on qualitative study design.

**Study week 8.** A follow-up was completed during this week. The onsite collaborator helped arrange the follow-up session between The PI and each participant. The PI met with each participant for another 15-minute discussion, which followed the same format used in the study. The participants were asked how many times they were

able to perform the SMP that week. The results of the study were shared with the onsite collaborator after final data analysis for each cohort through encrypted email.

### **Qualitative Study**

**Week 3: Sampling.** There are no rules regarding sample size for qualitative inquiry (Patton, 2015). It is suggested that the sample size be small so that experiences can be examined in-depth (Mapp, 2008). Five participants were recruited using the purposeful sampling strategy of time-location sample. Time-location sample is a strategy where the PI interviews everyone available at a particular time and location (Patton, 2015). In this case, the PI included the participants who were available and agreed to participate in a 60-minute interview during the fourth week of the study.

**Week 4: Data collection.** Data collection occurred during the fourth week of the study. The PI directly asked the participant if she was willing to participate in an interview at the end of the 15-minute discussion during the third week of the study. Participants were interviewed via Zoom or phone call during the fourth week of the study. The interview was estimated to last for 60 minutes. However, the actual interviews lasted for 20 to 45 minutes. The interview stopped once all the questions were asked and the participant provided similar responses to the probing questions, indicating that data saturation had been reached. Each participant was only interviewed one time. The interview was audio-recorded using a voice recorder. The PI used in-depth, semi-structured interview questions to gain a deeper understanding of the participant's lived experiences of performing the SMP for BCRL and perception of her life with BCRL following occupational therapy. Interview questions were developed based on the focus



of phenomenology. The interview guide focused on the participant's source of motivation to manage the BCRL, her daily habits, and the skills that were involved in the occupational therapy program (see Appendix S). The interview followed 3 main questions, with probing questions that were individualized for each participant based on the insights and observations gathered in the weekly field notes.

The qualitative approach of the study provided flexibility and allowed the PI to explore topics that emerged during the interview aside from the planned set of questions (see Appendix S). Field notes and the transcription of the interviews were used in the triangulation of qualitative data. The PI documented her observations, insights, preliminary interpretation, her own feelings, and reactions through journaling in order to bracket her own perception and maintain the tradition of descriptive phenomenology (see Appendix U). These were also used in the triangulation of data.

**Week 5: Data transcription.** The PI transcribed each interview using NVivo 12 Transcribe. The PI reviewed the transcription generated by the software for accuracy. Each participant was given a copy of her own transcript a week after the interview to give them time to review the document. Participant 1, 2, and 6 received their transcription through encrypted email. Participant 3 and participant 7 did not have access to the Internet. The transcriptions were sent to the onsite collaborator through encrypted email. The onsite collaborator then provided the two participants with a printed copy for review. The PI completed the member checking during the follow-up discussion on the eighth week of the study. Field notes were used to document the information obtained during the follow-up. The field notes, journal entries, and information from the participants'

collaborating institution's data collection forms (see sample in Appendix V) were collected at the end of the study to be used in the triangulation of qualitative data.

## **Data Analysis**

### **Quantitative Data Analysis**

The independent variable is the time between pretest and posttest. Dependent variables are the data from the outcome measures. Table 3 shows the planned data analysis.

Table 3

#### *Planned data analysis*

<b>Research Questions</b>	<b>Outcome Measure</b>	<b>Analysis</b>
How does the Remotivation Process change the daily performance of lymphedema management techniques?	Average # of days participant completes Self-Management Program in a 7-day period	Paired <i>t</i> -test or Wilcoxon signed-ranks test
How does the Remotivation Process affect the client's manifestation of BCRL?	Girth measurement <ul style="list-style-type: none"> <li>• Pretest girth of affected arm vs Pretest unaffected arm</li> <li>• Posttest girth of affected arm vs Pretest unaffected arm</li> <li>• Pretest vs Posttest girth of affected arm</li> </ul>	Paired <i>t</i> -test or Wilcoxon signed-ranks test
How does the Remotivation Process affect the client's occupational participation and quality of life?	Model Of Human Occupation Screening Tool (MOHOST) LyQoLI	Paired <i>t</i> -test or Wilcoxon signed-ranks test Pearson's correlation or Spearman's rho

Comparison between participants who completed the study and those dropped out	Girth measurement frequency count	Independent <i>t</i> -test or Mann-Whitney U test
Comparison of outcome measures at the end of the 4-week study and during follow-up after 1 month	All outcome measures possible	Repeated measures ANOVA or Friedman's analysis

Non-Parametric analysis was used since the sample size is still less than 42 and the basic assumptions (e.g., normality, equal variance, and no outliers, etc.) for parametric data analysis were not met. Analysis of the quantitative data follows:

**RQ 1: How does the Remotivation Process, an occupational therapy intervention, affect the daily performance of the lymphedema management techniques?** Frequency count determined the number of times the participant performed the SMP during the first and fourth week, which is a 7-day period. The average number of days during the first and fourth weeks was recorded. The average number of days in a week is a continuous variable. Wilcoxon signed-ranks test was used to determine if the difference in frequency of weekly performance is significant. Friedman's analysis was used to compare the frequency of performing the SMP at pretest, posttest, and eight-week follow up.

**RQ 2: How does the Remotivation Process affect the manifestation of the client's upper extremity lymphedema?** Circumferential measurement was obtained from each participant, which is a continuous variable. Arm girth of each of the participants was calculated to determine the difference in girth of the affected limb before and after the 4-week period as well as the difference in girth between the affected and non-affected extremity after the fourth week of the study. A difference of 2 centimeters between the

affected and non-affected extremity is significant and indicative of lymphedema (Taghian et al., 2014; McGrath, 2013). Paired t-test was used to determine if there is a difference in the average change in girth over time. Wilcoxon signed-ranks test was used to verify the findings of the t-test since the sample size is too small.

**RQ 3: How does the Remotivation Process affect the client's occupational participation and quality of life?** The MOHOST and LyQoLI were used to measure occupational participation and QOL respectively. The MOHOST has six sections with 4 items in each section, with a total of 24 items. It involves a Likert Scale, which was converted to a numeric score: 4 = *Facilitates occupational participation*, 3 = *Allows occupational participation*, 2 = *Inhibits occupational participation*, and 1 = *Restricts occupational participation*. The average score of each of the 6 sections, as well as the total score, were calculated to determine the change score. Chronbach's alpha was used to determine if the averaged items are conceptually related. Chronbach's alpha was calculated at pretest.

The LyQoLI has 61 items divided into three sections, each representing a concern due to lymphedema. The physical concern section has 17 items, the social concern section has 10 items, and the practical concern section has 18 items. It also involves a Likert Scale, which was converted to a numeric score: 4 = *None*, 3 = *A little bit*, 2 = *Somewhat*, and 1 = *A little*. The average score of each of the 3 sections, as well as the total score, were calculated to determine the change score. Chronbach's alpha was used to determine if the averaged items are conceptually related.

Wilcoxon signed-ranks test was used to compare the pretest and posttest scores of the MOHOST, and LyQoLI. The Spearman's rho was used to determine the correlation between the score from the MOHOST and scores from the LyQoLI. The correlation between the MOHOST and LyQoLI was used to determine if a change in occupational participation measured by MOHOST is related to a change in the quality of life measured by LyQoLI and vice versa.

### **Participant Drop-out**

The difference in girth and frequency of SMP performance between the single group of participants who completed the study and each participant who dropped out of the study was also compared. Mann Whitney-U test was used to compare the scores of 2 groups: the mean score of the participants who completed the study, and the score of each participant who dropped out.

### **Combining Data From the Cohorts**

The pretest and posttest scores of the participants from each cohort were analyzed at the end of the study period. The pretest score of each participant during the first week of the intervention was matched with her own posttest score at the end of the intervention, which is during the fourth week. Each cohort has a different set of participants. Each cohort received the same intervention, following the same schedule. The Wilcoxon signed-ranks test was used to analyze the quantitative data. since the study did not meet the assumptions of the parametric *t*-test.

## **Qualitative Data Analysis**

**Step 1.** The PI used NVivo qualitative data analysis Software Version 12q. The PI transcribed the interviews for analysis during week 5. The PI was able to verify both the transcription and interpretation of the transcription during the eighth week follow up with all of the participants. All participants stated that the transcriptions were accurate and that the interpretation reflected their thoughts and perspective on the phenomenon of interest. Field notes were used to document the main points discussed during the individual follow-up but were not audio recorded. The transcript was read once to have an initial impression of the content. The PI read the transcript 2-3 times to gain an intuitive overview of the phenomenon under investigation.

**Step 2.** Giorgi's method of analysis states that it is necessary to break the transcription into manageable sections to enable the researcher to analyze the person's experience. The researcher must identify the shifts in the person's expressions or change in the meaning of what is being said in the transcript. These shifts or changes are called Natural Meaning Units (NMUs). NMUs can be a phrase or a group of sentences that the person used to convey the intended message. Each NMU represents one intended message. For example, these two NMUs seem to convey the intended message of adaptation:

My coping mechanism is that I make special little covers to cover up my arm when I wear my sleeve or when I dress up so it's not so gross. All things being all wrapped up you know when I'm wrapped up it looks like I have a broken arm from here to wherever. But I mean

little covers that are really cute to match my clothes and they look  
you can see it's just spacing. It is just pretty much it. I cope with it  
and I make jokes about it all. But I would, I would just go with  
humor. You know, “ what happened to your arm?” I say “It's a fight  
gone bad on a Saturday night.

We expected a certain how I will react to my therapy. So, we were  
ready. And they are very flexible so it was ok. I got their full support  
all throughout.

The researcher then rereads the NMU and identifies the intended message through what  
Giorgi considers a psychologically sensitive perspective that reflects the phenomenon of  
interest (Giorgi, 2009). In the example, both participants expressed how they adjusted  
and coped with BCRL. The participant's adaptation to BCRL was the identified  
phenomenon of interest.

The PI used NVivo qualitative data analysis Software Version 12 to identify the  
NMUs with the coding function. The PI highlighted each NMU, which is differentiated  
from the other NMUs by color. Each color was assigned a node, which was labeled  
according to the intended message based on the PI's interpretation of the NMU. Giorgi  
acknowledged that the assignment of meaning units is arbitrary and cannot be considered  
objective (Giorgi, 2009). Peer examination was used to provide rigor in the qualitative  
data analysis. The PI solicited the assistance of a peer to be both the second coder and  
peer examiner of the study (see Appendix W). The peer was an occupational therapist

who is knowledgeable in qualitative methodology and familiar with the MOHO practice framework. The PI provided the peer with a de-identified copy of all the interview transcripts. The peer and PI coded each of the transcripts separately and completed their own thematic index. The PI created a table of nodes, which was generated by NVivo 12 as a thematic index. The thematic index of the PI and peer examiner were consolidated into a single table. The PI and peer examiner discussed the consolidated table and interpretation of the nodes to ensure accuracy. The PI and peer examiner both agreed on the nodes listed on the thematic index. These nodes were labeled as “Child nodes/Codes” in NVivo 12. In the example, adaptation to BCRL was identified as one child node and labeled “adaptation”. These will be presented and discussed in the next section.

**Step 3.** The third step in Giorgi’s approach involves the transformation of the NMUs into expressions that relate to the research questions (Giorgi, 2009). Giorgi’s approach considers NMUs as separate entities, which are then organized into themes based on the research questions (Giorgi, 2009). The nodes listed on the thematic index that are identical or synonymous were grouped together. The PI identified commonalities and common NMU expressions were reduced to central themes. (Corby et al., 2015; Flood, 2010; Giorgi, 2009). The PI eliminated redundant central themes to form another column on the thematic index, which was labeled “Parent Nodes/Categories” in NVivo 12. In the example, the “adaptation” child node was grouped with the “individuality” and “ownership” child nodes. This group became one parent node/category and labeled “Participant’s responses to BCRL”. Central themes were transformed into psychological language with emphasis on the phenomenon of BCRL. The PI created a rigorous



description of the interpretation of these themes in relation to BCRL. The PI and peer examiner reviewed the themes once more to ensure agreement.

**Step 4.** The transformed meaning units are the basis of the researcher's description of the participants' experience as a whole (Giorgi, 2009). The transformed central themes were synthesized into a consistent statement to answer the questions that guided the qualitative inquiry. In the example, the parent node/category "Participant's responses to BCRL" was used to create a statement to answer the first research question. These statements were listed on the thematic index under the column "Parent Nodes/Themes" in NVivo 12. The PI verified the final qualitative data with all participants of the study through member checking via individual phone calls. All participants stated that the transcriptions were accurate and that the interpretation reflected their thoughts and perspective on the phenomenon of interest.

Descriptive phenomenology was the main approach of the qualitative study. The PI needed to suspend her interpretations and biases as a provider of therapy to explore the experience through the lens of the recipient of therapy. However, the inquiry is also guided by the MOHO practice framework. Hermeneutic phenomenological analysis involves a theoretical approach or conceptual framework during the inquiry (Flood, 2010; Lopez & Willis, 2004). Therefore, the qualitative analysis also applied hermeneutics to further explore the meaning of the parent and child nodes and strengthen the study's relevance to occupational therapy. Central themes were also transformed into concepts from the MOHO, with emphasis on the phenomenon of BCRL. The PI also created a

rigorous description of the interpretation of these themes in relation to MOHO. The PI and peer examiner once again reviewed the themes once more to ensure agreement.

### **Trustworthiness Techniques**

Trustworthiness strategies include included triangulation, member checking, bracketing, and peer examination (Krefting, 1991; Patton, 2015). The PI also studied qualitative research methods and practiced her interview techniques prior to the study. The PI addressed trustworthiness through the interview techniques, peer examination and use of the dense description of research methods (Krefting, 1991). Field notes by the PI were also included in the analysis. Triangulation included a comparison of data from the quantitative phase, participant observation, and analyst triangulation (Krefting, 1991). The PI coded the transcript two times during analysis with a 1-week interval in between coding. The PI clarified the parent node/category during the follow-up discussion during the eighth week, four weeks after the face-to-face interview. The follow-up discussion during the eighth week of the study did not uncover new themes.

A field journal was completed once a week, which contained the PI's weekly plan for the study, ideas on the methods for data collection and analysis, and personal reflections on the progression of the project. The field journal also allowed the PI to record her feelings, assumptions, and biases regarding the observations and data collected during the study. The journal was the means for bracketing. The PI must bracket, or set aside, his or her own biases and preconceptions so it does not influence the interpretation of participant responses. Bracketing, or epoche, is necessary to maintain objectivity throughout the study. In phenomenology, bracketing is a process where the PI reflects on

his or her assumptions on the phenomenon under investigation (Corby et al., 2015; Flood, 2010; Giorgi, 2009; Mapp, 2008; Patton, 2015).

The PI also addressed trustworthiness through the interview techniques, which included reframing, repetition, and expansion of questions (Krefting, 1991). For example, the PI asked participant 6 what has limited her ability to perform the SMP every day. The participant shared that she has not been able to use the affected arm due to her ongoing shoulder pain and described the movements that made the shoulder painful. The PI reframed the question about the limitation after the participant finished speaking:

PI: You mentioned that it was challenging to do the home programs because of your shoulder because you had that shoulder fracture. Is that correct?

P6: And then a shoulder replacement.

PI: Oh yes, shoulder fracture. And it was a reverse shoulder replacement.

P6: Correct.

During the conversation, the participant also mentioned that she has adapted to the home program. The PI then expanded the question:

PI: You still persevered, and you said you were doing the best you can. You did feel like you have adapted to the program.

P6: Yes.

PI: What has helped you adapt to the program?

P6: Less pain in my shoulder so the shoulder is getting better it really is.

The impact of pain on the phenomenon of interest was once again underscored during the interview. The PI then repeated the question regarding pain as a factor that limited the participant's ability to perform the SMP every day:

PI: Oh OK. That's the problem?

P6: Well I mean you've got to work to make it better. It's just that when I'm really uncomfortable and it's painful I can't do it. I could do that I do my best I can do it every day.

PI: Yeah but when you don't when you can't do it every day, is it because of the shoulder or is it because of the whole program itself?

P6: It's because of pain, my shoulder pain.

### **Combining Data From the Cohorts**

Each interview transcript was analyzed separately for common themes. The themes from each individual interview were combined and analyzed at the end of the study period. Data saturation was reached since the themes that were identified in each interview were already repeated.

### **Integration of Data From Quantitative and Qualitative Studies**

In a concurrent triangulation design, data from the quantitative and qualitative studies are gathered separately then combined during analysis (Creswell, 2009). Results from the quantitative study were compared with the themes gathered from the qualitative study. Data gathered to answer the research question of the quantitative study were combined with the corresponding themes that answered the questions for the qualitative study (see Figure 6). Results were presented with the research questions for the

quantitative study. The results of the study were shared with the onsite collaborator at the end of the eighth week of each cohort. The onsite collaborator then shared the information with treating therapists. Feedback from the treating therapists was relayed to the PI by the onsite collaborator. Feedback regarding each participant was documented in the participant's field note and was included in the analysis. The integration of qualitative and quantitative studies also provided insight regarding unexpected outcomes. An example of an unexpected outcome was a positive change in QOL based on the perspectives of the participants even if there is no significant difference in the girth measurements before and after the intervention.

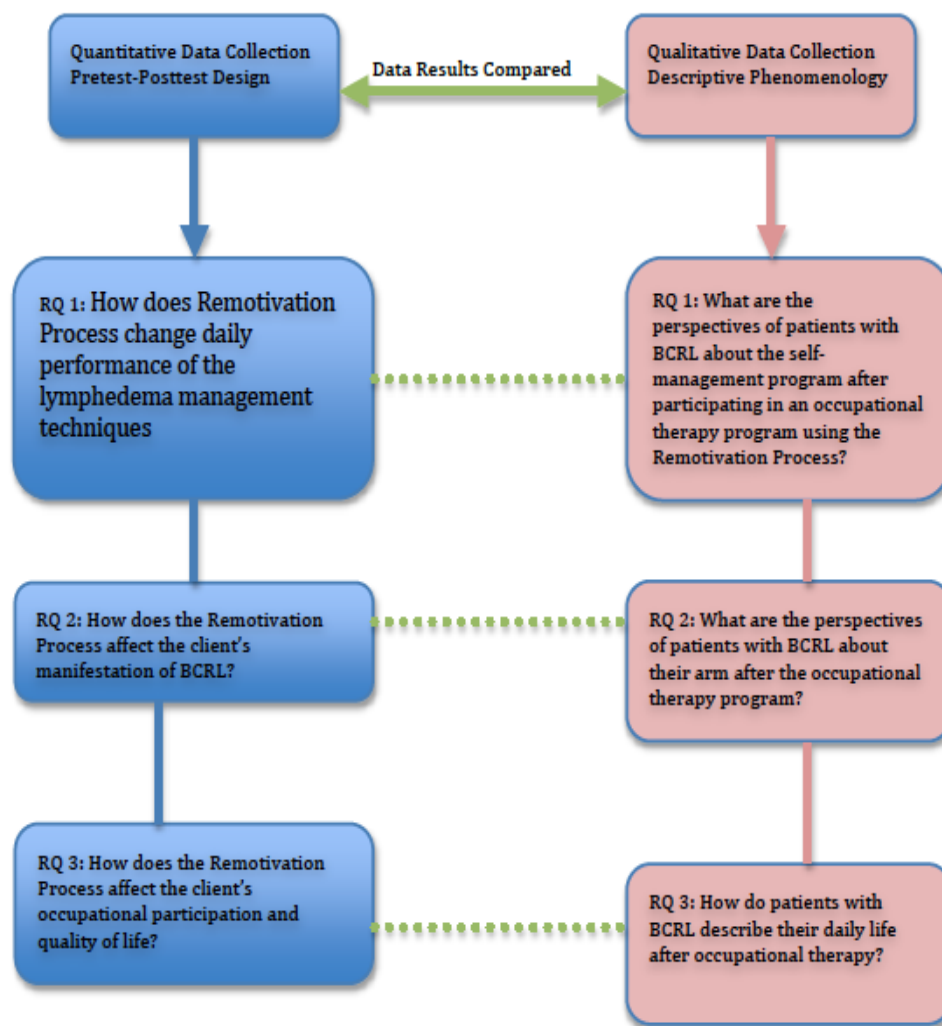


Figure 6. Integration of Quantitative and Qualitative Data

### Qualitative Research Questions

**RQ 1: How does the Remotivation Process, an occupational therapy intervention, affect the daily performance of the lymphedema management techniques?** The PI compared the average number of days out of the week that the participants performed the SMP between the first, fourth, and eighth weeks using Mann

Whitney U test. The PI then compared the quantitative data with the perceived ability to perform the SMP of the participants who were interviewed.

**RQ 2: How does the Remotivation Process affect the manifestation of the client's upper extremity lymphedema?** The average difference in the two girth comparisons was calculated for each participant. Wilcoxon signed-ranks test was used to determine if there is a difference in the average change in girth before and after the intervention. The PI then compared the quantitative data with the interviewed participants' perception of their affected arm based on the thematic analysis.

**RQ 3: How does the Remotivation Process affect the client's occupational participation and quality of life?** The MOHOST and LyQoLI were used to measure occupational participation and QOL respectively. Wilcoxon signed-ranks test was used to determine if there are differences in the scores before and after the study. The PI then compared the quantitative data with each of the interviewed participants' perceived ability to perform daily activities based on the thematic analysis.

## CHAPTER IV

### RESULTS

#### **Participant Demographics**

The study involved three cohorts. The collaborating facility received very few referrals with BCRL during the duration of the study, which was between May 2019 and December 2019. Most of the patients referred did not meet the inclusion criteria. Nine referred patients met the criteria at the end of the recruitment period. Nine participants were recruited over eight months; however, three withdrew from the study. The first cohort had four participants. Participants 1, 2, and 3 completed the study and also participated in the interview for qualitative data gathering. The second cohort had three participants. Participant 5, 6, and 7 completed the four-week intervention involving the Remotivation Process. However, participant 5 decided not to engage in the interview due to time constraints. The third cohort had two participants who initially agreed to the study, but both eventually withdrew.

#### **Participant Drop-Outs**

Participants 4, 8, and 9 did not complete the intervention. Participant 4 dropped out during the second week of the study. The PI was only able to speak with her during the first week and had scheduled the discussion session for the second week. She no longer responded to the video calls, phone calls, and emails sent during the remainder of the 4-week study period. Participant 8 initially agreed to participate during the recruitment period. She asked the PI to reschedule the discussion during the first week of the study. She then informed the PI that she no longer wanted to participate during the



call in the second week. The PI was unable to initiate any of the discussions with participant 9 during the first 2 weeks of the study. She asked the PI to call at another time during the first week then did not respond to any further attempts of the PI to initiate the discussion. Participant 9 informed the onsite collaborator that she wanted to withdraw during the third week of the study.

Six participants completed the 4-week intervention. Four participants developed BCRL in the left arm and two on the right. All six participants underwent ALND, three underwent breast conserving surgery, while three underwent total mastectomy. Four also underwent chemotherapy while five received radiation therapy. Four participants received therapy for lymphedema elsewhere prior to their referral to the collaborating institute. Table 4 presents the demographics of the participants.

Table 4

*Participant Demographics*

<b>Participant Demographic</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>5</b>	<b>6</b>	<b>7</b>
Age	55	42	80	49	70	75
Affected UE	L	L	R	L	R	L
Date of first BCRL onset	2017	2018	2018	2012	2005	2003
Employment status						
Employed						
Retired			x		x	x
Other	x	x		x		
Type of surgery						
Breast conserving	x	x	x			
Total Mastectomy				x	x	x
Axillary treatment						
ALND	x	x	x	x	x	x
SLNB						
Chemotherapy						
Yes	x			x		
No		x	x		x	x
Radiation therapy						

Yes	x	x	x	x		x
No					x	
Received CDT prior to current referral at the collaborating institute?						
Yes	x			x	x	x
No		x	x			

*Note.* *R* = Right arm; *L* = Left arm.

Quantitative data analysis used the pretest and posttest data of participants 1, 2, 3, 5, 6, and 7 ( $N = 6$ ). Quantitative data were analyzed using SPSS software. These methods used were verified by a statistician with TWU's Center for Research and Data Analysis (CRDA). The qualitative analysis involved the interview and field notes from participants 1, 2, 3, 6, and 7 ( $N = 5$ ). Qualitative data analysis was completed using Nvivo 12 software. The analysis was also sent to CRDA for expert review.

### **Results of the Quantitative Study**

All outcomes were measured and compared from pretest to posttest to determine if there is a significant difference in the scores of the single group of participants who completed the study ( $N = 6$ ). Non- parametric tests were used since the data did not meet the assumptions of the parametric test and the sample size was small. Table 5 shows the data analysis used to answer the research questions.

Table 5

*Implemented Data Analysis*

<b>Research Questions</b>	<b>Outcome Measure</b>	<b>Non-parametric</b>
How does Remotivation Process, as an occupational therapy intervention, change daily performance of the lymphedema management techniques?	Average # of days participant completes Self-Management Program in a 7-day period	Wilcoxon signed-ranks test (pretest and posttest)  Friedman's analysis (pretest, posttest, eighth week follow up)
How does the Remotivation Process affect the client's manifestation of BCRL?	Girth measurement	Wilcoxon signed-ranks test
How does the Remotivation Process affect the client's occupational participation and quality of life?	MOHOST LyQoLI	Wilcoxon signed-ranks test  Spearman's rho
Comparison between participants who completed the study and those dropped out	Girth measurement MOHOST	Mann Whitney-U test
Comparison of outcome measures at the end of the 4-week study and during follow-up after 8 weeks	All outcome measures possible	Wilcoxon signed-ranks test (pretest and at the end of the 4-week period)  Friedman's analysis (pretest, at the end of the 4-week period, and at the end of the eighth week)

**Research Question 1: How Does the Remotivation Process, an Occupational Therapy Intervention, Change the Daily Performance of the Lymphedema Management Techniques?**

Frequency count was used to record the number of times the participant performed the SMP during the first and fourth week, which is a 7-day period. The Wilcoxon signed-ranks test was used to compare the frequency of performing the SMP at pretest and posttest since data were not normally distributed and small sample size ( $n = 6$ ), which is less than 30. This showed that the difference between pre and posttest were not significant for compression ( $Z = -1.41, p = 0.16$ ), manual lymphatic drainage ( $Z = -0.54, p = 0.60$ ), and exercise ( $Z = 0.00, p = 1.00$ ).

Friedman's analysis was used as a non-parametric test to determine if there is a significant difference in the performance of each component of the SMP between pretest, posttest, and follow-up.

**Compression.** Friedman's analysis determined that there is no statistically significant difference in the mean frequency of between time points ( $F(2,10) = 22.5, P < 0.13$ ). Friedman's analysis also did not show statistical significance ( $\chi^2(2) = 4.0, p = 0.14$ ). Therefore, we can conclude that the use of the Remotivation Process does not elicit a statistically significant increase in the performance of wearing compression garments.

**Manual lymphatic drainage.** Friedman's analysis determined that there is no statistically significant difference in the mean frequency of between time points ( $F(2,10) = 0.60, P < 0.57$ ). Friedman's analysis also did not show statistical significance ( $\chi^2(2) =$

0.8,  $p = 0.67$ ). Therefore, we can conclude that the use of the Remotivation Process does not elicit a statistically significant increase in the performance of the manual lymphatic drainage.

**Exercise.** Friedman's analysis determined that there is no statistically significant difference in the mean frequency of between time points ( $F(2,10) = 1.58$   $P < 0.25$ ). Friedman's analysis also did not show statistical significance ( $\chi^2(2) = 2.0$ ,  $p = 0.37$ ). Therefore, we can conclude that the use of the Remotivation Process does not elicit a statistically significant increase in the performance of the exercise program.

## **Research Question 2: How Does the Remotivation Process Affect the Client's Manifestation of BCRL?**

Circumferential measurement was obtained from each participant, which is a continuous variable. Arm girth of each of the participants was calculated to determine the difference in girth of the affected limb before and after the 4-week period as well as the difference in girth between the affected and non-affected extremity after the study. The average difference between the two girth comparisons was calculated for each participant. A difference of 2 centimeters between the affected and non-affected extremity is significant and indicative of lymphedema (McGrath, 2013; Taghian et al., 2014). Wilcoxon signed-ranks test was used to determine if there is a difference in the average change in girth over time. A negative value (-) during the analysis means that (1) the affected arm has a smaller girth than the unaffected arm, or (2) that the posttest girth is smaller than pretest girth. The difference between the affected and unaffected arm at pretest and the difference in the girth of the affected arm at pretest and posttest were

compared. These differences were also totaled. Negative values, which indicate a decrease in girth, were subtracted.

The Wilcoxon signed-ranks test was used to compare the girth and total girth between pretest and posttest. There is a statistically significant decrease in size in the wrist ( $Z = -2.26, p = 0.024$ ), 4 cm from the wrist ( $Z = -2.37, p = 0.02$ ), 8 cm from the wrist ( $Z = -2.20, p = 0.03$ ), 12 cm from the wrist ( $Z = -2.20, p = 0.03$ ), and 16 cm from the wrist ( $Z = -2.37, p = 0.02$ ).

Paired *t*-test was used to verify if there was a difference in the average change in girth over time. T-test also showed a statistically significant decrease in these areas, wrist ( $M = 0.414, SD = 0.23, t(6) = 4.68, p = 0.003$ ), 4 cm from the wrist ( $M = 1.13, SD = 0.84, t(6) = 3.57, p = 0.01$ ), 8 cm from the wrist ( $M = 1.5, SD = 1.37, t(6) = 2.89, p = 0.03$ ), 12 cm from the wrist ( $M = 1.63, SD = 1.19, t(6) = 3.62, p = 0.01$ ), 16 cm from the wrist ( $M = 1.49, SD = 0.70, t(6) = 5.63, p = 0.001$ ). However, these results cannot be generalized due to the small sample size.

The volumetric difference of the affected arm decreased in two out of the three participants with volumetric measurements taken at pretest and posttest, while one showed an increase in volume (see Table 6). The treating occupational therapist of participants 5, 6, and 7 did not report volumetric measurements. Data was not complete therefore not used in the analysis. However, girth reduction was observed at the end of the 4-week intervention.

Table 6

*Reduction In Volume*

Participant	Change
Participant 1	3% reduction
Participant 2	4% reduction
Participant 3	5% increase
Participant 5	None reported
Participant 6	None reported
Participant 7	None reported

**Research Question 3: How Does the Remotivation Process Affect the Client's Occupational Participation and Quality of Life?**

The LyQoLI and MOHOST were used to measure QOL and occupational participation respectively. The LyQoLI is also a Likert scale that has 61 items divided into three sections. The average score of each of the 3 sections, as well as the total score, was calculated to determine the change score. Cronbach's alpha was also calculated to determine if the items in each of the three overarching questions were conceptually related. Chronbach's alpha of the averaged items of each section shows that 98% of the variance is the true score and these items are conceptually related. The difference between the pretest and posttest scores of the LyQoLI was not statistically significant

The MOHOST is a Likert Scale with six sections with 4 items in each section. The average score of each of the 6 sections, as well as the total score, was calculated to determine the change score. Chronbach's alpha was calculated at pretest and used to determine if the averaged items are conceptually related. The alpha value is 0.553; this may indicate that the score for each of the items may not be conceptually related.

However, 49 items show inter-item correlation of 0.30 to 0.70 (see Appendix X), which may indicate good internal consistency of these items (Ferketich, 1991) These items include problem solving, strength and effort, physical resources, energy, social support, and occupational demands. The Wilcoxon signed-ranks test showed that there was a statistically significant difference between the pretest and posttest scores for the MOHOST subtest Motivation for Occupation ( $Z = -2.07, p = 0.04$ ), Pattern of Occupation ( $Z = -2.04, p = 0.04$ ), Process Skills ( $Z = -2.21, p = 0.03$ ).

The Motivation for Occupation subtest refers to the MOHO concept of Volition. It looks into the person's motivation to engage in activities related to self-care, productivity, and leisure. Some of the behaviors that the subtest evaluates include the person's ability to show awareness of strengths and limitations, shows pride and curiosity, seeks challenges, and identifies personal goals (Parkinson et al., 2006). An improvement in this subtest may indicate an improvement in volition. It is worth noting that the behaviors included in the Motivation for Occupation subtest are also included in the VQ. The pretest and posttest scores on the VQ also showed a statistically significant difference.

The Pattern for Occupation subtest refers to the MOHO concept of Habituation. It looks into the person's ability to organize and sequence the activities related to self-care, productivity, and leisure. Some of the behaviors that the subtest evaluates include the person's ability to maintain habits and routines, ability to cope with disruption or change, ability to maintain engagement in the task, and ability to fulfill responsibilities. An improvement in this subtest may indicate an improvement in the participant's ability



to incorporate the components of the SMP into their daily routine and find time to perform the SMP despite challenges.

The Process Skills subtest refers to the person's ability to anticipate and make decisions, retain the information necessary to complete the activity, initiate and sustain concentration on the task, and organize the space and objects involved in the task (Parkinson et al., 2006). An improvement in the Process Skills subtest may indicate that the person has an improved knowledge of BCRL and SMP, improved ability to plan ahead to make time for the SMP, identify and organize the items that she needs to perform the SMP, and identify possible solutions to the challenges she encounters when performing the SMP. It is worth noting that the item "Problem Solving" in the Process Skills subtest also includes the ability to solve problems and correct mistakes, which are also items on the Volitional Questionnaire. An improvement in this subtest may also impact volition. Two items in the Process Skills subtest showed a statistically significant difference are knowledge ( $Z = -2.00, p = 0.05$ ) and timing ( $Z = -2.24, p = 0.03$ ). Knowledge is the person's ability to seek and retain information, use the knowledge that was retained to successfully complete the task, correctly use objects, and demonstrate understanding and orientation to the situation (Parkinson et al., 2006). Timing is the person's ability to concentrate on the activity, as well as initiate, sequence, and complete the tasks involved in the activity (Parkinson et al., 2006). The individual scores for both items on the Process Skills subtest of participants 1, 2, 5, and 6 progressed from 3 or "Allows occupational performance" during the pretest to 4 or "Facilitates occupational performance". This may mean that an improvement in this item may indicate that in the

Knowledge item, the participants improved from having a general knowledge of the SMP to having the ability to seek and retain information and improved knowledge of the components of the SMP. An improvement in the Timing item may indicate that the participants show the ability to sustain concentration, initiate the steps involved in the SMP, and complete the SMP within the appropriate time. Participant 7's score was 2, or "Inhibits occupational performance," during the pretest, which means that she has difficulty with asking for help or retaining information and shows fluctuating concentration, initiation, or sequencing the steps involved in the SMP. She progressed to 3, or "Allows occupational performance," at posttest, which means that she may demonstrate the general ability to seek and retain information, concentrate, sequence, and complete the steps of the SMP. There was also a statistically significant difference in the overall MOHOST scores during pretest and posttest ( $Z = -2.21, p = 0.03$ ). This may indicate a significant change in the participants' occupational participation or engagement in self-care, productivity, and leisure (Parkinson et al., 2006).

The study also aimed to determine if a change in occupational participation can lead to a change in the quality of life and vice versa. The study used Spearman's rho to determine if there is an association between LyQoLI and MOHOST scores. The results were not statistically significant. Therefore, the study found that the Remotivation Process may have a significant change in the participant's occupational participation. However, a change in occupational participation may not lead to a change in the participants' quality of life and vice versa.

### **Comparison Between the Participants and Those Who Dropped Out**

The onsite collaborator was only able to gather pretest and posttest girth measurements of participant 4 and participant 8. Inferential statistics cannot be applied to compare the girth measurements of the participants who dropped out at pretest and posttest. However, pretest girth measurement and MOHOST scores of participants 4, 8, and 9 were available. The Mann Whitney U test was used to compare the girth of the participants who completed the study and the three participants who dropped out. It showed that the difference between the girth of the affected arm between the two groups was not significant during the pretest. The difference in girth between the affected and unaffected arm between both groups was also not significant. This may indicate that the pretest girth between the participants of the two groups may be similar and may not have affected their performance in the study.

The Mann Whitney U test was used to compare the MOHOST scores of the participants who completed the study and those who dropped out. It showed that the difference between the pretest MOHOST scores between the two groups were only significant in timing ( $Z = -2.12, p = 0.048$ ), organization ( $Z = -2.24, p = 0.048$ ), and physical resources ( $Z = -2.83, p = 0.024$ ). The individual scores showed that the participants who completed the study had a lower score for timing and organization and a higher score for physical resources. The participants who withdrew from the study all scored 4, or “Facilitates occupational participation,” for timing and organization. Participant 7 scored a 2, or “Inhibits occupational performance,” Participants 1 and 2

scored a 3, or “Allows occupational performance,” while participants 3, 5, and 6 scored a 4.

The Timing sub-item pertains to the ability to initiate and complete a task, sequencing, concentration, and prioritization. It seems that the participants who withdrew from the study are able to sustain concentration, start the SMP sequence, and complete the SMP at appropriate times. The participants who completed the study, particularly participants 1, 2, and 7, need assistance or encouragement. Participants 1, 2, 5, and 6 scored a 3 while participant 7 scored a 2 in the organization sub-item. It seems that the participants who withdrew are able to efficiently search for, gather, and organize the items that they need to correctly perform the SMP while the participants who completed the study also needed assistance. The lower score in timing and organization in the Process subtest may reflect the difficulty experienced by the participants when they try to incorporate the SMP into their daily routine. The participants who withdrew scored lower in the sub-item. Physical resources, which includes but is limited to clothing, aids and adaptations, and technology. Physical resources can also include the availability of compression garments, bandages, or pneumatic compression pump. The participants who withdrew all received a score of 3 while those who completed the study all received a score of four. This means that according to MOHOST, the participants who withdrew either have restricted or unmet needs. Their resources generally allow the performance of the SMP but may present some obstacles. The participants who completed the study seem to have the physical resources that they need. The higher score may reflect the availability of resources and a supportive environment, which is in the Environment

subtest of the MOHOST. The difference in pretest scores of the MOHOST may have affected the decision to continue with the study. The participants who withdrew seem to already have the necessary process skills but needs the necessary items to perform the SMP. The participants who completed the study seem to need assistance and encouragement since they cannot adequately sequence, prioritize, and organize.

The occupational therapy intervention using the Remotivation Process may have provided the assistance that they need. Note, that the participants who completed the study also showed a statistically significant improvement in timing, as discussed earlier. It may seem that the occupational therapy intervention using the Remotivation Process may have addressed this need. However, the statistical findings cannot be generalized due to the small sample size. The participants who completed the study expressed that the occupational therapy program and Remotivation Process provided them with the support they needed. This will be explored in the next sections.

### **Volitional Questionnaire**

The Wilcoxon signed-ranks test was used to compare the placement of the participants on the volitional continuum in the first week and fourth week of the study. There was a statistically significant difference in the Volitional Questionnaire score ( $Z = -2.07, p = 0.038$ ). Participants 1, 2, and 6 were at the exploration stage during the first week of the study. They progressed to the achievement stage during the fourth week of the study. Participants 3 and 5 were also at the exploration stage during the first week of the study and progressed to the competence stage during the fourth week. Participant 7

was already at the achievement stage during the first week, which she maintained throughout the study.

### **Results of the Qualitative Study**

Five of the six participants were willing to participate in the interview. Each participant opted to only participate in one phone call without the video recording. The interviews averaged 30 minutes and lasted between 20-45 minutes.

#### **Step 1: Transcription and Reading of the Transcript to Make Sense of the Whole**

Audio recordings of the interviews were transcribed word-for-word using NVivo 12 transcription. All of the participants verified the transcription and agreed to include all of its contents in the analysis. The PI noted that there were similarities in the expressions of the participants, which seems that data saturation was reached.

#### **Step 2: Identification of the NMUs**

The PI used the coding function of NVivo 12 to identify the NMUs. Each NMu was differentiated from the other NMUs by color and identified as one node. The PI and the second coder compared nodes after 2 weeks, which were all similar. These nodes were labeled as “Child nodes/Codes” in NVivo 12. The nodes were combined in NVivo, which revealed 65 child nodes (see Table 7).

Table 7

*Child Nodes/Codes that were Identified in Step 2*

<b>Child nodes/codes</b>	<b>References/NMUs that support this child node</b>
Adaptations	8
Attitude of Participant	16
Attitude of the occupational therapist	4
Awareness of limitations	4
Challenges	11
Commitment to recovery	8
Communication	10
Compression sleeve	7
Decision	25
Depression	2
Effect of RP	5
Effect of occupational therapy	6
Effect on family	12
Effect on function	22
Emotions	0
Faith	16
Family coping	5
Family demands	4
Family Support	6
Feedback	3
Frequency	8
Frustration	3
Hope	4
Independence	1
Individuality	5
Knowledge	10
Lack of information or understanding	2
Limitation	30
Medicine	2
Motivation	27
Negative Factors	1
Observation of improvement	21
Optimism	4
Outside support	3
Ownership	10

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Pain	10
Participation in Occupation	9
Perception of OT	20
Perception of SMP	2
Expressions of emotions	14
Realistic	2
Reminders	4
Resilience	14
Resource Management	2
Return to occupation	8
Roles	8
Seeking support	1
Self-advocacy	3
SMP	10
SMP components	1
SMP Participation	8
Spiritual	6
Support	9
Support for SMP	16
Symptom Relief	9
Symptoms	9
Therapy revisions	3
Treatment site	4
Understanding of the condition	24
Unmet Expectation	4

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### **Step 3: Transformation of NMUs into Psychological Language**

The PI reviewed the child nodes listed in the thematic index once again to identify those that are identical, redundant, or synonymous. Child nodes that were only referenced once were combined with nodes with similar meaning. For example, the child node “seeking support” was only referenced once. The NMU was “I told [my husband] ‘you have to be ready to take care of the luggage for me because I am not the old me from before.’” This NMU was also referenced in the child node “self-advocacy.” The participant advocates for herself by being vocal about her need for support or



assistance. These child nodes were grouped together into central themes (Corby et al., 2015; Flood, 2010; Giorgi, 2009). Eight central themes were identified and each had several ideas and expressions that supported its meaning (see Table 8).

Table 8

*Central Themes that were Identified in Step 3*

Parent nodes/Categories (Central Themes)	References/NMUs that support this central theme
Participant's Response to BCRL	66
Family's Response to BCRL	30
Volition	110
Negative Factors	70
Impact on Human Occupation	48
Perception of SMP	44
Perception of Occupational Therapy	58
Support for SMP	114

The central themes were reviewed and were grouped together according to their perceived meaning (see Table 9). The central themes were added to the thematic index to form another column, which was labeled "Parent Nodes/Categories" in NVivo 12. The PI and the second reviewer reviewed the child nodes that were organized into parent nodes/categories. Both agreed on the organization of the child nodes and parent nodes/categories.

Table 9

*Parent Node and Child Nodes that were Identified in Step 3*

Parent node/Category (Central Theme)	Child node	References/NMUs that support each child node
Participant's Response to BCRL	Attitude of the Participant	16
	Adaptations	8
	Individuality	8
	Ownership	15
	Expressions of emotions	14
	Subnode: Emotion - Depression	2
	Subnode: Emotion - Frustration	3
Family's Response to BCRL	Effect on Family	12
	Family Coping	13
	Family Demands	5
Volition	Motivation	29
	Commitment to recovery	9
	Decision	25
	Faith	16
	Optimism	8
	Realistic	5
	Resilience	14
	Self-advocacy	4
Negative Factors	Challenges	13
	Lack of information or understanding	3
	Limitation	39
	Subnode: Pain	10
	Unmet Expectation	5

Impact on Human Occupation		
	Effect on function	22
	Return to occupation	18
	Roles	8
Perception of SMP		
	SMP Participation	10
	Subnode: Frequency	8
	SMP	
	Subnode: SMP components	24
	Subnode: Resource Management	2
Perception of Occupational Therapy		
	Perception of the occupational therapist	27
	Communication	10
	Effect of RP	5
	Effect of occupational therapy	11
	Treatment site	4
Support for SMP		
	Observation of improvement	22
	Outside support	26
	Subnode: Feedback	3
	Subnode: Reminders	4
	Spiritual	7
	Symptom Relief	9
	Subnode: Medicine	2
	Understanding of the condition	27
	Subnode: Awareness of limitations	4
	Subnode: Knowledge	10

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#### **Step 4: Development of a Statement to Answer the Research Question**

The final step is the transformation of the themes into a psychologically pertinent statement. The transformation of the meaning units, which began with the second step, is the basis of the researcher's description of the participants' experience as a whole (Giorgi, 2009). The PI reviewed the child nodes and parent nodes/categories once again to begin the final transformation of the meaning units. The transformed central themes were

synthesized into a consistent statement in order to answer the questions that guided the qualitative inquiry. These statements were listed on the thematic index under the column “Parent Nodes/Themes” in NVivo 12 (see Table 10).

Table 10

*Nodes in the Thematic Index*

Parent node/Category (Central Theme)	Child Node/Codes	Parent Node/Themes (Statement)
Participant’s response to BCRL	Attitude of the participant Adaptations Individuality Ownership Expressions of emotions Subnode: Depression Subnode: Frustration	Psychosocial aspects of the participant that may or may not facilitate the performance of SMP  (RQ1)
Family’s response to BCRL	Effect on family Family Demands Family Coping	How lymphedema and SMP affects the family  (RQ3)
Volition	Motivation Commitment to recovery Decision Faith Optimism Realistic Resilience Self-advocacy	How motivation is manifested  (RQ1)
Negative Factors	Challenges Lack of information or understanding	Factors that may hinder the daily performance of SMP

Parent node/Category (Central Theme)	Child Node/Codes	Parent Node/Themes (Statement)
Impact on Human Occupation	Limitation Subnode: Pain Unmet Expectation	(RQ1)  Perspective of participants after OT
	Effect on function Return to occupation Roles	(RQ2)  Effect or impact of occupational therapy and Remotivation Process to function, occupation, and participation
		(RQ3)
Perception of SMP	SMP Participation Frequency SMP SMP components Compression sleeve Resource Management	Perspectives of the participants about the SMP after OT and the Remotivation Process
Perception of OT		(RQ1)
	Attitude of occupational therapist Communication Effect of RP Effect of occupational therapy Therapy revisions Treatment site	Participants' thoughts on the OT program and Remotivation Process, which may or may not facilitate daily performance of SMP
		(RQ 1 and 2)
Support for SMP	Observation of improvement Outside support Feedback	Factors that facilitate daily performance of SMP
		(RQ1 and 2)

Parent node/Category (Central Theme)	Child Node/Codes	Parent Node/Themes (Statement)
	Reminders Support Spiritual Symptom Relief Medicine Understanding of the condition Awareness of limitations Knowledge	

The themes were translated into statements to answer the research questions for the qualitative study (see Table 11).

Table 11

*Statements that Answer the Research Questions*

Research Question	Statement
RQ 1: What are the perspectives of patients with BCRL about the self-management program after participating in an occupational therapy program using the Remotivation Process?	The SMP is effective in addressing lymphedema. The perceived improvement, environmental support, and better understanding of the situation motivate them to perform the SMP daily.
RQ 2: What are the perspectives of patients with BCRL about physical appearance in their arm after the occupational therapy program?	The physical manifestation of lymphedema seems to improve but it still affects participation in occupation.
RQ 3: How do patients with BCRL describe their daily life after occupational therapy?	Lymphedema still affects their daily life, but the occupational therapy program has helped them gain a better understanding of the situation, become aware of what can they do to manage lymphedema, and serve as a

support system as they cope with the breast cancer and its side effects.

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## **Exploration of the Nodes and NMUs**

### **Volition**

Volition is a MOHO concept, which pertains to the person's motivation for occupation. It is the innate drive for action, seen in the person's selection of activities that she finds important, meaningful, enjoyable, and feels competent in doing. It is also seen as the person who decides to develop capacities and abilities to be competent in doing things that she considers valuable, meaningful, and important. Volition is a woman's thoughts and feelings about herself, which is shaped by experiences, her interpretation of the present situation, and her anticipation of the future as a breast cancer survivor (Lee & Kielhofner, 2017; Taylor, 2017). These thoughts and feelings guide her decision-making process as she adjusts to life after breast cancer and life with BCRL. This parent node centered on eight child nodes, which are motivation, commitment to recovery, decision, faith, optimism, resilience, realistic, and self-advocacy.

**Motivation.** Motivation was revealed as the drive that keeps the participants moving forward with their daily lives despite the challenges due to cancer and BCRL.

Participant 1:

I don't allow it to affect me. No. It's there, but I keep doing what I am supposed to do. The arm hurts, but it's not like constant the whole time. No, sometimes there is a stabbing pain, an ache, then it disappears. The aching pain comes and goes. There are gaps, the arm hurts, but then it

goes away... We are all busy, we have stuff to do. But you have to find time. I find time to do it. NO excuse. That's me ... It is my faith that sees me through and has. You know, it will pass. And I am hopeful everything will be fine. I have great expectations that I will be better. Like they say, this is just a setback, and God is preparing a good come back for me. So that's what gets me through each and every day. I wake up and I am thankful for the gift of life, another day for me. I deal with what I have deal with.

Participant 2:

The home program is okay. You know, you just stay with that consistently. It works, it's better than nothing at all... And I just at this point I was frustrated with not being able to move my arm and having so much pain. I, you know I'm willing to do anything to figure out what's wrong and how to fix it.

Participant 3:

What was challenging was wondering why having to wear that sleeve and the glove kind of thing. I mean it's not hard, it's a little bit limiting and that. But it is not challenging... and you know actually, I can do most everything even though with my hand, I have this glove thing on.

Participant 6:

I've got so many things happen to me to just let this lymphedema pretty much stop me. I mean it's just that I've had so many issues that lymphedema is actually at the bottom of the list. So we just keep on keeping on.



Participant 7:

I ... because I need to use this arm and I only have to. I just feel that as long as I have movement in this arm, I just keep moving it constantly. So, you know I know when I moved there and made it easier for me to use that.

I do some of those exercises, and I have 2-pound weights and do some stretching

It's just sometimes but I mean you have to be careful not to give too much.

I think you have to keep at it.

**Commitment to recovery.** Commitment to recovery pertains to the participant's commitment to control BCRL as well as other conditions that they are going through. Participants have observed that the SMP makes their arm feel better. The participants noticed that the arm decreases in girth when they perform the SMP. Being able to find time to do the SMP makes them feel that they can eventually recover from other conditions such as ovarian cancer and pain. Participant 6 stated that she does the SMP so that the arm decreases in size that will allow her to undergo lymph node transplant. She stated: "I understand it. I don't like it and I don't have much of a choice right now working on it. I want it. I'm working toward being able to get a lymph node transplant. That's my goal. " Participant 1 stated that being able to overcome BCRL gave her the drive to overcome ovarian cancer. The participant considered her battle with breast cancer and BCRL the hardest part. She felt that the procedures related to ovarian cancer can be overcome. Her health issues are things that she will be able to deal with.

I deal with what I have to deal with. I still have some issues, I have my neuropathy, have to have my surgery to think of. My ovaries, you know, my oncologist who I met last week is recommending I do endocrine therapy for one year. He said that it is aside from the Letrozole that I am supposed to take for the next 5-7 years. This one was only for one year. Then I asked what will be side effects. He said loose bowel movement, like 7 times a day. I asked, “how long will that be?” he said, “For a month at least for the body to respond to the therapy.” It is a pill I have to take also for endocrine therapy. Then ... so it's not like I am done since I finished my last cycle last week. So, I completed my 17 cycles. But there are still things that I need to keep up with. But I am good. I am fine. I know I think the hardest part ... I have been through the hardest part.

BCRL is a condition that all five participants have experienced for several years.

Participant 7 felt that the SMP prevents it from developing other complications such as cellulitis:

I learned that there's something I can get if there's too much done. I can get, um some, I can get some kind sepsis if you do something wrong in the arm. I didn't know what it was called. She did explain that to me yesterday. [Was it cellulitis?] Yes, yes. Yes. It's (cellulitis) discussed just yesterday.

The other participants who were interviewed also felt that they have no choice but to perform the SMP and that they will suffer the consequences if they do not follow the recommended program. For example, Participant 2 stated, “I'll do my exercises, the ones

that I, you know think that I need and that I mean other than that I just, you know when it's just a follow-up.” Participants seem to acknowledge the chronic nature of the condition, which drives them to make the choice to perform the SMP.

Participant 1 stated:

I guess I have no choice but to stick to it. I know that it helps me. So, I really have to do it... We are all busy, we have stuff to do. But you have to find time. I find time to do it. NO excuse. That's me... I have no choice. You suffer the consequences by not doing it. If it helps you, why not do it.

Participant 6 stated:

I understand it. I don't like it and I don't have much of a choice right now working on it. I want it. I'm working toward being able to get a lymph node transplant. That's my goal.

Participant 7 stated:

I ... because I need to use this arm and I only have to. I just feel that as long as I have movement in this arm, I just keep moving it constantly. So, you know I know when I moved there and made it easier for me to use that... It's just sometimes but I mean you have to be careful not to give too much. I think you have to keep at it.

**Decision.** The performance of the SMP is a decision that participants make every day. They acknowledged that the SMP is time-consuming and cumbersome. However, they decide to make time for it. NMUs that strongly expressed this child node include participant 1 stating, “We are all busy, we have stuff to do. But you have to find time. I

find time to do it. No excuse.” Participant 3 stated, “[I] decide to go on day by day about it and decide what to do. Right now, I can do exercises. But the massage we have not really been doing.” Participant 6 stated, “I deal with what I have to deal with”, “I decide to go on day by day about it”, “So we just keep on keeping on.” Participants face challenges each day, but they expressed that it is up to them to make the decision to perform the SMP.

**Faith.** Participants 1 and 6 expressed faith in a higher power, which is God. They acknowledged that the human body is weak and that their strength comes from God. NMUs that strongly expressed this child nodes include:

Participant 1:

We are just humans. we are so weak, but in God, you know, He has made perfect the weakness. I cling to Him, I cling to His promises, I cling to all the verses in the Bible, He will lift me up and get me going. Whatever happens. That's what is seeing me through all these. The Lord will always see me through. He has me in the palm of His hand all these times. He will not abandon me because He is always there for me. He is in control. He will take care of me. I will be good. I am good”, and “Just like I said, it's all in God's hands. Even the way I look at this whole thing, it's something that can really be overcome. And if it is not this time, if it comes back the second time around, well, I will deal with it next. But for now, I am good. Everything's doing great. You know. I cannot complain, in spite of all these, what I went through, my struggles and everything. I can say I am still truly blessed.

Participant 7:

It's God. It's Jesus. He's the only way I get here each and every day. Now God has given me the grace to just reach every day and not dwell on all of the stuff that's happened. You know when my doctor calls me a Mack truck because I just I guess I've been through a lot. But after I've gone through it it's over, it's done. I live in denial that it ever happened but that's the grace of God that keeps me through. I was seeing my doctor the other day and he says you know I don't have sympathy for you but I do have empathy. I go, "for what?" (laughs) He says, "I see all these scars and I have empathy for you." It's like it's nothing. That's God's grace. It's God's grace. And that's how I get through it. Through Him.

These seem to suggest that the participants felt the weakness of the human body as they experienced the challenges brought about by cancer, cancer treatments, BCRL, and other concomitant conditions. They felt that their bodies were weakened and they needed to draw strength from an external source, which in this case is God. They find the strength to do what they need to do every day, which included finding time for the SMP.

**Optimism.** Participant 1, 6, and 7 expressed that they have experienced recurring cancer and BCRL for several years. Participant 1, as discussed in the previous child node, is still battling ovarian cancer. Participant 7 have had BCRL since 2003, while Participant 6 since 2005. They expressed that they have been through the worst times and believe that better days are ahead. Participant 1 strongly felt that she has been

through many challenges, but believed that they are slowly recovering from cancer and BCRL:

But there are still things that I need to keep up with. But I am good. I am fine. I know I think the hardest part ... I have been through the hardest part. And since I have been getting good results. After what I have been through, I am able to manage all that. So, I am really looking forward to better days. And it won't be as difficult as I have been through. I told myself, what I have been through, what I was able to overcome, the next few years cannot be compared to what I have been through. I don't think so. I think I have been through the most difficult part of the whole thing ... as far as (the collaborating institution), I have good people. I am blessed, even though we need to drive more than an hour to get to the hospital. I even told my husband, based on its name, I should be hopeful (laughs).

This belief gives her hope that she will eventually overcome the condition. This child node seems closely related to the next one, which is optimism. Hope and optimism help them move forward with their daily lives despite BCRL. Hope and optimism seem to foster resilience, which will be discussed in the next child node.

**Resilience.** All five participants believed that lymphedema is a condition that can be overcome despite the challenges. Participant 7: "I think you have to keep at it." Participant 1 stated:

Even the way I look at this whole thing, it's something that can really be overcome. And if it is not this time, if it comes back the second time around,

well. I will deal with it next. But for now, I am good. Everything's doing great. You know. I cannot complain, in spite of all these, what I went through, my struggles and everything. I can say I am still truly blessed.

Participant 2 stated:

I was in a lot of pain and I didn't want, you know, my lymphedema to get worse. And I just at this point I was frustrated with not being able to move my arm and having so much pain. I, you know I'm willing to do anything to figure out what's wrong and how to fix it... I need to get myself going.

Participant 3 stated:

What was challenging was wondering why having to wear that sleeve and the glove kind of thing. I mean it's [SMP] not hard, it's a little bit limiting and that. But it is not challenging.

Participant 6 stated:

No, I just you know I've learned I mean I've had this for a long time so I've learned to live with it and not do so sometimes I'm not even conscious of it. I go out without my sleeve on and then I realized my arm was exposed but I, you know I guess you kind of learn to live with it.

The challenges included the time it takes for the SMP, the long drives to the collaborating institute for treatment, the impact of BCRL on their daily function. Resilience did not only pertain to BCRL but the cancer treatments as well. Participants were able to find the time and the means to drive to the collaborating institute, which is far from their homes. One participant had to drive an hour each way, while another said

that her commute can take up to three hours. In terms of BCRL, participants stated that they try to not let the condition affect them. It is a condition that can be managed if they perform the SMP consistently. It is a condition that they have learned to live with.

**Realistic.** Participant 1, 6, and 7 also expressed that they have realistic expectations despite being hopeful. They can recognize their limitations, especially in daily activities. A common NMU that expressed this child node is that participants are realistic regarding how much they can use their arm. They can identify which activities they can and cannot perform anymore. Participant 1 stated that she knows she cannot use her affected arm to lift her suitcase to store in the overhead bin when traveling by plane. She also stated:

I am being realistic about what I can and cannot do. They are ok with that, “O ma, don't worry”, they're good. And I do not hesitate to ask for help when I need help. For example, I bought a watermelon. Before, I can carry it with no problem. Now you know, I think I am wise enough to know that I cannot use my arm too much.

Participant 7 stated that she is careful not to injure her affected hand when gardening:

Similar things. I was able to do most of the things, things like that. Now when in the garden I have to be careful if I'm in the yard. I got the gloves because if I don't want to keep my hand hurt.

They have learned to observe the precautions for BCRL. However, some participants struggle with their expectations with occupational therapy. Participant 6 said that she knew that her lymphedema will not go away immediately and recovery will take time:



[How long did it take for you to pretty much see a big impact on how you used your arm?] Probably about four months. I would say four months of going in and out of the program often a lot of you know. [So, when you started this program with (the occupational therapist) you had an idea that it's not, it's not going to go away in just a few sessions?] Oh no.

Participant 7 stated that she knows her lymphedema has its ups and downs, which meant that the size will fluctuate:

My arm would get, the swelling would have eased when it is really cold. My arm starts swelling again in the spring and the fall is not too bad but that summer it would get really swollen. So I would like to break it up entirely into two. I'll have it twice a year instead of once a year.

However, Participants 2 and 3 expressed that the girth is not as small as they expected it to be at this point in their occupational therapy program. This will be discussed in the parent node “negative factors” under the child node “unmet expectations.”

**Self-advocacy.** Self-advocacy also pertains to seeking support or assistance when needed. Participants are realistic with their abilities given the condition as mentioned in the previous theme. They expressed statements such as “You pretty much know what to expect,” “I am being realistic about what I can and cannot do,” and “I think I am wise enough to know that I cannot use my arm too much.” They feel that they know when to ask for help from others.

Participant 1 stated that she knows when to ask for help from her children during activities around the house. She tells her therapists when something in her occupational therapy program needs to be revised:

I am not 100% as before. My husband said “We should travel, we should go to the east coast. We should go to New York with the kids. “But I told him, “you have to be ready to take care of the luggage for me because I am not the old me from before. Somebody has to pick up my luggage.” I said, “my arm is not the same as before.” You know, I was very self-sufficient, but now I need help... if I feel like it not helping me or doing me any good, I would tell the therapist. Even if you were not around, I would give feedback, I would tell the therapist directly.

Participant 7 also stated that she knows when to schedule her appointments for occupational therapy so that she can receive the maximum benefit from the sessions:

I would like to do it maybe three times a year. My arm would get, the swelling would have eased when it is really cold. My arm starts swelling again in the spring and the fall is not too bad but that summer it would get really swollen. So, I would like to break it up entirely into two. I'll have it twice a year instead of once a year. [Oh, so you do try to break it into like give up periods of being a therapy.] Yeah, I like it like that. That's what I used to do and I just started that recently in July. I keep my mind focused on lymphedema when I go. I am focused now on lymphedema but if I go in the summer, if not I will forget about it. [If] I'm in pain

and I know I got to go. I would tell my doctor that I got to go [back to occupational therapy].

### **Participant's Response to BCRL**

This central theme pertains to the thoughts, reactions, and emotions expressed by the participants during the interview. Five child nodes were identified, which include the attitude of participant, adaptations, individuality, ownership, and psychosocial factors.

**Attitude of the participant.** This child node pertains to each participant's feelings towards BCRL, how they responded to the condition and its effect on their daily lives. Each participant showed different ways to respond to BCRL. Participant 2 stated, "Well, I have my good and my bad days. I don't want to say it feels better. I feel more comfortable than I did before." And take it day by day. Participant 3 describes it as a condition that affects people differently, "I don't know, I am still, should I decide to go on day by day about it and decide what to do... [It is] an individual thing." Participant 1 also stated that the condition varies from one person to another and it is up to the person to decide how to respond to BCRL:

I guess it depends on the person. And the person's situation. I think lymphedema can be managed and it can better in time... I don't allow it to affect me. No. It's there, but I keep doing what I am supposed to do. The arm hurts, but it's not like constant the whole time. No, sometimes there is a stabbing pain, an ache, then it disappears. The aching pain comes and goes. There are gaps, the arm hurts, but then it goes away... I don't allow it to affect me. No. It's there, but I keep doing

what I am supposed to do. The arm hurts, but it's not like constant the whole time.

Participant 6 uses humor to respond to BCRL:

My coping mechanism is that I make special little covers to cover up my arm when I wear my sleeve or when I dress up so it's not so gross. All things being all wrapped up you know when I'm wrapped up it looks like I have a broken arm from here to wherever. But I mean little covers that are really cute to match my clothes and they look you can see it's just spacing. It is just pretty much it. I cope with it and I make jokes about it all. But I would, I would just go with humor. You know, “What happened to your arm?” I say, “It's a fight gone bad on a Saturday night.”

Participant 7 places emphasis on maintaining her independence despite BCRL:

I hate to ask people, like my friend just told to take you somewhere or take my car now. I hate it because I asked a friend to take me yesterday. I hate to keep calling people asking to take me there because (the collaborating institution) isn't really close to me like right there. It's not close, it's a little away from me.

**Adaptations.** BCRL is a chronic condition and four participants shared ways with which they have adjusted to it. They stated that their abilities and overall disposition vary from day to day. Participant 2 described this as, “Well, I have my good and my bad days. I don't want to say it feels better. I feel more comfortable than I did before.” Pain and discomfort are common sensations expressed by the participants, but these sensations will come and go. Participant 6 stated:

No, I just you know I've learned I mean I've had this for a long time so I've learned to live with it and not do so sometimes I'm not even conscious of it. I go out without my sleeve on and then I realized my arm was exposed but I, you know I guess you kind of learn to live with it.

Being flexible helped them adjust to these variations. The appearance of the arm with BCRL has affected two participant's choice of clothing. Participant 6 decided to make her own arm covers to make the arm less noticeable.

When my arm is wrapped and it's really bulky or when I have my compression sleeve on, I make covers out of leggings and I cut the leg off these leggings. And at the, at the ankle of the leg and I put a thumb hole and then I kind of move my arm with that, that's been wrapped with the compression sleeve and it looks really, it's cute. It's, it's just a nice way of having the garments on without it being quite so drastic looking because when it's wrapped it's pretty drastically. Oh my God, I've got to cover it up with that one too sparkly. And it's not quite so drastic.

Participant 7 stated:

Yeah, I have to find larger because some clothes can't go over the sleeve. If I had a large, I have to get an extra-large just so it will let the arm with the sleeve through it. And then you can't buy a jacket with the garter on the sleeve. It does not let the arm through.

Both participants also stated that they buy larger-sized clothes to cover the arm.

Participant 1 shared that she not only has to adapt, but her family also had to adapt

depending on how she feels each day. This will be discussed in the child node that pertains to the impact of BCRL on the family.

**Individuality.** Participants expressed that managing BCRL depends on the person and the person's situation. Participant 1 stated that she was able to go through her cancer treatments and lymphedema therapy because of the strong support from her family.

I guess it depends on the person. And the person's situation. I think lymphedema can be managed and it can better in time... much the same way when I was doing the worst of my chemo. The first 6, the third round, 3, 4, 5, 6. those were the worst round. 1 and 2 were a breeze, it was nothing, the first 2 rounds. But there is a cumulative effect, so I was always sick but I knew 2 days after a cycle, I can still drive a pick up my kids, but I cannot do that on the 3<sup>rd</sup> day so they had to take Uber to get home. So, we knew, we expected a certain how I will react to my therapy. So, we were ready. And they are very flexible so it was ok. I got their full support all throughout, 19 months since my diagnosis... o, we are truly lucky, we were truly blessed, we have resources, we have people we know. My husband's work schedule. Things fell into place that somehow; we found a way.

Participant 2 expressed that it was difficult for her because she lives alone. Individuality was also expressed as the effort to express oneself. Participant 6 did not like the way the compression sleeve looked. She made different arm covers that match her clothing and personality. She stated that she feels so exposed without the arm cover, so she makes arm covers to match her outfit. Participant 6 stated:

Yeah well, it's when you talk to other people who have lymphedema and you have to get this sleeve. A lot of times they don't know where because they're, they're not attractive at all. However, I get a girl's sized leggings and you can make a sleeve for like three or four dollars rather than going to a website paying 24 dollars for the cover and you can buy all of their style to match your clothing... So, if you want, you know, you want to go out but you don't want you aren't looking so exposed. Just go to Target and buy some cheap little league and the little girls and cut offcut off the leg the same. Put a thumb hole and you've got a pretty cover.

Participant 7 expressed her individuality by maintaining her independence, which includes being able to participate in daily activities. Even though they have expressed that they know when to ask for assistance, they also try not to ask for assistance too often:

I hate to ask people, like my friend just told to take you somewhere or take my car now. I hate because I asked a friend to take me yesterday. I hate to keep calling people asking to take me there because (the collaborating institution) isn't really close to me like right there. It's not close, it's a little away from me.

**Ownership.** Ownership pertains to the participant's acknowledgment of the chronic nature of BCRL and their responsibility to perform the SMP. Four participants expressed that they do what they need to do and performing the SMP is a decision they make. They perform the SMP because they see the benefit and they experience the consequence themselves if they do not do so. The NMUs that reflect this child node also reflected the participants' choice to commit to the SMP, which was discussed in the child

node “commitment to recovery” under the parent node “motivation.” Participant 2 stated, “I’ll do my exercises, the ones that, I, you know think that I need and that I mean other than that I just, you know when it’s just a follow-up.”

Participant 1 stated:

I guess I have no choice but to stick to it. I know that it helps me. So, I really have to do it... We are all busy, we have stuff to do. But you have to find time. I find time to do it. No excuse. That’s me... I have no choice. You suffer the consequences by not doing it. If it helps you, why not do it?

Participant 6 stated:

I understand it. I don’t like it and I don’t have much of a choice right now working on it. I want it. I’m working toward being able to get a lymph node transplant. That’s my goal.

Participant 7 stated:

I ... because I need to use this arm and I only have to. I just feel that as long as I have movement in this arm, I just keep moving it constantly. So, you know I know when I moved there and made it easier for me to use that... It’s just sometimes but I mean you have to be careful not to give too much. I think you have to keep at it.

Participant 7 also expressed her ownership by trying to learn as much as she can about the condition:

You know I did learn about these different surgeries that they have and the therapists, they do a little different. Everybody does they do the same. And just I



don't. I guess I read too much about lymphedema. I can actually hold a conversation with them about it. I can't say there was a lot of different things that was told to me. I'm always looking up things about lymphedema.

However, Participant 3 had expressed that she performs the SMP and follows the recommendations because “Oh, it, I don't I think they might fire me!” referring to her lymphedema therapist. She depends on her therapists to remind her to do the SMP: “Oh, I can't think of anything [the occupational therapist] thinks more of the things than I do. (laughs). I can't think of anything... I think so because if it were not for it [occupational therapy sessions] I would be going off and forget about it [SMP].” The participant shared that she had asked her occupational therapist a few times if the BCRL will eventually go away and when she can stop doing the SMP:

I asked her if it was completely down which she did not say (laughs)  
[You said last week that you can ask her and she didn't say if it's ever going to go away.] Right, yeah. well I have not talked to her since then. So, she is not committing to it so I suppose sometimes it does and sometimes it does not.

When asked about her thoughts regarding her arm, she stated:

Oh, I think it's going down. I think it's gone down. Just taking some foam stuff out of it. It's just puffy, especially my hand is puffy and I think I think my arm is gone down and things like that. You know she measures that so you'd have to ask her, so that.

Unlike the other participants, she depends on other people, especially the therapists, to manage BCRL. She does not seem to acknowledge the chronic nature of the condition.

**Expressions of emotions.** The NMUs in this child node showed the emotions expressed during the interviews. Participants expressed both positive and negative emotions during the interviews. Positive emotions include being thankful, being satisfied with the occupational therapy program and feel that the arm is getting better. Negative emotions include feeling depressed, overwhelmed by the impact of BCRL, at embarrassment from the appearance of the affected arm. Participant 1 shared that she felt overwhelmed at times, but continues to use faith to handle this emotion:

Sometimes ... you get overwhelmed? You know the logistics, the time, the kids? What now? It was really overwhelming. But you know, like I said, God was in control. He took care of stuff for us. He took care of everything. He will make a way and we just have to believe He will always be there, and he has been and he will never fail. We all cling to, to that promise and we rest in him.

Participant 3 expressed that she is still thankful despite the condition: “Well I think it's been very good. I'm very very thankful for.” Participant 6 expressed embarrassment over the appearance of her arm: “Well I do pretty much everything the same it's just you know, so close to what they used to. I cover my arm a lot because it's embarrassing or sleeveless tops anymore.” Two emotions that were shared by more than one participant were depression and frustration due to BCRL.

Depression comes from not being able to do the activities that they need to or want to do because of the pain and discomfort in the arm. Two NMUs that strongly expressed depression are from Participant 1 and Participant 2. Participant 1 stated:

You know how every now and then I will still get that pain. But not as bad, maybe 10 weeks ago, but it was really bad. You know, and I was feeling kinda depressed. I was getting depressed because of the pain.

Participant 2 stated, “It's just kind of depressing when you're sick, you really can't do nothing because you're sick.” Depression seems to arise from the condition itself and not SMP. However, Participant 2 also expressed frustration:

Yes, I was because I really, I was in a lot of pain and I didn't want, you know my lymphedema to get worse. And I just at this point I was frustrated with not being able to move my arm and having so much pain.

Participant 6 expressed that the SMP has caused her frustration, “Oh yeah it's frustrating, and the home therapy. I mean it's, it's very time consuming.” SMP is time-consuming, which at times causes frustration. Frustration also arises from the condition itself. The chronic nature of BCRL made one participant feel frustrated and discouraged. Another participant expressed frustration over not being able to use her arm because of the pain. Pain is a common condition that will be discussed in another child node.

### **Family's Response to BCRL**

Three participants live with their family or significant other while two live alone. However, all participants expressed that BCRL and cancer have affected their families or participation in family activities. They have had to ask for assistance from family on at least one occasion (e.g., to drive them to the collaborating institute for treatment). This parent node represents how the family responded to BCRL and is expressed in three themes: effect on family, family coping, and family demands.

**Effect on family.** Participant 1 shared that her children were especially troubled at first and she had to keep reassuring them. She stated:

They [my kids] were ... through all these .... They were concerned at first last October. They asked me, “Ma are you ok?” I said, “I will be ok.” My son was 15 then, he's my youngest. The girl was 15. So, I explained to them what we could expect, “But do not be afraid, I will be fine.” So, it was ok. They were not traumatized or anything.”

However, she expressed her concern that her children may be at risk for developing cancer:

Especially since I have the BRCA that they might have also. So, when they are old enough. They have to find out and they have to deal with it if they have it or not.

The cancer diagnosis also affected the family. Participant 1 also said that her children were especially worried when she was first diagnosed with cancer. She said her family's faith in God helped ease the worry of her children.

**Family coping.** The occupational therapy and cancer treatment schedules of Participants 1 and 6 have affected the schedule of the family. They are still able to perform activities such as childcare, grocery shopping, and household activities. However, the timing of these activities is affected since they have to make time for SMP as well as visits to the collaborating institute for cancer treatments and occupational therapy. Participant 1 said that her husband had to change his work schedule so that he can drive her to the collaborating institute:

It just happens that our insurance allows me to go to (the collaborating institution). Then my husband's schedule allows him to take Wednesdays off. He has a private practice so he can move his patients as long as we know in advance so he can move his patients around. He will not see patients if I have an appointment. So, he was there through all of my 17 cycles. He was there for my surgery or important appointments. But during the time of radiation or for therapy, we hired somebody to drive me to (the collaborating institution). Her children also helped her with household responsibilities that she may not be able to perform due to the discomfort in her affected arm. She stated:

The first 6, the third round [of chemotherapy], 3, 4, 5, 6. those were the worst round. 1 and 2 were a breeze, it was nothing, the first 2 rounds. But there is cumulative effect, so I was always sick but I knew 2 days after a cycle, I can still drive a pick up my kids, but I cannot do that on the third day so they had to take Uber to get home. So, we knew, we expected a certain how I will react to my therapy. So, we were ready. And they are very flexible so it was ok. I got their full support all throughout, 19 months since my diagnosis.

Participant 6's family helped her adjust to her activity restrictions:

Family support is wonderful. They're always you know they're always there to take care of me. Keep an eye on me. Tell me don't do that. I'll do it. Don't do that. Don't do that. I'll do that. They act like I'm a little rose ready to fall off the vine but they're very good. They're very good. Yes, family is amazing. Wonderful family support.

The family provides support as they cope with the participants' condition. The participants expressed that they can perform SMP and go through the cancer treatments due to the support of the family. Their family and significant others are flexible since their lymphedema and overall disposition can vary from day to day.

**Family demands.** Participants still try their best to engage in activities as much as they can. Participant 2 and her significant other were in the middle of moving to a new house during the study. Participant 3 still helps her husband with the family business. Participant 6 still takes care of her grandson to help her daughter:

I take him to from the school. I've got so many things happen to me to just let this lymphedema pretty much stop me. I mean it's just that I've had so many issues that lymphedema is actually at the bottom of the list. So, we just keep on keeping on.

Participant 1 still has children who go to school:

If there is heavy traffic, that is a problem. But we are still blessed even if it is far. I even asked myself "can I do this radiation?", my husband has to work, he has to see patients, right? That is Monday through Friday. And depending on the time, the schedule is not fixed. Then we have our kids to drop-off in the morning.

Participant 1 and 7 were caregivers for a relative at one point during the study.

Participant 1 was providing emotional support and guidance to her husband's cousin who was recently diagnosed with breast cancer. Participant 7 was a caregiver for a relative for a brief period. The participants once again stated that they do what they can every day

and they take things day by day. However, they acknowledge that their performance of the activities is not the same as before. Participant 1 said, “I am not 100% as before.” She shared that she was able to travel with her family and participate in outdoor activities. However, she told her husband that she can travel but she will need help carrying her luggage because “my arm is not the same as before.” The participants are still able to meet the demands of the family, but they share their limitations with their family.

### **Impact on Human Occupation**

**Participation in human occupation.** As mentioned in the previous theme, the participants still engage in human occupations even though BCRL and SMP have affected their ability to do so. MOHO defines human occupation as the doing of work, play, or activities of daily living within the person’s temporal, physical, social, and cultural context (Taylor, 2017).

**Effect on function.** Participants experienced a decrease in the strength of their affected arm. They are affected by the pain, swelling, stiffness, and pulling sensation. Participant 1 stated that she experienced pain related to BCRL. Pain, however, is often caused by an injury or condition such as arthritis, shoulder fracture, or shoulder replacement. This will be further explored in the parent node “negative factors” in the child node “other conditions.” Participant 2 stated:

I haven't really tried like doing anything out of the ordinary. You know I, just, it's not, it's not like I'm moving furniture every day or if I am washing dishes. I

mean I noticed my arm looks tired really quickly if I'm cleaning. I have to take breaks.

Movement is also limited. For example, Participant 2 stated:

I was in a lot of pain and I didn't want, you know my lymphedema to get worse. And I just at this point I was frustrated with not being able to move my arm and having so much pain. I, you know I'm willing to do anything to figure out what's wrong and how to fix it.

Participant 7 said that they cannot move her arm because of the pain. Participant 7 stated that she cannot raise her arm because the swelling made her arm too heavy:

Well, sometimes it hurts and sometimes it does not. I try not to do too much with my shoulder and my back. It's a lot of things that you can't use. If you don't think about it then you carry stuff with this arm, then you are like. "Oh my God. I should not use this arm". And if I'm back in my garage, moving things around. I try not to do too much there because I know I lift too much. It not mostly in my arm that hurts, it's mostly in my shoulder and my back area so I can't do a lot of things like, like I like to do especially in the yard. I can't do a lot of things like that and the mopping and just moving things around the house I can't do that. I used to.

The compression bandages or compression gloves also limit the flexibility in their affected arm. They also have to take extra precautions to prevent injury when engaging in household chores. Participants are instructed to wear gloves when performing household chores such as washing the dishes or gardening to avoid injuring the skin,



which may lead to infection and cellulitis. They also have to limit the amount of lifting that they can do, including carrying bags of groceries.

This was very well described by Participant 7:

[What were some of the things that you were able to do before the lymphedema started in 2003?] Similar things. I was able to do most of the things, things like that. Now when in the garden I have to be careful if I'm in the yard. I got the gloves because if I don't want to keep my hand hurt ... Anything that I don't want to get any cuts in the arm even with the glove ... I can do a little more with my right hand. But I try not to let the left hand out because even if you have a glove, it don't even get farther up of your arms. ... I learned that there's something I can get if there's too much done. I can get, um some, I can get some kind sepsis if you do something wrong in the arm. I didn't know what it was called. She did explain that to me yesterday. [It is maybe cellulitis?] Yes yes. Yes. It's discussed just yesterday.

Neuropathy is also a common condition that Participants 1 and 3 experienced, which limited their ability to manage fasteners during dressing activities. Participant 3 stated:

But if I'm able to move my arm and you know actually, I can do most everything even though with my hand, I have this glove thing on. But it's just, it's just you know little things like buckles and small things like that because of the neuropathy.

However, participants felt that neuropathy was a condition separate from BCRL.

Participants expressed frustration over these limitations. However as discussed in the

previous nodes, they also expressed that they know they have to do what they have to do and make the necessary adaptations or ask for assistance. Participant 1 shared:

I am being realistic about what I can and cannot do. They are ok with that, “O ma, don't worry,” they're good. And I do not hesitate to ask for help when I need help. For example, I bought a watermelon. Before, I can carry it with no problem. Now you know, I think I am wise enough to know that I cannot use my arm too much.

**Return to occupation.** Participants expressed that they try to do as much as they can despite the BCRL and having to make time for SMP. Participants 1 and 7 stated that they are still able to do gardening. Participant 1 also shared that she can still participate in leisure activities with her family, but she had to ask for assistance to carry her luggage and took frequent rest breaks.

Actually, this past weekend, we went to San Diego, the four of us, my 2 kids and my husband. We met up with my sister, my mom, and my 2 nephews. Then on Sunday, we even went kayaking in the ocean... Yeah, but I am not 100% as before. My husband said “We should travel, we should go to the east coast. We should go to New York with the kids”. But I told him, “you have to be ready to take care of the luggage for me because I am not the old me from before.

Somebody as to pick up my luggage”. I said, “my arm is not the same as before”.

You know, I was very self-sufficient, but now I need help.

All participants can perform household activities but with adaptations and frequent rest breaks. Participants 1, 2, 6, and 7 are still able to drive despite the swelling in the

affected arm. They can complete basic self-care and expressed that the BCRL does not affect the basic activities of daily living. Participant 7 shared:

Well sometimes it hurts and sometimes it does not. I try not to do too much with my shoulder and my back. It's a lot of things that you can't use. If you don't think about it then you carry stuff with this arm, then you are like. "Oh my God. I should not use this arm". And if I'm back in my garage. Moving things around. I try not to do too much there because I know I lift too much. It not mostly in my arm that hurts, it's mostly in my shoulder and my back area so I can't do a lot of things like, like I like to do especially in the yard. I can't do a lot of things like that and the mopping and just moving things around the house I can't do that. I used to. [It sounds like it affected how you do your household chores and hobbies such as gardening.] It did. It did affect that one. [Did it affect the basic things that you do for yourself like getting dressed or go into the bathroom showering sometimes getting dressed, something like that?] No that's fine. I push it aside. Oh, I just can't reach up high. I found a way to use the towel to work with that go across my back and like that. I have to find larger because some clothes can't go over the sleeve. If I had a large, I have to get an extra-large just so it will let the arm with the sleeve through it. And then you can't buy a jacket with the garter on the sleeve. It does not let the arm through.

Participant 2, however, expressed frustration since she is still unable to work due to the limited use of her arm and has no job at this time. She stated:

A normal day is usually just waking up, by taking the dog out to use the bathroom and cleaning up the house taking a shower getting dressed and taking out my friend from school. I don't you know just cleaning and I mean that's it. There's nothing I don't work right now or I don't have a job.

**Roles.** Participant 2 had expressed the desire to be able to work once again, as seen in the previous child node. Participants 1 and 6 expressed sentiments related to their role during the interview. Participant 1, as was discussed in the previous nodes, discussed at length her role as a mother in her responses. She stated that she can engage in activities related to her role as a mother despite BCRL. She is also able to find time in between her activities as a mother to do the SMP. She also shared how cancer and BCRL affected her family, especially in the early stages of her treatment. Participant 7 shared that she schedules her days so she can still take care of her grandson.

### **Perception of Occupational Therapy**

The participants expressed that occupational therapy had a significant effect on BCRL and their overall function. Five child nodes were identified that were pertinent to the occupational therapy program: perception of the occupational therapist, communication, effect of occupational therapy, treatment site, and effect of the Remotivation Process.

**Perception of the occupational therapist.** The participants felt that the therapists may have different approaches to address BCRL. However, they also felt that the therapists are knowledgeable and competent in their ability to address BCRL.

Participant 3 stated:

Well you know, they've got two that do the lymphedema for 35 people out there. I think they're both working in different ways to help you. I was with her and the other guy was the other one. It's fine I had him a couple of times but you know it's sometimes sort of just get going with somebody you know, but she really does a great job.

Well, I think it's been very good. I'm very, very thankful for. (The occupational therapist) she, she really works with it and, you know, tries to figure out you know or try to feel and, you know, or do different things. So, she's really, I think she's really good. Yeah. Yeah. And so, I think I am you know I guess I am using it more. I, she thinks more of the things than I do. (laughs).

The therapists are also able to respond to their changing needs by making occupational therapy revisions. The participants felt that the therapists revise the treatment plan when necessary. The therapists measure their arm and listen to the participants' thoughts and experiences. Participant 6 shared: "He just goes over the exercise, the home exercises and what I could be doing to make it to where it doesn't get worse." Participant 3 shared how her occupational therapist adjusts her program:

She's keeping working on it I've got; I am scheduled with her every week for the next couple of months which is really nice. I mean she's just you know she measures and she does this and that she just knows you can feel her mind working... Yeah, she looks at things to do, or you know maybe we should try this and do this.

**Communication.** The participants stated that the occupational therapist and the PI were able to explain the nature of BCRL. They were able to communicate the importance of the SMP and provide clear answers to their questions. The therapists' and PI's ability to communicate this information have helped them understand BCRL, which helped encourage them to perform the SMP every day. Participant 2 stated that the occupational therapist helped her understand the importance of the SMP, "I think just, you know like you're doing a great job just having the patients understand what lymphedema is and, you know that you know the home program and the benefit." Participant 3 looks to her occupational therapist to provide her with feedback and information regarding what to expect, "I asked her if it [lymphedema] was completely down which she did not say (laughs) ... So, she is not committing to it so I suppose sometimes it does and sometimes it does not. Is that right?" Participant 6 also shared that the occupational therapist helped her understand the nature of the condition and how to address BCRL, "[The occupational therapist] helps me understand explaining what they're doing and why they do it. It is good that they have been giving information to the patient educating the patient on the proper process on what it takes to work with lymphedema." Participant 1 stated that the occupational therapist's ability to explain BCRL and neuropathy helped her overcome depression. She shared that she was depressed over the tingling sensation in the arm, but she became hopeful after her therapists explained that the neuropathy in her arm can be a sign that the nerves are regenerating. She felt that being able to understand the condition made her feel better:

You know, and I was feeling kinda depressed. I was getting depressed because of the pain. But then I met (the occupational therapist) and a couple of days after or a day after. And I told that it was painful. And she said it was the nerve regenerating. And last night I was telling my husband, you know since that time when I started getting the pain. At first it was that bad. Then I was told it was because of the regeneration of nerve, and then once it while I would get it. But overall, I think my arm is better. So maybe the nerve regenerating is helping with the flow or something or I don't know. But it is so much better than from when we started.

Participant 2 stated that she had no idea that lymphedema can get worse. She understood the importance of the SMP after her occupational therapist explained that even her lymphedema is at the early stage, it can progress to a stage two or three if she does not perform the SMP:

[Did the occupational therapist give any more details about stage 1 and why does he think it's a stage 1?] Yes, he spoke a little bit about because of the tightness that I'm having and the swelling you know, but like with you, he just goes over the exercise, the home exercises and what I could be doing to make it to where it doesn't get worse. [Do you feel that you know enough about lymphedema at this point?] Honestly, I think you probably know enough about anything, but I understand it a lot better.

**Effect of occupational therapy.** The participants expressed that occupational therapy helped them understand BCRL and gave them a way to prevent the swelling from

getting worse. However, when asked about the overall effect of occupational therapy, only four participants stated that the arm is better. Participants also stated that they learned the SMP through the occupational therapy sessions. They were not familiar with BCRL until they were seen by the occupational therapists. Participant 1 stated:

From 4 weeks ago compared to today I think it is better... I did notice that, uh, I don't know if I mentioned this to you the last time, we talked more than a week ago, (pause) um, I feel like a shooting pain... I don't allow it to affect me. No. It's there, but I keep doing what I am supposed to do. The arm hurts, but it's not like constant the whole time. No, sometimes there is a stabbing pain, an ache, then it disappears. The aching pain comes and goes. There are gaps, the arm hurts, but then it goes away.

Participant 3 stated:

Oh, I think it's going down. I think it's gone down. Just taking some foam stuff out of it. It's just puffy, especially my hand is puffy and I think I think my arm is gone down and things like that. You know she measures that so you'd have to ask her, so that... It feels like it looked today because I had it off and I went for a manicure and I didn't put it looked like to me that it was down. Not quite down as it should be, but down from what I remember it to be.

Participant 6 stated:

I think it's excellent. I've had very good results. I'm going to (the collaborating institution) for my lymphedema. And before I broke my shoulder, we had wonderful progress to the point that I thought that I had wrinkles on my arm I



never knew I had yeah it was that was good news and bad news. The good news is my arm is smaller, the bad news is I've got wrinkles.

Participant 7 stated:

Well it's easier to use it and then my arm is done a little lighter. And also, there's not, it doesn't hurt but sometimes my back from carrying the weight of the arm [And then you did say the last time the exercises sort of helps address the pain in your back and your shoulder] Yeah. Because it feels lighter. [Did the program at (the collaborating institution) help you understand lymphedema a bit better than before.] Yes. [What was the new information that your occupational therapist provided you were over there?] You know I did learn about these different surgeries that they have and the therapists, they do a little different. Everybody does they do the same... I learned that there's something I can get if there's too much done. I can get, um some, I can get some kind sepsis if you do something wrong in the arm. I didn't know what it was called. She did explain that to me yesterday. [It is maybe cellulitis?] Yes yes. Yes. It's discussed just yesterday.

Participant 2 stated that her function was the same as when occupational therapy started. However, she stated that the pain is what is causing the limitation in function and her ability to perform the SMP. Her main concern is the pain in her arm, which has not improved through both occupational and physical therapy. Occupational therapy gave her something to do to address the pain:

[Has the occupational therapy made any difference to how you use your arm or do you feel that you get tired less or pretty much the same since you started

occupational therapy?] It's the same. [Did the occupational therapy help with, with the pain?] Um, no ... I don't think it helped with the pain. I think it just helped me understanding how to stretch properly. I think occupational therapy is good. I'm glad I actually am doing therapy right now for the lymphedema. You know like we talked about last week, catching it early on, than just living my life in pain not knowing.

**Treatment site.** Participants also expressed satisfaction with the services at the collaborating institution when sharing their thoughts about occupational therapy. They also expressed that the drive to the collaborating institute is stressful, with the commute taking up to 2 hours because of traffic. However, they continue to go there because of the excellent service they have received. Participant 1 stated:

As far as (the collaborating institution), I have good people. I am blessed, even though we need to drive more than an hour to get to the hospital. I even told my husband, based on its name, I should be hopeful (laughs)! When I was diagnosed, my primary provider here at Riverside already called a local surgeon and made an appointment for me to see the surgeon, then my husband said: “No I have reading up, let's make an appointment at (the collaborating institution).” It just happens that our insurance allows me to go to (the collaborating institution). Then my husband's schedule allows him to take Wednesdays off. He has a private practice so he can move his patients as long as we know in advance so he can move his patients around. He will not see patients if I have an appointment. So, he was there through all of my 17 cycles. He was there for my surgery or

important appointments. But during the time of radiation or for therapy, we hired somebody to drive me to (the collaborating institution)...It is very stressful because it is very far. The traffic is heavy depending on the time. Sometimes it takes 2 hours to get home.

Participant 7 stated:

I hate to ask people, like my friend just told to take you somewhere or take my car now. I hate because I asked a friend to take me yesterday. I hate to keep calling people asking to take me there because (the collaborating institution) isn't really close to me like right there. It's not close, it's a little away from me.

Participant 6 stated:

I think it's excellent. I've had very good results. I'm going to (the collaborating institution) for my lymphedema. And before I broke my shoulder, we had wonderful progress to the point that I thought that I had wrinkles on my arm I never knew I had yeah it was that was good news and bad news. The good news is my arm is smaller, the bad news is I've got wrinkles.

**Effect of the remotivation process.** The participants felt that the discussion sessions using the Remotivation Process help them be more mindful of their performance of the SMP. Participant 6 stated that talking about the SMP “helped me keep on track.” Participant 3 stated, “Yes, I think so because if it were not for it I would be going off and forget about it,” and Participant 2 stated, “I mean the information yes. As far as the follow up goes it just depends on my case. If I'm having a good day that day physically and mentally, then I'll do my exercises, the ones that I, you know think that I need.”

Participant 1 felt that she would have continued with the daily SMP even if she did not participate in the study. She attributes this to her attitude, which she expressed:

Personally, if you were not involved in the study, if I did not take part in the study and I don't have anybody like you calling every week for the past 4 weeks. I will still stick to the program. I am the kind of person that does what I need to do. As long as I know why I should be to do it if I feel like it is benefiting me. But if I feel like it not helping me or doing me any good, I would tell the therapist. Even if you were not around, I would give feedback, I would tell the therapist directly. So, it's just me. I don't know with others. Personally, I am like that.

### **Perception of the SMP**

The participants were asked about their thoughts regarding the SMP and how often they perform it. Participant 2 stated, “The home program is okay... It works, it's better than nothing at all.” Participant 1 expressed that SMP is important in lymphedema management. She stated:

We are all busy, we have stuff to do. But you have to find time. I find time to do it. No excuse. That's me... I will still stick to the program. I am the kind of person that does what I need to do. As long as I know why I should be to do it if I feel like it is benefiting me. You suffer the consequences by not doing it. If it helps you, why not do it?

This parent node looks into the participants' thoughts regarding components of the SMP and their participation in the activity.

**SMP components.** Each participant has individualized SMPs depending on the recommendations of the occupational therapist. However, the basic components of the SMPs include compression, massage, and exercises. The participants shared the components of their individual SMPs and how often they perform each component at home. Participant 2 stated, “I’ve been wearing the program sleeve every day. The exercises I probably them about three times three times.”

Participant 1 stated:

I kept up with it the whole time. I use my sleeve 100% of the time. So everyday single day when I wake up, I do my massage, then I wear my sleeve. Then I get up from the bed. Then I take my sleeve off at night.

Participant 3 stated:

[Were you able to do any of the massage or the exercises that she wanted you to do?] Right now I can do exercises. But the massage we have not really been doing. Yes. [And are you wearing the sleeve?] Yes, the sleeve and the glove.

Participant 6 stated:

Yes. I’m still being bandaged. As a matter of fact, I’m gonna be bandaged. I just, I just got back from (the collaborating institution). I am just going to have my lunch. (The occupational therapist) just did a bit of a massage then I am just going to wrap my hand... I did about four. I was out of town on the weekends so I couldn’t do it during this weekend but about four times I did it the wrapping up, it was actually OK.

Participant 7 stated:

So she did the massage for my arm then I did five ... five different exercises for the arm. [When we talked the last time it did it did sound like you are very familiar with the home program. You have the Ready Wrap, the one with the Velcro. You are familiar with the exercises and the massage for the arm] Yeah. I do some of those exercises, and I have 2-pound weights and do some stretching *Compression*. All of the participants were given a compression sleeve.

Participants 3, 6, and 7 have expressed that it was cumbersome to don the sleeve.

Participant 6 has tried donning aides to help her with the task:

If I'm home alone the challenges wrapping my arms but I still can do it just takes a little while. [So you had mention of the donning aides. I did send the video of the Medi Butler and the Jobst donning sleeves. But I think you already have those, right?] Yeah I have the donning sleeve, which is very difficult to use because it only goes halfway.

All participants have also experienced having to apply serial compression, which was also difficult. They have expressed that the layers of short-stretch bandage made the arm stiff and difficult to move. Compression is also challenging during the warm months because it makes the arm feel hot. Participant 6 expressed that the appearance of the sleeve made her feel embarrassed: "My coping mechanism is that I make special little covers to cover up my arm when I wear my sleeve or when I dress up so it's not so gross." The compression glove can also limit the use of the fingers. However, the participants stated that they wear the compression sleeves every day. Participants 1, 2, 6,

and 7 also wear a nighttime garment, such as the Ready Wrap or Solaris Tribute. They also wear these every night.

**Massage.** Participants 1, 2, 3, and 6 were provided with instructions on a self-administered massage sequence to facilitate lymph flow. Participant 6 and 7 used a four-chamber compression pump, which served the same purpose.

**Exercises.** All of the participants were provided with exercises, although these exercises were designed to address stiffness and flexibility. The exercises are a combination of stretches and lightweight training.

**Resource management.** Participants expressed that it was important to have the compression sleeve. Time is also a resource that is important for performing SMP every day. Participant 1 stated: “You know what? We are all busy, we have stuff to do. But you have to find time. I find time to do it.” Participant 6, however, stated: “Oh yeah it's frustrating, and the home therapy. I mean it's, it's very time-consuming! ... It is time-consuming and cumbersome!” Access to therapy services is also important. Participant 7 stated that she divides the number of therapy visits authorized by her insurance in a year into shorter periods. She observed that the swelling gets worse during the hottest and coldest months, so she makes sure that she is seen by the occupational therapist during these months. Participant 7 stated:

I would like really to not to do it all at one time but different times they give you. I would like to do it maybe three times a year. My arm would get, the swelling would have eased when it is really cold. My arm starts swelling again in the spring and the fall is not too bad but that summer it would get really

swollen. So I would like to break it up entirely into two. I'll have it twice a year instead of once a year.

**SMP participation.** This child node refers to the frequency with which the participants performed the SMP. Although the participants reported that they wear their sleeves every day, the frequency of performing the massage and exercises vary between three to five times a week as was seen in the quotes above. The factors that may affect the participation in SMP will be discussed in the next two parent nodes.

### **Negative Factors**

Negative factors refer to the reasons participants were not able to perform the SMP. These include the challenges they experienced, lack of information, limitations, and unmet expectations.

**Challenges.** Among the challenges was the distance of their home to the collaborating institute. While this may not be directly related to the SMP itself, the time it takes them to travel to and from the collaborating institute takes away the time for them to perform the SMP. Their visits to the collaborating institute involve occupational therapy and appointments with the other members of their medical team. Participants often feel tired after the appointments. They sometimes have multiple appointments during the week or during the day that they feel overwhelmed. Participant 1 stated:

But during the radiation, I was very tired, I would fall asleep on the way home.

That's why I cannot drive after radiation. If there is heavy traffic, that is a problem. But we are still blessed even if it is far. I even asked myself "can I do this radiation?", my husband has to work, he has to see patients, right? That is



Monday through Friday. And depending on the time, the schedule is not fixed.

Then we have our kids to drop-off in the morning.

Participant 7 stated:

I have to cancel [the appointment] now because my car's broke down and don't have a car. I have to cancel tomorrow. I don't have a car tomorrow and Friday.

Hopefully, my car will be ready by Saturday... I hate to ask people like my friend just told me to take you somewhere or take my car now. I hate because I asked a friend to take me yesterday. I hate to keep calling people asking to take me there because (the collaborating institution) isn't really close to me like right there. It's not close, it's a little away from me. [You did say it was about 30 minutes away.]

Yeah it is. But just on the freeway.

Participants 2 and 7 stated that they were not feeling well for several days during the study and it made it more difficult for them to perform the exercise and massage.

However, they were still able to wear the compression sleeve. Participant 2 stated: "It's just kind of depressing when you're sick you really can't do nothing because you're sick".

Applying the compression bandages was also challenging since this has to be done with one hand. Participant 6 stated, "If I'm home alone the challenges wrapping my arms but I still can do it just takes a little while." Participant 1 stated that she had to ask for help from family members to complete the massage and bandaging.

**Lack of information.** The participants stated that it was important for them to understand BCRL and the purpose of the SMP. Participant 1 stated that she was getting depressed from the pain, neuropathy, and swelling:

You know, and I was feeling kinda depressed. I was getting depressed because of the pain. But then I met (the occupational therapist) and a couple of days after or a day after. And I told that it was painful. And she said it was the nerve regenerating. And last night I was telling my husband, you know since that time when I started getting the pain. At first, it was that bad. Then I was told it was because of the regeneration of nerve, and then once it while I would get it. But overall, I think my arm is better. So maybe the nerve regenerating is helping is helping with the flow or something or I don't know. But it is so much better than from when we started.

Participant 2 was surprised at how much she did not know about lymphedema:

I ... I really, I, I didn't know it was it could be as serious as it can be and was like I didn't know it could restrict you know your daily life if you didn't have you know some type of exercise to... I didn't know I could get worse as it could.

Participant 3 expressed that she needed to know if the arm is getting smaller in size when the occupational therapist measures her arm, “You know she measures that so you'd have to ask her, so that... I asked her if it was completely down which she did not say (laughs).” Understanding lymphedema and knowing that the arm is getting better encourage them to perform the SMP. The lack of information seems to discourage them from the SMP.

**Limitations.** Cancer treatments and BCRL itself have negative effects on the participants' daily performance of SMP. In addition to that, they experience other

conditions in addition to BCRL. Participants stated that they get tired easily, more so during their appointments at the collaborating institute. Participant 2 stated:

I haven't really tried like doing anything out of the ordinary. You know I, just, it's not, it's not like I'm moving furniture every day or if I am washing dishes. I mean I noticed my arm looks tired really quickly if I'm cleaning. I have to take breaks.

Participant 1 stated:

The first 6, the third round, 3, 4, 5, 6. those were the worst round. 1 and 2 were a breeze, it was nothing, the first 2 rounds. But there is a cumulative effect, so I was always sick but I knew 2 days after a cycle, I can still drive a pick up my kids, but I cannot do that on the third day so they had to take Uber to get home.

So, we knew, we expected a certain how I will react to my therapy.

They have limited strength and endurance. Pain is also a limiting factor. Participants 1, 2, 6, and 7 were limited by shoulder pain while Participants 1,3, and 6 experience pain and neuropathy in the hands. These limit their ability to use the unaffected arm and hand to perform the massage and apply the compression garment or bandages. Pain and stiffness in the shoulder of the affected arm limited their ability to perform the exercises. These issues were also shared by these participants during the weekly discussion sessions. Their ability to perform the SMP every day is limited by pain. The inability to perform all components of the SMP is largely due to pain and not the components of the SMP itself. Participant 2 and 6 both underwent shoulder replacement. Participant 2 stated:

It's just that when I am really uncomfortable, it is painful I can't do it ... oh well, that's hard because I had my surgery and so I was having ... I was doing physical therapy before I did my lymphedema therapy and I didn't have very much function in my arm to begin with... And I just at this point I was frustrated with not being able to move my arm and having so much pain.

When asked further, she stated that the shoulder pain is the main reason for not doing the SMP. Participant 6, who is also experiencing severe pain in her shoulder, expressed that she was frustrated because her orthopedic surgeon cannot seem to give her an answer regarding her shoulder pain:

At this point nothing I have an appointment with an orthopedic surgeon on the sixth of June. The last time I saw him and I asked him why I was in so much pain afterward. [Have you tried to get a second opinion?] He is kind of my second opinion. He is the one who did the surgery so after, after this appointment on the sixth of September. Then I'll see if I'll be going to somebody else.

She stated, "I've had so many issues that lymphedema is actually at the bottom of the list. So we just keep on keeping on." In addition to pain, participants experience neuropathy. Participant 1 expressed that the neuropathy began after the cancer treatment. Participant 3 stated that she has had neuropathy prior to BCRL:

It still pulls. But that's from the surgery here. It's different. So yes. Yeah, she looks at things to do, or you know maybe we should try this and do this. But if I'm able to move my arm and you know actually, I can do most everything even though with my hand, I have this glove thing on. But it's just, it's just you know

little things like buckles and small things like that because of the neuropathy. But no, I don't think that it's anything to do with the lymphedema.

Neuropathy has limited their grasp and coordination. They experience difficulty holding the sleeve during donning. Participant 1 stated that it was difficult for her to complete the massage because her hand would hurt. She also stated:

I still have some issues, I have my neuropathy, have to have my surgery to think of. My ovaries. You know, my oncologist who I met last week is recommending I do endocrine therapy for one year.

Participants experience the symptoms differently. Participant 2 stated that the pain in her shoulder is constant, while participant 1 stated that the pain comes and goes. Participants 2 and 7 stated that they often feel tired, which was not expressed by the other three participants.

**Unmet expectations.** Three participants have expressed negative sentiments over unmet expectations. Participant 3 stated, “Oh I think it's going down. I think it's gone down ... Not quite down as it should be, but down from what I remember it to be.” It is noteworthy that the participant wonders if the swelling was ever going to go away or if she can stop performing the SMP despite the chronic nature of the condition, “What was challenging was wondering why having to wear that sleeve and the glove kind of thing.” Participant 2 stated that the swelling and amount of fatigue is the same after 4 weeks of occupational therapy and SMP. Participants 2 and 6 expressed feeling discouraged over the persistent pain in their shoulder. Although their unmet expectations

pertain to pain and not BCRL itself, these unmet expectations seem to affect their attitude towards SMP and motivation.

Participant 2 stated:

[So how was the pain now?] I'm on a different they gave me different pills to take because the other one was making me too drowsy. So we're trying a different pill and I either I can't really tell the difference at this point it's just, it's just I also use a cream and I think the cream numbs it out more than the pills. [How about the therapy? Did the therapy help with the pain?] Um, no ... I don't think it helped with the pain. I think it just helped me understanding how to stretch properly.

Participant 6 stated:

At this point nothing. I have an appointment with an orthopedic surgeon on the 6th of June. The last time I saw him and I asked him why I was in so much pain afterward. [Have you tried to get a second opinion?] He is kind of my second opinion. He is the one who did the surgery so after, after this appointment on the sixth of September. Then I'll see if I'll be going to somebody else.

### **Support for SMP**

This parent node pertains to the experiences and factors in the environment that encouraged the participants to perform the SMP despite the challenges. The child nodes are observation of improvement, outside support, spiritual, symptom relief, and understanding of the condition.

**Observation of improvement.** Participants expressed that they notice their arm getting smaller in size when they perform the SMP. Participants 2 and 3 both expressed unmet expectations in terms of the size of the swelling of their affected arm in the prior child node. However, they still observed some improvement, which motivates them to continue with the SMP. Participant 2 stated, “Well, I have my good and my bad days. I don't want to say it feels better. I feel more comfortable than I did before.” Participant 7 said, “Well it's easier to use it and then my arm is done a little lighter. And also, there's not, it doesn't hurt but sometimes my back from carrying the weight of the arm.”

Participant 1 stated:

OK, hmmm ... from 4 weeks ago compared to today I think it is better ... I think it is better. I did notice that, uh, I don't know if I mentioned this to you the last time, we talked more than a week ago, (pause) um, I feel like a shooting pain... I consider it growing pain now. And overall effect? I think my arm is better.

Participant 3 stated:

Oh, I think it's going down. I think it's gone down. Just taking some foam stuff out of it. It's just puffy, especially my hand is puffy and I think I think my arm is gone down and things like that.

Participant 6 stated:

Well, that seems like today. My hand is getting smaller... I have less swelling and hands and I can see the veins in my hand... I think it's excellent. I've had very good results. I'm going to (the collaborating institution) for my lymphedema. And before I broke my shoulder, we had wonderful progress to the point that I thought

that I had wrinkles on my arm I never knew I had yeah it was that was good news and bad news. The good news is my arm is smaller, the bad news is I've got wrinkles!

The participants also stated that the arm felt better and seem to be able to use the affected arm more when they perform the SMP as much as they can. They reported feeling more comfortable and the arm feels lighter or not as heavy. They notice that they can see the veins on the back of their hands, which was not possible when the hand was very swollen. They also notice that wrinkles form on the hand and arm as the swelling subsides. They feel that the SMP is important because of these observations. Participant 1 described this when she stated, “ As long as I know why I should be doing it, if I feel like it is benefiting me. But if I feel like it not helping me or doing me any good, I would tell the therapist. Even if you were not around, I would give feedback, I would tell the therapist directly” when the PI asked why she performs the SMP every day.

**Outside support.** Outside support includes medical professionals and family members. Three other child nodes were identified that pertain to this node: feedback, reminders, and support. However, the NMUs for these three child nodes were the same and were collapsed into this child node. Participants felt that the therapists provided them with the instructions for the SMP as well as helped them understand the importance of the SMP, which was discussed in the child nodes under the parent node “Perception of Occupational Therapy.” The therapists also provided feedback regarding their performance of the SMP by informing them of any change in the girth measurements. The PI provided weekly discussions using the Remotivation Process helped keep them on



track and be more mindful of the SMP. These were once again discussed in the parent node “Perception of Occupational Therapy.” The family is also a source of support as the participants went through cancer treatment and lymphedema therapy. This was already discussed in the parent node “Family’s response to BCRL”. The NMUs that pertain to the presence of other people remind them to do the SMP every day also pertain to this theme. Family members and medical professionals serve as outside support and remind them to do the SMP daily.

**Spiritual.** Spiritual support helped the participants overcome the challenges the experienced during cancer treatment. It also helped them go through the daily challenges involved in living with BCRL. This theme was already presented in a previous child node of “Faith” under the parent node “Volition.”

**Symptom relief.** Relief from pain enables the participants to perform the SMP. Participant 2 stated that she was encouraged when she received a special cream to ease the pain in her shoulder despite being discouraged by the pain. She was initially prescribed medication but this made her drowsy. She was unable to consistently perform all the components of the SMP as a result of the drowsiness:

I'm on a different they gave me different pills to take because the other one was making me too drowsy... So, we're trying a different pill and I either I can't really tell the difference at this point it's just, it's just I also use a cream and I think the cream numbs it out more than the pills.

The SMP itself helped ease the swelling and discomfort in the affected arm, which made it easier for the participants to perform the SMP every day. These were seen

in the NMUs that showed the participants' statements in the previous child node "observation of improvement."

**Understanding of the condition.** An understanding of the condition of BCRL also comes with the awareness of their limitations. Participant 1 stated that they know what they can and cannot do and know when to ask for assistance:

And I do not hesitate to ask for help when I need help. For example, I bought a watermelon. Before, I can carry it with no problem. Now you know, I think I am wise enough to know that I cannot use my arm too much.

NMUs that pertain to the participant's knowledge of BCRL also pertained to an understanding of the condition. Participant 2 stated, "Honestly, I think you probably know enough about anything, but I understand it a lot better." Participant 3 stated, "I understand that the swelling and the lymph nodes are because of my mastectomy."

Participant 6 stated:

It's great. I mean just. Help me understand explaining what they're doing and why they do it. It is good that they have been giving information to the patient educating the patient on the proper process on what it takes to work with lymphedema.

Participant 7 stated:

You know I did learn about these different surgeries that they have and the therapists, they do a little different. Everybody does they do the same. And just I don't. I guess I read too much about lymphedema. I can actually hold the conversation with them about it. I can't say there was a lot of different things that

was told to me. I'm always looking up things about lymphedema. I learned that there's something I can get if there's too much done. I can get, um some, I can get some kind sepsis if you do something wrong in the arm. I didn't know what it was called. She did explain that to me yesterday.

The participants expressed that they felt relief after they received more information about BCRL. They also find that they understood the benefit of the SMP after they became knowledgeable of BCRL. They also expressed that their therapists provided patient education, which helped them understand BCRL. An understanding of the condition made them feel that they can manage BCRL. It also encourages them to do what they need to do and perform the SMP.

### **Triangulation of Qualitative Data**

Triangulation included a comparison of data from the quantitative phase, field notes, and analyst triangulation. A comparison of data will be discussed in the next section when the results of the qualitative analysis are integrated with the quantitative data. Analyst triangulation was in the form of the second coder, which was already discussed in the previous paragraphs. The PI used field notes to record her observations as well as the statements and expressions of each participant during the weekly discussion sessions. The weekly sessions involved their thoughts regarding lymphedema and BCRL. The questions used during the weekly discussions were guided by the Remotivation Process and MOHO. The PI did not audio or video record these discussions. The field notes were compared with the statements made during the

interview. These comparisons are presented according to the parent nodes that were identified and presented earlier.

### **Parent Node: Volition**

Participants shared statements such as “You do the best you can by yourself,” “I just keep doing what I have been doing,” and “I just need to get over it” when describing how they felt about the SMP and lymphedema. Participants shared that they try their best to do what they have to do every day, including the SMP as well as daily activities. Two participants both stated that they will do what they have to do to control lymphedema. These statements reflect the child nodes “resilience” and “decision.” The participants made the decision to keep doing their daily activities. Resilience was manifested as the decision to keep going despite the challenges. One participant stated that she has been sick for several days, but she was still able to perform the SMP daily. She also stated that she kept the compression bandages on her arm even though it made the arm feel too hot especially in the summer. These are also reflective of resilience. The child node “faith” was verbalized by one participant during the weekly discussions. She stated, “God is the Maker. He will heal me, here on earth or heaven. Either way, I will be healed. I am not afraid.” The NMUs that reflect these child nodes are similar to the NMUs identified in the interview.

### **Parent Node: Participant’s Response to BCRL**

Participants expressed emotions such as depression and frustration during the weekly discussion sessions. These two emotions were also expressed in the interview. Two participants shared that they felt depressed over the size of the affected arm and

being unable to find clothes that fit. Another participant stated that she is frustrated because the affected arm is still significantly swollen compared to the unaffected arm despite the decrease in size. She is more frustrated over the pain in her shoulder that does not seem to go away. She was frustrated because she has seen two orthopedic specialists but was still unable to find answers for her pain. These reflect the child node “expressions of emotions,” similar to the interview. The child node “ownership” was also identified in the weekly discussions. One participant stated that she feels that she will be able to control her lymphedema even after she is discharged from occupational therapy. Another participant stated that her main goal was to have her lymphedema under control so that she can undergo surgery for lymph node transfer. These statements during the weekly discussions seem to show the child node “ownership.” These participants felt that they can do what needs to be done towards a personal goal. One participant stated, “There is more to life. I am more than my boob.” This participant felt that she can control lymphedema. The participants who felt that they have a goal or have control also performed the SMP every day based on their weekly self-report. These are consistent with the child node “ownership” from the interview, which pertains to the acknowledgment that they are responsible for controlling lymphedema despite being a chronic condition.

### **Parent Node: Family’s Response to BCRL**

Two participants stated that their husbands help with the self-administered manual lymphatic drainage. However, the massage feels different from the lymphatic drainage administered by the occupational therapist. Another participant receives

assistance from her daughter when applying the compression bandages. The participants shared the importance of a strong support system. These reflect the child node “family coping,” similar to the statements shared by the participants during the interview.

However, two of the participants also stated that they still have to fulfill their roles within the family. The weekly discussion sessions revolved around their schedule with the family. One participant preferred an afternoon appointment while her children are at school. She stated that her daily schedule is very busy with the activities of her children. Another participant wanted the weekly discussions in the morning so she can spend time with her grandson later in the day. The participants are still able to meet the demands of their families. These demands play an important role in their daily activities. These reflect the child node “family demands” from the interview.

### **Parent Node: Impact on Human Occupation**

Participants continued to engage in daily activities. All five participants were able to complete basic self-care, including the SMP. They were also able to participate in instrumental activities of daily living. One participant was still able to take care of her grandson. Another participant was still able to take care of her children and husband. Two were still able to spend time in the garden. Another participant was able to move into a new home during the first 2 weeks of the study. They all stated that they might be slower in completing these activities due to the swelling. However, other conditions such as pain and neuropathy have a greater impact on their function and participation in daily occupations than lymphedema. These are consistent with the NMUs that were identified

in the interview that reflected the child nodes “effect on function,” “return to occupation,” and “roles.”

### **Parent Node: Perception of Occupational Therapy**

Participants shared that they found occupational therapy helpful in the management of lymphedema, which was consistent with the statements shared during the interview. Statements such as “It [occupational therapy] is helping me be more independent,” “very fine,” and “She [occupational therapist] is very thorough.” They reported that they were satisfied with the occupational therapy program during each weekly discussion sessions. The participants also shared that the therapists were able to provide the instructions for the SMP and explain the nature of lymphedema clearly. The therapists were able to help them understand lymphedema through simple and clear instructions. These reflect the child nodes “perception of the occupational therapist,” “communication,” and “effect of occupational therapy.” The therapists are able to communicate the information needed by the participants. Knowledge of lymphedema and SMP support the daily performance of SMP, as discussed in the following parent nodes. The positive effect of occupational therapy on lymphedema was also reflected in the interview and the weekly discussion sessions.

### **Parent Node: Perception of SMP**

Statements that refer to the time to perform the SMP and availability of the proper compression garment are NMUs that were identified in the interview. These NMUs reflected the child node “resource management.” Similar statements were also shared during the weekly discussions. The time it takes to complete the SMP is an important

issue during the weekly discussions. SMPs that only take up a short amount of time is easier for them to adhere to. Two participants stated that the SMP only takes 10 minutes to complete, which fits in their schedule. One participant stated, “I still need to be out and about” when she described the amount of time it takes her to perform all of the components of the SMP. Another participant asked her occupational therapist for a shorter SMP. She stated that the shorter SMP was only 10 minutes and was “doable.” Participants also schedule the SMP according to their daily activities. One participant stated that she wears the sleeve during the day because she does not have time to do the entire SMP in the morning. She needs to take her kids to school. She has more time to complete the entire program at night. On the other hand, another participant completes the SMP in the morning as soon as she gets up because she knows she will forget about it as she goes about her day.

The availability of the compression garment or compression alternative was also brought up. Participants were able to wear the compression garment or apply the compression bandages every day. One participant used a Circaid ReadyWrap, which is an alternative form of compression. Another participant wore the Solaris Tribute at night, which is an alternative to compression bandaging. Participants also complained that the compression bandaging limits their movement. However, they continue to wear it because they feel that it helps keep the swelling down. One participant described it as a soft cast and stated, “it slows me up.” Two participants complained that the bandages make the arm feel hot. Another participant was looking for a device to make donning easier.



The child node “SMP components” was also reflected in the weekly discussions as the participants talked about the components of the SMP that they were able to do during the week. The participants find the self-administered manual lymphatic drainage massage more difficult to perform. Two participants use a pneumatic compression pump instead of the massage. Participants also perform stretching exercises, which are also meant to address their flexibility. One participant also does deep breathing exercises as part of her home exercise program.

#### **Parent Node: Negative Factors**

Pain was brought up several times during the weekly discussions. The statements that reflect this child node are similar to those shared during the interview. Pain limited their range of motion, which also limited their ability to perform the SMP. Pain is caused by shoulder fracture or shoulder stiffness from another condition. One participant stated that she has pain due to the heaviness of the swollen arm. One participant stated that the neuropathy in her hands makes it difficult to don the compression sleeve, although she still manages to wear it every day. Two of the participants stated that they did not feel well for a few days during the four-week intervention period. However, both participants were still able to wear the compression sleeves every day. Only one participant was still able to perform the self-administered manual lymphatic drainage massage while she was sick.

#### **Parent Node: Support for SMP**

The child node “understanding of the condition” was shared by two participants. One participant stated that she is familiar with lymphedema after being in occupational

therapy. Another participant expressed that the occupational therapist provided her with illustrations so that she can understand the importance of the massage to facilitate the flow of lymph fluid. This child node was also identified in the interview.

The child node “outside support” was also shared by the participants during the weekly discussions. Outside support was described as having someone to remind them to perform the SMP. One participant considered her doctor as her support. She stated that “If I get discharged from [occupational therapy] and it comes back, I can always contact the doctor” and considers the collaborating institute as her “safety net.” These are similar to the NMUs that reflected the child node during the interview.

The child node “observation of improvement” was often brought up during the weekly discussions as well as during the interview. Statements include “I see the difference [in the size of the arm],” “My arm is getting better with therapy,” “I am doing very well and I do not have much swelling,” “I feel it is improving,” “There is less swelling and my arm feels better, which is the proof of the importance [of SMP],” and “I think what I did for now helped, that’s why my arm is smaller.” The participants felt that the occupational therapy and the SMP have led to the improvement in their arm, which was the reason for the performance of the SMP. Their observations of improvement include a visible decrease in size, the arm feels less heavy, improved flexibility, and improved use of the affected arm. Three participants stated that they know the arm is getting better based on the actions of the therapists. Two participants stated that the occupational therapist did not include the grey foam layer during the second and third weeks. The occupational therapist used the grey foam layer if the swelling is severe.

These three participants also transitioned from serial compression bandaging to a compression sleeve. They stated that the occupational therapist explained that they can be transitioned to a compression sleeve when the girth reduces to a certain size. However, the participants were unable to recall the targeted girth measurement.

### **Integration of the Results of the Concurrent Quantitative and Qualitative Studies**

#### **The Remotivation Process and VQ**

The study explored the use of the Remotivation Process to facilitate the volitional process in the participants as they received occupational therapy intervention. The quantitative analysis showed a statistically significant increase in the VQ scores of the participants after the study. However, qualitative analysis found that the participants moved forward in their position on the volitional continuum through the use of the volitional questionnaire. The following presents how each participant moved through the continuum during the 4-week period. The PI used the guide questions and strategies based on the Remotivation Process (see Appendix F) to facilitate the participants's forward progression on the VQ.

**Participant 1.** Figure 7 shows Participant 1's progression through the VQ. Participant 1 explored new ways to manage lymphedema, meaning she was trying new things. She says she understood the value of occupational therapy, which shows that the activity is significant for her. She also expressed preferences for a shorter or abbreviated version of the SMP to fit her schedule. The PI used the guide questions for the exploration stage during the discussion. The PI facilitated self-reflection by asking the participant her thoughts regarding the SMP, reasons that she finds the SMP difficult to

perform every day, and factors that may help her do the SMP every day. The PI provided an explanation of BCRL and CDT and validated her concerns. The PI also provided validation of the participant's efforts, even when she had stated that she did not perform all the components of the SMP and that she also skipped some steps of the lymphatic massage that she was supposed to do. The PI also encouraged her to clarify with her occupational therapist and ask for more information regarding the SMP. She appeared to be between the competency and achievement stage during the second week.

Participant 1 stated she keeps doing what she has been doing, showing that she remained engaged. However, she was still trying between an SMP with the full MLD sequence and another SMP with an abbreviated sequence. She also tried to solve the problem of stiffness in the arm by trying the elliptical. The participant stated that she clarified the instructions with her occupational therapist, who said that she can choose to perform the abbreviated version of the SMP. The PI helped her reflect on her daily activities to identify the possible changes she can do to perform all of the components of her SMP. She seemed to be in the achievement stage during the third week since she was able to pursue the program to completion. The PI asked her how she feels about the SMP during the past week. The participant stated that she feels that she has mastered the routine. She seemed to be at the achievement stage during the fourth week. She continued to pursue the activity to completion even when she and her family went on vacation. She also pursued the SMP even through the pain and fatigue. Although she has not sought challenges yet, she stated that she felt ready to take on new treatments for ovarian cancer. The PI provided validation of her efforts during the conversation.

Wk1														
Wk2														
Wk3														
Wk4														
	Shows Curiosity	Initiates Action	Tries new things	Shows Preference	Shows activity is significant	Indicates Goals	Stays Engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenges
	Exploration					Competency					Achievement			

Figure 7. Volitional Questionnaire of Participant 1

**Participant 2.** Figure 8 shows Participant 2's progression through the VQ. The participant started at the exploration stage. She was having difficulty with the SMP as she was in the middle of moving to a new home during the first week. She also received new information from her occupational therapist regarding BCRL and the importance of the SMP. The PI facilitated the conversation by asking for the participant's thoughts regarding the SMP. The conversation also discussed the possible challenges that she will encounter the following week as she tries to balance moving to a new house and the SMP. The PI validated the participant's effort to try and do what she can do during the following week. The PI also helped the participant understand the value of SMP by explaining the different stages of lymphedema. The PI explained that the SMP will help prevent the progression of BCRL.

The participant seemed to show some characteristics of the competence stage during the second week since she showed that the SMP is significant and solves problems by asking for assistance. She stated that the information regarding the stages of lymphedema helped her understand the value of the SMP. She stated that she was able to wear the sleeve every day, during the day and takes it off at night. Her partner helped her perform the MLD every day. She does the exercise program every other day. She was

able to wear the sleeve, but she needed some assistance to adjust the sleeve. She sometimes needed help to don the sleeve. She also shared that the sleeve initially felt weird but now she is starting to get used to it. The PI once again validated her efforts to perform one or more of the components of the SMP. The PI also encouraged her to continue with the SMP by highlighting the availability of her partner as a support for the SMP. She seemed to be in the competence stage during the third week. She was not feeling well and thinks she is still adjusting to the new home. The PI once again validated her efforts and provided encouragement during this setback.

The participant seemed to show characteristics of the achievement stage during the fourth week. The PI asked if she was satisfied with the SMP and if she feels that she is ready to manage BCRL on her own even without the presence of the therapists or the PI. She stated that she is satisfied with the SMP. She performs the SMP because she feels the effects if she does not do the massage or wear the sleeve. She feels the heaviness when she does not do the SMP. She also stated that the SMP fits her current routine because she does not work at the moment. She will be able to continue with SMP every day even after she returns to work because the SMP is easy and only takes 10 minutes.

Wk1														
Wk2														
Wk3														
Wk4														
	Shows Curiosity	Initiates Action	Tries new things	Shows Preference	Shows activity is significant	Indicates Goals	Stays Engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenges
	Exploration					Competency					Achievement			

Figure 8. Volitional Questionnaire of Participant 2

**Participant 3.** Figure 9 shows Participant 3's progression through the VQ. The participant seems to be in the exploratory phase during the first week. She only wore the sleeve, which is one component of the SMP that she initiates. The PI still validated her efforts, even if she did not perform the lymphatic massage and exercises. She goes to occupational therapy even if she does not understand what it is for, showing that she shows curiosity. The PI attempted to provide her with a detailed explanation of BCRL and SMP. The participant stated that she will continue to try to do the SMP.

She still seemed to be in the exploration phase during the second week. She initiates actions, performing two components of the SMP. She stated that she was satisfied with the activity but does not do it every day. It shows that the activity is significant. The PI once again validated her effort and asked which components of the SMP can be changed so that she can perform all of it. The participant stated that she is satisfied with the SMP and will continue to try the following week. She was still in the exploration phase, moving towards competence during the third week. She is still trying to adjust to the condition, hoping that it will go away. However, the activity seemed significant for her as she expressed satisfaction with the therapists and the home program. She stays engaged and performs half of the components of her SMP. She seemed to progress to the competence stage during the fourth week. She was externally motivated and feels that she needs to do it because she is instructed to do it. She does not quite understand why she needs to do the SMP at the end of the study. The PI provided encouragement and validation during these weeks.

Wk1															
Wk2															
Wk3															
Wk4															
	Shows Curiosity	Initiates Action	Tries new things	Shows Preference	Shows activity is significant	Indicates Goals	Stays Engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenges	
	Exploration					Competency					Achievement				

Figure 9. Volitional Questionnaire of Participant 3

**Participant 5.** Figure 10 shows Participant 5's progression through the VQ. The participant seemed to be in the exploration stage during the first week. She shows curiosity, she initiates actions related to the SMP, shows preferences in the type of compression. She showed that the activity is significant even though the SMP took time. The PI validated her efforts to perform one or more components of the SMP. The PI and participant discussed the possible reasons for not doing all the components of the SMP. The participant expressed that pain limits her participation in the SMP, which she then said that she will address this pain with her physical therapist. The PI and participant also discussed the importance of the SMP to further encourage her for the following week. She seemed to progress to the competence stage during the second week as the participant indicated her goal when asked by the PI. She wanted the arm to reduce in size so she can wear a sleeve instead of the bandages. The PI once again validated her efforts and encouraged her to keep doing the SMP so that she achieves her goal.

She stayed in the competence stage and kept working on her goal during the third and fourth weeks. She wanted the arm to reduce in size so she can wear a sleeve instead of the bandages. Once again the PI validated her efforts and encouraged her to continue. The participant experienced a set back since the girth of her arm did not change this



week. The PI encouraged her during this setback. The PI and participant discussed the SMP once again to identify the challenges she encountered when she tried to perform the SMP. The participant stated that she still has pain, which is another setback. The PI again encouraged her and facilitated a discussion about her challenges in performing the SMP. The participant identified that pain is the main issue that affected her performance of the SMP. The PI and participant identified that pain reduction can be a goal during her physical therapy sessions.

Wk1														
Wk2														
Wk3														
Wk4														
	Shows Curiosity	Initiates Action	Tries new things	Shows Preference	Shows activity is significant	Indicates Goals	Stays Engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenges
	Exploration					Competency					Achievement			

Figure 10. Volitional Questionnaire of Participant 5

**Participant 6.** Figure 11 shows Participant 6's progression through the VQ. The participant seemed to be in the exploration stage during the first week. She shows curiosity, she initiates actions related to the SMP, shows preferences in compression. Even though the SMP took time, she showed that the activity is significant. The PI facilitated the discussion by asking for the participant's thoughts regarding SMP. The participant stated that the thickness of the compression bandaging hinders the use of the arm. The PI provided her with information regarding compression alternatives and encouraged her to continue with the compression. The PI also shared more information regarding the importance of compression as well as performing deep breathing exercises.

The participant stayed engaged during the second week. She continued to ask questions regarding assistive devices to help her don and doff the compression sleeve. She stated that she prefers to wear the compression sleeve but could not do so due to shoulder pain. This is still characteristic of the explorations stage. However, she also indicated her goal during the second week, which is characteristic of the competence stage. She wanted the arm to reduce in size and lose weight. She expressed frustration over her shoulder pain. The PI and participant discussed the challenges she encountered when performing the SMP. Similar to Participant 5, Participant 6 identified shoulder pain as the main reason for not being able to perform the SMP. The PI encouraged her during this setback. The PI and participant also discussed possible solutions to address her pain. The participant stated that she will be speaking with her orthopedic doctor.

She continued to show characteristics of the stage during the third and fourth week as she stayed engaged even through the busy week. She tries to solve problems by continuing to look for better donning aid for the compression sleeve. She also pursued the activity to completion since she performs the SMP every day despite the time and effort involved along with the pain in her right shoulder.

Wk1														
Wk2														
Wk3														
Wk4														
	Shows Curiosity	Initiates Action	Tries new things	Shows Preference	Shows activity is significant	Indicates Goals	Stays Engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenges
	Exploration					Competency					Achievement			

Figure 11. Volitional Questionnaire of Participant 6

**Participant 7.** Figure 12 shows Participant 7's progression through the VQ. The participant seemed to show characteristics of the achievement stage during the first week. She pursues the activity through completion. She said that she always applies the bandages, even when she is out of town. She does the exercises every morning. She tries to solve problems and invested additional energy by looking for alternative compression garments herself, which is how she got the Circaid Ready Wrap Velcro compression system in place of the compression bandages. She said this made compression easier to don and doff. She has been doing this home program for 15 years. She has yet to call the representative of the DME company to recalibrate her pneumatic compression pump. She continued with her SMP and showed characteristics of the achievement stage during the remainder of the study.

The participant stayed engaged even though she was not feeling well during the second week. She pursued the activity through completion even though she was light-headed. She tried to solve the problem of feeling ill when she stood up by completing the SMP while seated or sitting up in bed. She invested additional energy by participating in the discussion. The PI kept providing encouragement and validation during these weeks. The participant seemed proud of her experience and knowledge of BCRL and SMP since she has been dealing with the swelling for several years. The PI focused on the participant's thoughts and feelings about being discharged from occupational therapy to encourage the participant to reflect on her readiness. The participant stated that she feels comfortable managing BCRL on her own during the discussion sessions.

Wk1															
Wk2															
Wk3															
Wk4															
	Shows Curiosity	Initiates Action	Tries new things	Shows Preference	Shows activity is significant	Indicates Goals	Stays Engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenges	
	Exploration					Competency					Achievement				

Figure 12. Volitional Questionnaire of Participant 7

The study showed that there was a statistically significant improvement in the participants' placement on the VQ. The improvement is seen as the progression from the exploration stage to the next stage, which is competency then achievement. The improvement in the VQ scores may reflect an improved motivation to perform the SMP. As discussed in the literature review, the motivation to perform the SMP is important since research has found that women who do not continue to perform the SMP after lymphedema therapy experience a reoccurrence of the condition (Lashinski et al., 2012; Loh & Musa, 2015). The participants in the study expressed behaviors toward the SMP that seem to show that SMP is significant. The participants stayed engaged and completed the components of the SMP as much as they can despite the challenges. The Remotivation Process and VQ enabled the PI to articulate the self-reported behaviors of the participants in a language within the volitional continuum. The study also allowed the PI to relate the terms used in the volitional continuum to the behaviors and actions involved in the management of BCRL. Furthermore, the effectiveness of the Remotivation Process on SMP and lymphedema has not been conducted. The results of

the quantitative data and the statements from the qualitative data analysis will be combined to explore the effect of the Remotivation Process.

### **Integration of the Qualitative and Quantitative Findings of Research Question 1**

Quantitative RQ 1: How does the Remotivation Process, as an occupational therapy intervention, change the daily performance of the lymphedema management techniques?

Result: The use of the Remotivation Process did not elicit a statistically significant increase in the daily performance of the SMP.

Qualitative RQ 1: What are the perspectives of patients with BCRL about the self-management program after participating in an occupational therapy program using the Remotivation Process?

Statement: The SMP is effective in addressing lymphedema. The perceived improvement, environmental support, and better understanding of the situation motivated them to perform the SMP daily.

Participants reported that they wear the compression sleeve or compression bandages every day, although the increase in the frequency of performing the SMP was not statistically significant. This may be due to the inconsistent performance of the remaining components of the SMP, which are the exercise program and the self-administered lymphatic massage. Participants reported that they only perform the massage and exercise three to five times a week. The participants reported that it was cumbersome and time-consuming to perform all of the components of the SMP. Time seemed to be an important resource that allows the consistent performance of the SMP. Participants sometimes have multiple medical appointments and responsibilities that take

time away from the SMP. Other factors that make it difficult to perform the SMP include challenges such as depression, difficulty performing the SMP with only the unaffected arm, lack of information, pain, other conditions such as neuropathy, and lack of external support. However, the participants also reported that they have observed that the SMP makes their arm feels better. They also experience an increase in the symptoms of BCRL, such as heaviness and swelling, when they do not perform the SMP. Their observation of improvement when performing the SMP and the experience of the negative consequences when they do not do the SMP seems to motivate them to make the decision to find the time to perform components of the SMP every day.

Factors that seem to positively affect the daily performance of the SMP include the attitude of the participant, perception of the SMP, effect on occupation, perceived improvement, and family dynamics. The participants' attitudes included their individual perception of the situation and ownership of one's recovery. For example, one participant considered the situation as a blessing from God to make her stronger while another participant stated that she would like the situation to go away. In terms of ownership, one participant says that it is her responsibility to make her arm better, while another indicated that she relies on her occupational therapist to make the swelling go away. Perception of the SMP includes the ease of following the steps, the time it takes to complete the SMP, and their perception if the SMP makes the arm feel better. These factors motivated them to perform the SMP every day.

The participants also expressed that the weekly discussions using the Remotivation Process help them “keep on track” and be mindful of their decision to

perform the components of the SMP. The patient education provided by the occupational therapist allowed them to understand lymphedema, which also facilitated adherence to SMP in addition to the improvements that they have observed. An understanding of the condition, which also includes knowledge of the condition, facilitates the performance of SMP. Breast cancer and breast cancer treatment cause other conditions and side effects such as pain and neuropathy. The relief of these symptoms also facilitates the performance of the SMP. Spirituality, such as faith in God, also facilitates adherence despite the challenges. Outside support, such as family, medical professionals, and therapists, also facilitate improvement. External feedback and reminders from others help them perform the SMP daily. The participants perceived the occupational therapy program as helpful. They have observed that the therapists revise their treatment according to their needs. The Remotivation Process helped them think about their adherence to the SMP. The participants showed motivation to engage in the SMP although the frequency of performing the SMP in a 7-day period did not show statistically significant change. Motivation is manifested as a commitment to recovery, making the decision to perform the SMP, faith or spirituality, hopefulness, optimism, being realistic, resilience, and self-advocacy.

### **Integration of the Qualitative and Quantitative Findings of Research Question 2**

Quantitative RQ 2: How does the Remotivation Process affect the client's manifestation of BCRL?

Result: There was a significant decrease in the size of the affected arm, which indicates a decrease in swelling.

Qualitative RQ 2: What are the perspectives of patients with BCRL about physical appearance in their arm after the occupational therapy program?

Statement: The physical manifestation of lymphedema seems to improve but it still affects participation in occupation.

There was a significant decrease in girth in the measurement points of the affected arm after the intervention. The therapists measured the participants' arms during the session and make the necessary revisions to the occupational therapy plan when needed. Aside from the objective measurements, the participants also expressed that they have observed an improvement in their symptoms. According to the participants, they have observed improvement in the affected arm by regularly performing the SMP. They stated that "It [arm] feels better," or "It [SMP] works, so I do." Participants also stated that "I have no choice but to do it," or "there's nothing else I can do, it [lymphedema] will just get worse if I don't," which indicates that the participants are aware of the negative consequences if they do not perform the SMP. These observations motivated them to perform the SMP every day since they believe that it makes the affected arm feel better. The participants also expressed that they found the occupational therapy program at the collaborating facility very helpful in the management of BCRL. The therapists helped them understand the chronic nature of BCRL, provided them with the necessary treatment, and gave them the means to manage the lymphedema.

### **Integration of the Qualitative and Quantitative Findings of Research Question 3**

Quantitative RQ 3: How does the Remotivation Process affect the client's occupational participation and quality of life?



Result: The use of the Remotivation Process did not elicit a statistically significant increase in the LyQOLI, which was used to measure the quality of life. There was a statistically significant increase in the MOHOST scores, which was used to measure occupational participation.

Qualitative RQ 3: How do patients with BCRL describe their daily life after occupational therapy?

Statement: Lymphedema still affects their daily life, but the occupational therapy program has helped them gain a better understanding of the situation, become aware of what can they do to manage lymphedema, and serve as a support system as they cope with the breast cancer and its side effects.

The results of the quantitative study seem to indicate that the intervention did not lead to an improvement in QOL. There was a statistically significant improvement in some aspects of occupational participation. However, an improvement in both QOL and occupational participation have been reflected in the expressions of the participants in the study as they expressed observation of improvement in their symptoms, function, and occupational participation. The quantitative analysis may not show a significant change in QOL. However, the sample size may be too small to show statistically credible results. The verbalizations and perceptions of the participants during the discussions and interviews seem to show that participation and QOL improve as the manifestation of BCRL improves. Also, the insignificant change in scores may reflect that the participants did not let BCRL hinder their participation in daily activities and roles.

The quantitative analysis showed a statistically significant increase in MOHOST scores, which measured occupational performance. Lymphedema affects participation in occupation, especially being able to return to work and perform activities related to their role as a wife, mother, grandmother, and sister. For example, one participant stated that she needs to ask help from her husband or children when she needs to load and unload groceries in the car. Another participant was in the middle of moving to another house. Lymphedema made task performance slower than usual since the affected arm “gets tired easily,” and she needed needs to take a break. However, the participants still try to do what they can despite the change in their abilities. It seems that the value of their roles and the improvement of symptoms motivated the participants to stay engaged in occupations.

Lymphedema has affected the family since the participants need help from their family members to either perform the occupations or the components of the SMP. However, the participants stated that their family members or partners are willing to help when needed. The presence of environmental support, which includes the helpfulness of the family and significant others, facilitate the performance of SMP and occupational performance.

## CHAPTER V

### DISCUSSION

This study aimed to address the significance of adherence by a client population of women with cancer-related lymphedema. The study used the Remotivation Process from the MOHO practice model as a motivational strategy to facilitate the identification of the participants' priorities and routines and to help them transition from a stage of exploration to competence and ultimately to achievement.

#### **Relationship to Theory: Translating the Parent Node/Category (Central Theme) from the Qualitative Study into MOHO Concepts**

The MOHO practice framework guided this study and the translation of the qualitative findings is the final step in the qualitative analysis. The table below is an attempt to identify the MOHO concepts that closely relate to each node. However, it is difficult to identify a single MOHO concept that relates to each node due to the dynamic nature of the MOHO practice framework. Table 12 highlights the prominent MOHO concepts that can be derived from the description of each node. The five main MOHO concepts that were identified were volition, habituation, environment, performance capacities, and the volitional cycle. These concepts were discussed at length in chapter two; however, a brief review of these concepts is discussed in the following paragraphs.

Table 12

*Translating the Nodes Into MOHO Concepts*

Parent node/Category (Central Theme)	Child node	MOHO Concept		
<b>Participant's Response to BCRL</b>	Attitude of the Participant	Personal causation	Performance capacities: Lived body	<b>Volitional Cycle</b>
	Adaptations	Performance capacities: Lived body		
	Individuality	Performance capacities: Lived body		
	Ownership	Personal causation	Performance capacities: Lived body	
	Expressions of emotions		Performance capacities: Lived body	
<b>Family's Response to BCRL</b>	Effect on Family	Environment: social	Roles	
	Family Coping	Environment: social	Roles	
	Family Demands	Environment: social	Roles	
<b>Volition</b>	Motivation	Volition		
	Commitment to recovery	Volition		
	Decision	Volition		
	Faith	Value	Environment: social	
	Optimism	Personal causation		
	Realistic	Personal causation		
	Resilience	Personal causation		
	Self-advocacy	Personal causation	Environment: social	
<b>Negative Factors</b>	Challenges	Environment: Physical & Occupational	Objective performance capacities & Lived body	
	Lack of information or understanding	Performance capacities: mental capacities and lived body	Environment: Occupational	
	Limitation	Performance capacities: physical capacities and lived body		
	Unmet Expectation	Performance capacities: physical capacities and lived body	Environment: Occupational	Personal Causation

Parent node/Category (Central Theme)	Child node	MOHO Concept			
Impact on Human Occupation					Volitional Cycle
	Effect on function	Lived body			
	Return to occupation	Volition	Roles		
	Roles	Value	Roles		
Perception of SMP					
	SMP Participation	Environment: Occupational	Volition	Habituation	
	SMP components	Environment: Physical	Volition	Habituation	
Perception of Occupational Therapy	Resource Management	Environment: Occupational	Volition	Habituation	
	Perception of the therapist	Environment: Occupational			
	Communication	Environment: Occupational			
	Effect of RP	Environment: Social and Occupational			
	Effect of therapy	Environment: Social and Occupational			
	Treatment site	Environment: Physical			
Support for SMP					
	Observation of improvement	Lived body	Personal Causation		
	Outside support	Environment: Social and Occupational			
	Spiritual	Environment: Occupational	Value		
	Symptom Relief	Lived body			
	Understanding of the condition	Performance capacities: mental capacities and lived body	Personal Causation		

*Note:* MOHO concepts in **red** pertain to Volition, **orange** pertain to habituation, **green** pertain to the Environment, **blue** pertain to Performance Capacities, and **purple** represents the volitional cycle.

Volition provides the motivation to act. It is further divided into (1) personal causation, which is the person's awareness of what she can do and the effectiveness of her actions, (2) valued goals, which gives a unique meaning to occupation; and (3) interest, which directs occupation toward a productive and satisfying end (Lee & Kielhofner, 2017; Taylor, 2017). The qualitative analysis highlighted value and personal causation. Values reflect the person's conviction and sense of obligation and define what is important for the person to do and the perceived “right way” to act. A person's values may be a source of disappointment if she is unable to perform according to her beliefs and contextual demands (Lee & Kielhofner, 2017; Taylor, 2017).

Personal causation refers to a person's sense of capacity and efficacy. Sense of capacity is the person's awareness of her capabilities. Self-efficacy allows the person to determine if her efforts are sufficient to accomplish her goals. Personal causation influences volition, which is also the motivation for occupation. It makes the person aware of her ability or inability to control herself and her surroundings (Lee & Kielhofner, 2017; Taylor, 2017). The awareness of limitations can lead to denial and avoidance, which may be an effort to protect oneself from psychological pain when limitations are acknowledged (Kielhofner, 2008). Habituation is a consequence of repeating patterns of behavior, influenced by a person's perceived roles and the environment. Roles pertain to the person's pattern of action, shaped by her perceived social status or identity.

Performance capacity includes the objective performance capacity, or the person's physical and mental capabilities, and the lived body, which are the subjective thoughts

and feelings she experiences as she uses these capabilities to perform an action. The interplay between the person's objective ability to perform a task and her subjective experience of the performance has a significant effect on volition patterns (Yamada et al., 2017).

The environment is the physical, social, and occupational dimensions that surround the person as she engages in occupations. Each dimension provides environmental components that either support or hinder occupational performance. The environment influences the person's motivation, patterns of behavior, capacities acquired, and her subjective experience when she uses these capacities. The environment provides opportunities to perform, support, demand for action, as well as barriers to performance (Fisher et al., 2017).

The definitions of these MOHO concepts will be used to compare the parent and child nodes in the discussion. The node "Participants' response to BCRL" reflects volition and the lived body. This node discussed the participants' experience of BCRL and how they responded to the change in their body. Examples of NMUs that reflect the lived body are "Well, I have my good and my bad days. I don't want to say it feels better. I feel more comfortable than I did before" and "It's just kind of depressing when you're sick, you really can't do nothing because you're sick." The participants experienced pain and discomfort in the affected arm. The swelling also limited the clothing that they can wear. Their subjective experiences of these changes within their bodies were expressed through emotions such as depression and frustration. Participants also expressed that managing BCRL depends on the person and the person's situation. An example of this

sentiment was that “ it [BCRL] is an individual thing”. Personal causation was seen in the participants' statements that they continue to perform the SMP because they see the benefit. The awareness of the benefits shows them that they can do something to effectively manage BCRL. Their condition fluctuates from day to day, and they need to decide what to do based on how they feel and what they need to do that day. The decisions that they make reflect personal causation since they need to evaluate if they have the capability to perform the activity effectively.

The node “Family’s responses to BCRL” reflects the participant's social environment. The social environment includes relationships with the family. The node included environmental qualities such as the availability of people and relationships, emotional support, and empowerment. All participants expressed that BCRL and cancer have affected their families or participation in family activities. They have had to ask for assistance from family on at least one occasion, e.g., to drive them to the collaborating institute for treatment. The family provides support as they cope with the participants’ condition. The participants expressed that they can perform SMP and go through the cancer treatments due to the support of the family. Their family and significant others are flexible since their lymphedema and overall disposition can vary from day to day. This shows the availability of support from the family who were able to share roles. For example, participant 1 can still maintain her role as a mother through activities such as grocery shopping. However, her children needed to help her carry heavy items. Family members, such as the spouse, assumed the role of a caregiver since the participant needed assistance to perform some steps of the lymphatic massage. Participants still try their



best to engage in activities as much as they can. The participants are still able to meet the demands of the family, but they share their limitations with their family. This shows that the support from the social environment empowers them to achieve their goal of meeting the demands of the family. An example of this came from participant 1 who said, “I am not 100% as before”. She shared that she was able to travel with her family and participate in outdoor activities. However, she told her husband that she can travel but she will need help carrying her luggage because “my arm is not the same as before”.

The node “Volition” reflected the drive that keeps the participants moving forward with their daily lives despite the challenges due to cancer and BCRL. The participants noticed that the arm decreases in girth when they perform the SMP. The observation of improvement, as mentioned earlier, shows the participants that they are capable of doing something to effectively manage BCRL. It seems to foster optimism and resilience, which is the ability to respond and adapt to changes (O’Brien & Kielhofner, 2017). This reflects personal causation. The performance of the SMP is a decision that participants make every day. They acknowledged that the SMP is time-consuming and cumbersome. However, they decide to make time for it. NMUs that strongly expressed this child node include, “We are all busy, we have stuff to do. But you have to find time. I find time to do it. No excuse.” “[I] decide to go on day by day about it and decide what to do. Right now, I can do exercises. But the massage we have not really been doing,” “I deal with what I have to deal with,” “I decide to go on day by day about it,” and “So we just keep on keeping on.” The awareness of the effect of the SMP makes the performance valuable, which motivated the participants to continue with

the SMP. Being realistic also reflects personal causation. The participants recognized the limitations in what they can do, which shows the awareness of their capabilities. Faith in a higher power reflects the participants' values. The environment is also involved in this node. The awareness of their limitations leads them to seek assistance or support when needed, which is a form of self-advocacy. Self-advocacy is the quality of the social environment. Faith in a higher power reflects the cultural aspects of the occupational environment.

The negative factors that affect the daily performance of BCRL reflected the MOHO concepts of the performance component, environment, and personal causation. The challenges included the time it takes to drive to the collaborating institute, which then takes away the time they have to perform the SMP. This reflects the accessibility of the physical environment. The lack of time reflects the time element, which is a component of the occupational environment. The performance of the components can be challenging. For example, applying the compression bandages was also challenging since this has to be done with one hand. NMUs that support this include, “If I'm home alone the challenges wrapping my arms but I still can do it just takes a little while.” And “It's just kind of depressing when you're sick you really can't do nothing because you're sick.” These challenging experiences reflect the lived body since the participants described their feelings toward the perception of their performance of the SMP.

The lack of information about BCRL and SMP reflects the participant's mental capacities and their awareness of their lack of knowledge reflects the lived body. It also reflects the match between the steps involved in the SMP with their cognitive and

physical capabilities, which are components of the occupational environment.

Limitations such as pain, fatigue, and lack of strength reflect the physical capacities of the participant. These limitations lead to feelings of frustration and depression, which were the lived body experiences described earlier. Unmet expectations reflect the participants' expectations of themselves when it comes to their own performance, instead of the expectations of others. For example, one participant stated that the arm is not as small in girth as she expected it to be. Two participants were also discouraged when they are severely limited by shoulder pain. These reflect the lived body experience. It also reflects the MOHO concept of personal causation. The participants assess their capabilities to perform their daily activities, including the SMP. Another MOHO concept reflected in unmet expectations is the occupational environment. The participant stated, “What was challenging was wondering why having to wear that sleeve and the glove kind of thing” when she feels that the arm is “not quite down as it should be”. This reflects the appeal of the activity since the participant questioned the value of the SMP. The appeal of the occupation/activity is a component of the occupational environment.

The node “Impact on human occupation” reflected the concepts of volition and the lived body. The lived body is seen in the child node “effect on function.” Participants experienced a decrease in the strength of their affected arm. They are affected by the pain, stiffness, and pulling sensation due to lymphedema and pain. The volition components of personal causation and value are seen in the participants' effort to engage in valued occupations and roles. The volitional components provide the motivation needed to re-establish valued roles or form new roles. Participants expressed

that they try to do as much as they can despite the BCRL and having to make time for SMP. They can complete basic self-care and expressed that the BCRL does not affect the basic activities of daily living. They expressed their desire to be able to work again and maintain the role of a mother or caregiver.

The node “perception of SMP” reflect the physical and occupational environment. The availability of compression garments reflects the availability of objects, which is a component of the physical environment. Time is a valuable resource to perform the SMP. The time element is a component of the occupational environment. The daily performance of the SMP requires the ability to establish and maintain new habits and routines. The participants made the choice to make time to perform the SMP because they see the value of the SMP and the positive impact on the swelling and function. The formation of a habit is strongly influenced by one’s volition to develop these new behaviors. However, the study cannot establish if the SMP became a habit at this time due to the short duration. The node seems to also reflect volition as the person evaluates her ability to follow the steps involved in the SMP. The availability of resources and supports can also affect the participants’ perception if she can effectively perform the SMP. Emotions such as feeling overwhelmed were shared during the discussions. The participants needed to make time for the SMP, other responsibilities, and multiple medical appointments. This reflects personal causation since the participants need to evaluate if they have the time or energy to do all of the responsibilities she has to fulfill.

The node “Perception of occupational therapy” reflects the environment. MOHO states that the occupational environment includes health care and occupational therapy

services (Fisher et al., 2017). The occupational therapists who provided customary lymphedema therapy services and the PI who provided the Remotivation Process are part of the social environment as well. They are the people who empowered the participants and gave them encouragement for goal-achievement, which is a component of the social environment.

The node “Support for SMP” reflects the MOHO concepts of the lived body, the environment, and volition. The observation of improvement and relief of symptoms are experiences expressed by the participants and reflects both objective capacities and the lived body. The improvement that the participants observed motivated them to continue with the SMP, which reflects the concept of volition. The understanding of the condition allowed the participants to be more knowledgeable in BCRL. The participants were able to understand their individual experiences of BCRL and SMP. Outside support includes medical professionals and family members. These reflect the availability of people and relationships, emotional support, and empowerment provided by the social and occupational environment.

The participant’s description in each of the nodes reflected the volitional cycle. MOHO forwards the concept of the volitional cycle, where the person experiences the present and interprets it according to experience. This leads to anticipation for the future. The person makes activity and occupational choices based on her anticipation. A person makes these choices based on her appraisal of her action or behavior, personal convictions, sense of obligation, and interest (de las Heras de Pablo et al., 2017; Lee & Kielhofner, 2017; Pepin, 2017; Taylor, 2017).

It is difficult to identify which of parent or child nodes pertain to the experience, interpretation, anticipation, and making choices aspects of the volitional cycle. The volitional cycle is embedded in the parent/child nodes since each node involves the participant goes through the dynamic process when she responds to the effects of BCRL, performs the SMP, engages in occupations, interacts with her family, and receives occupational therapy services. The following paragraph discusses the volitional cycle and its involvement in the daily performance of the SMP.

The participants in the study experienced a decrease in girth when they perform the SMP. Participants have observed that the SMP makes their arm feel better. They also experienced negative consequences when they do not perform the SMP. They also experience challenges when performing the SMP, which includes the time-consuming process of each SMP component and the effect of pain, decreased strength, fatigue, and loss of range of motion. The experience leads to the participants' interpretation that they have no choice but to perform the SMP every day. The participants experienced the consequences of doing or not doing the SMP and interpret BCRL as a condition that can be managed through the SMP. They were also able to identify the limitations and difficulties when trying to perform the SMP. Through this interpretation, the participants learned what they need to do to successfully perform the SMP. They anticipated that the symptoms of BCRL can vary from day to day so they learn to be flexible and ask help from the family when needed. The anticipation that the symptoms of BCRL improve with SMP gives them hope and optimism, which is an anticipation of a positive outcome. They become more motivated to make choices to continue to perform the SMP every

day. The participants expressed that it is up to them to make time for the SMP and do what needs to be done. They make the choice of not letting BCRL affect them by learning how to adjust to the symptoms and continue to engage in valued occupations.

MOHO defines occupational adaptation as being able to make the changes needed to continue to engage in valued activities or develop new activities. Adaptation is also the ongoing expression of one's occupational identity, which leads to a positive experience of competence within the woman's physical and social environment (de las Heras de Pablo et al., 2017; Taylor, 2017). The volitional cycle is one way a person engages in a change in order to regain her occupational identity and achieve occupational adaptation (Taylor, 2017). In this study, BCRL brought about a change that required adaptation. The participants in the study did not let BCRL control their daily lives. Instead, they learned to adapt to BCRL and make the necessary changes to continue performing the SMP while at the same time continue to participate in valued occupations. Participants also turned to the environment for support when they encounter challenges that they could not control. The observation of improvement seemed to provide the participants with the knowledge that she can control BCRL. The awareness provides a positive experience, which moves the volitional cycle forward. The following section discusses how the Remotivation Process as an intervention affected the volitional cycle.

### **Impact of the Remotivation Process**

The study used the Remotivation Process as an occupational therapy intervention. The PI provided the discussion sessions guided by the Remotivation Process while the treating therapists provided the occupational therapy program customary for BCRL. The

Remotivation Process seems to help move the participants' volitional cycle forward as their position on the VQ changed during the four-week intervention period.

Volition plays an important role in adherence, as was discussed in the previous sections. The Remotivation Process seemed to have a positive effect on the participants' volition during the intervention program. The sessions explored the participants' experience of the SMP, which is a step further from asking if they performed the program or not. The PI used questions to facilitate reflection that focused on the participants' thoughts and feelings regarding the SMP. The PI also used strategies outlined by the Remotivation Process that are intended for each stage of the volitional continuum.

The PI focused on validation and encouragement during the exploration stage. Validation provided a positive experience, which addressed the participants' personal causation. For example, Participant 3 admitted that she only wore the compression sleeve and not the components of her SMP. The PI praised her for her efforts and explained that compression is very important to control the swelling. The validation was meant to provide the participant with a positive experience and make her aware that she has the ability to control the swelling. The PI also encouraged the participants to continue with the SMP for the following week. The encouragement was meant to help the participant feel that she is capable of doing something to control BCRL. The discussions also identified the possible reasons that hindered the daily performance of the SMP. These discussions facilitated the participants' self-assessment of skills relevant to the SMP. It also helped them identify negative factors that they can control and environmental supports to address the factors that they cannot control. The discussion



was meant to help the participants realize that they are capable of addressing the negative factors that hinder their performance of the SMP. The PI provided the participants with information about BCRL and SMP that may not be provided by their treating therapists. The PI also reinforced the information that the participants learned from the therapists. This was meant to help the participant value the SMP and facilitate interest to actively engage in the SMP.

The PI continued to facilitate self-reflection and discussion during the competency stage. The discussions continued to help the participants identify the negative factors that affected the performance of SMP and what they can do to address these factors. The discussions continued to address the participants' personal causation by identifying factors that they can control and support for those that they cannot control. The discussion sessions also became an opportunity for the participants to think through the SMP. For example, Participant 1 had stated that the instructions for the massage may seem simple when she was with her occupational therapist. She will then realize the challenges once she experiences the SMP within the context of her daily life at home. The questions asked by the PI helped her identify aspects of her routine that she can change, or aspects of the SMP that can be altered, or possible support from her family that will help her perform the SMP every day. These discussions further helped the participants realize that they are capable of performing the SMP, which can again have a positive effect on personal causation.

The participants' realization that they are capable seems to facilitate the identification of new goals. For example, Participant 5 identified her goal of being able

to transition to a compression sleeve. She saw the improvement in the size of her arm with the SMP, which helped her realize that the goal can be achieved. This addressed her personal causation since she saw that her efforts led to a positive outcome. The realization of a positive outcome encouraged the participant to continue to perform the SMP, which allowed skills development and the formation of habits. This also helped her see that the SMP is important and kept her interested. She seemed to develop positive anticipation that the arm can reduce in size so she can wear a sleeve. Participant 1 engaged in a valued activity during the study, which was traveling with her family. She felt that the SMP and the occupational therapy sessions at the collaborating institution helped alleviate the swelling and discomfort, which encouraged her to travel again.

These two examples show the progression of the participants along the volitional continuum during the intervention based on the Remotivation Process. The participants also experienced setbacks during the study. For example, Participants 5 and 6 continued to struggle with shoulder pain. The PI focused on validating their efforts to perform the SMP despite the pain. The PI also helped them reflect on the factors that they can control and environmental supports to address those that they cannot. This was meant to help the participants realize that they are still capable of addressing BCRL despite the setback. The PI also encouraged the participants to perform all of the components of the SMP at this stage. This was meant to challenge the participants to give them a positive experience as they attempted to perform the SMP during the following week.

The PI focused on the participants' perception of continuing to perform the SMP without the presence of the PI or therapists during the achievement stage. The discussion

focused on the participants' thoughts and feelings about being discharged from occupational therapy. The participants were not being discharged by their treating therapists, however, the discussion was meant to help the participants reflect on their ability to be fully responsible for the SMP. This attempted to facilitate positive anticipation of the future based on their positive experience during the intervention.

Volition is a woman's thoughts and feelings about herself, which is shaped by experiences, her interpretation of the present situation, and her anticipation of the future as a breast cancer survivor. These thoughts and feelings guide her decision-making process as she adjusts to life after breast cancer and life with BCRL. MOHO states that a person will be motivated to engage in occupations if she feels capable and effective. She realizes her effectiveness through experience and therefore she must engage in occupations that lead to a positive experience and facilitate a sense of control and self-efficacy. It is important for the person to also identify aspects of her life that she is able to control or still successfully perform in order to regain a sense of self-efficacy and a sense of capacity while she adjusts to her condition.

The Remotivation Process provides guidelines for facilitating the forward movement of the volitional cycle. The guidelines were based on each participant's position on the volitional continuum, which was outlined by the VQ. The VQ enabled the PI to document the amount of environmental support, encouragement, and structure needed by the client to exhibit volitional behaviors. The items on the VQ are ordered in a sequence from less to more volition, where a client at the exploration stage will have less volition will need for environmental support, encouragement, or structure to

demonstrate the target behavior than those in the achievement stage. The VQ allowed the PI to formulate questions and responses unique to each participant's placement on the volitional continuum. The questions and responses helped facilitate actively problem-solve around the issues surrounding a person's volitional development.

Participants were provided with an opportunity to reflect on their performance of the SMP. These moments of reflection are necessary when the person confronts difficult occupational choices during the life-changing event of coping with BCRL. The moments of reflection helped them identify the positive experiences to facilitate positive anticipation, which led to the decision to perform the SMP. The moments of reflection also looked into the challenges they experienced when performing the SMP. The PI formulated questions based on the participant's placement on the VQ to help identify which challenging aspects of the SMP can each participant solve independently. The intervention sessions also helped each participant identify environmental supports that can be utilized to address the challenging components of the SMP that are out of their control and cannot be solved independently. The VQ allowed the PI to facilitate a sense of self-efficacy and influence each participant's personal causation through these structured discussion sessions.

The Remotivation Process seems to help the participants focus on a positive experience during the intervention. The guide questions and strategies used by the PI seem to facilitate a positive interpretation of the participants' efforts to perform the SMP. The discussions highlighted the participants' abilities despite the negative experiences and setbacks. The intervention seems to help create positive anticipation of future

challenges, such as being discharged from occupational therapy, creating personal goals, and engaging in valued roles and interests.

The Remotivation Process allowed the PI to identify the motivational needs of the participants, identify the helpful strategies, and use the appropriate discussion questions. The intervention protocol seems to enable the PI to identify the most appropriate strategy to address motivation. The Remotivation Process may be a useful intervention protocol that can be added to an occupational therapy program for BCRL. It can be used to articulate the motivational needs of the person. Some of the strategies outlined in the Remotivation Process manual are already being implemented by therapists.

The treating therapists in this study also contributed to the participant's progression on the volitional continuum despite not being involved in the intervention. For example, the treating therapists provided the participants with information regarding BCRL and SMP as part of patient education during the occupational therapy sessions. Patient education increases the participant's knowledge of BCRL and SMP and provides the skill needed to effectively perform the SMP. These actions have a positive effect on personal causation and volition as a whole. The therapists provided feedback on the effect of the SMP when they measure the participant's arm or when they tailor the SMP base on the participant's needs. For example, Participant 3 stated that the occupational therapist measured her arm and did not use the grey foam during compression bandaging. The participant interpreted the occupational therapist's actions as a sign that her arm was getting smaller. The occupational therapist's actions validated her efforts and encouraged

her to continue with the SMP. The occupational therapist was already applying the strategies outlined by the Remotivation Process. The Remotivation Process as a MOHO intervention protocol can enable the occupational therapy practitioner to select the strategies and questions to effectively structure the patient interaction and facilitate adherence to the SMP.

### **Comparing the Study with Literature Review**

The literature found that those who adhere to all four components of the SMP maintained 90% of their upper limb girth upon discharge and reported a positive effect on QOL and reduced symptoms of BCRL (Loh & Musa, 2015; Lashinski et al., 2012). The awareness of the consequence of non-adherence to SMP increased their decision to perform SMP (Kulesza-Broczyk et al., 2014). Adherence is enhanced when the person with BCRL sees the visible and satisfactory outcome of the SMP (Sander et al., 2012). Women tend to select their own strategies that they believe to be more effective and less time-consuming (Kulesza-Broczyk et al., 2014). Literature has discussed the importance of addressing a women's own needs, desires and abilities to facilitate behavior change needed to adapt to life with BCRL (Berger et al., 2018; Leland et al., 2017). Engagement in self-management that resulted in a positive effect on the person's health and positive feedback from the environment increases self-efficacy, which then led to further engagement in self-management (Carpenter et al., 2019; Chang et al., 2014; Holmes et al., 2014; Lorig & Holman, 2003; Ryan & Sawin, 2009; Trudeau et al., 2015).

The observation of improvement had a significant effect on the study participants' motivation to perform the SMP. The participants in the study adhered to the SMP

because they see the improvement in the manifestation of BCRL and on their ability to use the affected arm. Observation of improvement became a source of motivation for the participants to adhere to the SMP.

The literature discussed that women with BCRL experience conflict in roles (McGrath, 2013; Radina, 2009; Radina et al., 2014). Lymphedema management requires some degree of prioritizing the self over the needs of others (Radina, 2009). The literature stated that women with BCRL have a strong desire to preserve participation in occupations prior to BCRL has a negative effect on adherence to SMP (Fangel et al., 2013; Radina et al., 2014). The women's strong desire may lead to the tendency to choose to ignore self-management protocols. They choose to participate in activities related to their valued roles prior to breast cancer and BCRL instead of adhering to the SMP (McGrath, 2013). Literature also stated that women engage in self-sacrificing behaviors as they tend to neglect their own needs as they attend to the needs of the family first (Radina et al., 2014).

In contrast, self-sacrificing behaviors were not observed with participants in this study. In addition, the participants were able to continue their roles taking care of family members; they demonstrated that they can structure their day to involve both SMP and family responsibilities. Participants 1, 2, and 6 expressed that they ask for help from their families and rely on them for emotional and physical support. Their role in the family did not seem to negatively affect their adherence to SMP. Participants in this study kept moving forward with the SMP, encouraged by their observation of improvement. The themes of resilience and decision seem to reflect the volitional cycle.

The participants in the study expressed that they need to make lifestyle changes to adapt to life with BCRL.

According to the literature, motivation theories indicated the need to address behavior change involved in adherence to SMP (Cuevas et al., 2014; Friedman et al., 2006; Matthews & Cook, 2009; Muraca et al., 2011; Teo et al., 2015; Trinh et al., 2014). The theory of planned behavior (Trinh et al., 2014) and the transtheoretical model of change (Muraca et al., 2011; Prochaska et al., 1994) both identified the importance of self-efficacy. Self-efficacy reflects the person's confidence in her ability to accomplish a goal. The person should acquire the knowledge and skills needed to perform the new behavior in order to be confident (Ryan & Sawin, 2009; Turner et al., 2015). The motivation to engage in new behaviors as part of lifestyle change due to lymphedema is influenced by perceived benefits of the behavior, the person's belief in the ability to engage in the new behavior, purpose in life, and optimism (Cuevas et al., 2014; Friedman et al., 2006; Matthews & Cook, 2009; Muraca et al., 2011; Teo et al., 2015; Trinh et al., 2014). The literature stated that adherence leads to a sense of self-efficacy and confidence (Turner et al., 2015). Adaptation is observed when the woman is able to control lymphedema and not allow it to control her life. It is the ability to cope or adjust to life after the onset of BCRL (Friedman et al., 2006; Matthews & Cook, 2009). The health care professional should help women with BCRL incorporate the SMP in her daily routine. Addressing motivation enhances adherence to the SMP on a daily basis (Cuevas et al., 2014; Fu, 2005; Muraca et al., 2011; Teo et al., 2015; Trinh et al., 2014).



The study found that the MOHO concept of the volitional process can be used to meet this need to address motivation. The volitional process can be used to restructure a person's occupational identity and facilitate occupational competence. The Remotivation Process, together with the use of the VQ, enabled the PI to gain a deeper understanding of volition, and how it manifests in clients with BCRL. The Remotivation Process involves an ongoing assessment, which gave the occupational therapist a chance to adjust the program according to the client's needs (de las Heras de Pablo et al., 2003).

MOHO, specifically the Remotivation Process as a protocol of intervention, seems to support the positive impact of self-efficacy on readiness to change (de las Heras de Pablo et al., 2017; Pepin, 2017). The Remotivation Process as a protocol of intervention used volition as a pathway for change (de las Heras de Pablo et al., 2017; Pepin, 2017). According to MOHO, the person experiences the present and interprets it according to experience. This leads to anticipation for the future. The person chooses the activity and occupational choices based on her anticipation. The observation of improvement provides a positive experience that supports the decision to engage in new behavior and adhere to the change and adherence (de las Heras de Pablo et al., 2017; Lee & Kielhofner, 2017; Pepin, 2017). Participants in the study showed improved volition, or the motivation for occupation, through the progression in the VQ, where they moved from the stage exploration when the person may not feel able to manage BCRL, to either competency or achievement, when then the person feels more able to control BCRL.

### **Summary of Findings**

The Remotivation Process and VQ enabled the PI to articulate the self-reported behaviors of the participants in a language within the volitional continuum. The Remotivation Process was used as an intervention during the four-week period. The study showed that there was a statistically significant improvement in the participants' placement on the VQ. The improvement is seen as a progression from the exploration stage prior to the intervention to the next stage, competency, and then achievement at the end of the intervention. The improvement in the VQ scores may be a reflection of improved motivation to perform the SMP every day.

The participants showed motivation to engage in the SMP even though the frequency of performing the SMP in a 7-day period did not show statistically significant change. The participants expressed that the weekly discussions using the Remotivation Process helped them “keep on track” and be mindful of their decision to perform the components of the SMP. The participants' observations of improvement when performing the SMP seem to motivate them to perform the SMP every day. The patient education provided by the occupational therapist combined with the Remotivation Process provided by the PI allowed them to more fully understand lymphedema. The perception of having increased knowledge and skills appeared to facilitate adherence to SMP. There was a significant decrease in girth in the measurement points of the affected arm after the intervention. The participants also expressed that they have observed an improvement in their symptoms.

The LyQoLI was used to measure the change in the quality of life after the intervention using the Remotivation Process. The change in the score of LyQoLI did not show a significant change in the quality of life. However, the verbalizations and perceptions of the participants during the discussions and interviews seemed to show that quality of life improved as the manifestation of BCRL improved. Also, the insignificant change in scores may reflect that the participants did not let BCRL hinder their participation in daily activities and roles.

The MOHOST was used to measure the change in occupational participation after the intervention using the Remotivation Process. There was a statistically significant change in the score in the three subtests and overall MOHOST scores. The Motivation for Occupation subtest refers to the MOHO concept of Volition. An improvement in this subtest may indicate an improvement in volition. The Pattern for Occupation subtest refers to the MOHO concept of Habituation. An improvement in this subtest may indicate an improvement in the participant's ability to incorporate the components of the SMP into their daily routine and find time to perform the SMP despite challenges. The Process Skills subtest refers to the person's ability to anticipate and make decisions, retain the information, initiate and sustain concentration, and organization. An improvement in the Process Skills subtest may indicate that the person has improved knowledge of BCRL and SMP, improved ability to plan ahead, organize, and make time for the SMP.

There was a significant increase in occupational participation based on the MOHOST scores. However, the LyQoLI did not show a significant change in QOL.

One may expect a correlation between occupational participation and QOL, however, this was not reflected in the study. A possible explanation for this is the difference in the administration of the MOHOST and LyQoLI. The MOHOST was implemented by the treating therapists as an observational tool, while the LyQoLI was administered as a self-report questionnaire. The MOHOST may have reflected the perspectives of the treating therapists and the LyQoLI reflected the perspectives of the participants. The PI was unable to clarify the MOHOST scores with the treating therapists during the study due to the limitations imposed by the collaborating facility.

### **Implications**

Occupational therapy has a role in responding to the needs of breast cancer survivors with lymphedema. The Remotivation Process is one of the MOHO protocols of intervention used in occupational therapy. It was used as an occupational therapy program to support motivation to adhere to the SMP that is necessary to address upper extremity lymphedema in women with breast cancer. The combined qualitative and quantitative findings have several implications for occupational therapy practice:

- Adherence is crucial in the control of the symptoms of BCRL. Adherence to the SMP may facilitate improvement in BCRL, which provides a positive experience that further motivates the person to continue to perform the SMP.
- Motivation is a key factor in adherence. The Remotivation Process as an occupational therapy intervention may be used to facilitate motivation to adhere to SMP recommendations.

- The Remotivation Process along with the Volitional Questionnaire can be used to identify the motivational problems of women with BCRL that hinder adherence to the SMP. The identification of these motivation problems can enable the occupational therapist to identify ways to facilitate motivation.
- The Remotivation Process provides the occupational therapist with a guide to tailor his or her interactions with the patient as she moves through the volitional continuum. The movement from exploration to competence to achievement enables the patient to adhere to the SMP.

### **Limitations**

- It cannot be stated that the use of the Remotivation Process led to lasting change and habit formation since the study was only conducted for over 8 weeks. There is a need to expand the study over a longer period to fully appreciate the change in motivation.
- The sample size is too small to show statistically credible results that can be generalized. The recruitment of participants was also limited to one collaborating institution.
- The PI provided the intervention through a Telehealth platform, which may have affected the quality of interaction with the participants. Some participants were either not comfortable with the Zoom platform or did not have access to the computer during the discussion sessions. The participants preferred phone calls instead of video conferencing due to these circumstances. The PI was unable to

capture the non-verbal elements of the discussion sessions and interviews which would have provided valuable qualitative data.

- The study also involved participants who have had BCRL and are familiar with SMP. It did not compare the outcomes between participants who were not familiar with the SMP. The study also did not have a control group to fully appreciate the impact of the Remotivation Process.
- The study only explored the use of the Remotivation Process and did not compare the effect of the intervention with the other theories of motivation discussed in the literature review.
- The study was unable to separate the participants into treatment and control groups. The treatment group would have received the Remotivation Process in addition to the customary therapy program for BCRL, while the control group would only receive customary occupational therapy. This would have addressed the possibility of the customary occupational therapy being a confounding variable in the study.
- The PI was unable to thoroughly discuss the MOHOST scores with the treating therapists to address the similarities and differences between the perspectives of the therapists and those of the participants.

### **Future Directions**

This feasibility study explored the potential use of the Remotivation Process as an intervention for women with BCRL. Future research should address the limitations of the current study. The following future research can be pursued based on the findings of this dissertation study:

- A follow-up study can be completed over longer intervals to determine whether or not the Remotivation Process led to a lasting change in the participants' adherence to the SMP.
- The study can be continued to achieve the targeted 42 or even more participants to yield statistically significant results. The study identified the potential impact of the Remotivation Process in clients with BCRL. It needs to be replicated in other therapy centers in other regions of the United States to increase the number of participants and reach a more diverse participant population.
- A future study using face-to-face interaction may be considered to fully appreciate the impact of the Remotivation Process as an occupational therapy intervention. The study used a Telehealth platform to provide the intervention. A future study can investigate the possible difference in the effectiveness of the Remotivation Process delivered through Telehealth and one that is delivered in person. Such a study can identify the effect of a virtual platform on the delivery of the Remotivation Process and identify critical elements to be considered when designing a Telehealth program for BCRL.
- A study that compares the outcomes between participants with prior knowledge and those who have no prior experience in BCRL and SMP is recommended. A study that compares the volition of women who underwent therapy for BCRL in the past and those who have no prior experience of BCRL can identify the difference in each group's volitional cycle and motivational needs. A future study on this topic may identify other factors that affect volition and possible differences in women's

reactions toward chronic conditions such as BCRL. The future study can also explore the differences in habits of women with prior knowledge of BCRL and SMP and those who are experiencing the condition for the first time.

- Future studies can also compare the Remotivation Process as an intervention with the approaches that are based on theories of motivation from other disciplines.
- A future study that involves treatment and control groups can also show more credible results to support the use of the Remotivation Process in women with BCRL. A future study can also compare the Remotivation Process with other motivational approaches, such as Motivational Interviewing. The Remotivation Process is a MOHO protocol of intervention. A future study can also look into the possible use of other motivational approaches in conjunction with MOHO.
- A future study with a treatment and control group can investigate the impact of the Remotivation Process when compared with the outcomes of women who only received occupational therapy intervention that is customary for BCRL
- The difference in the administration of the MOHOST and the LyQoLI may account for the unexpected outcome of improvement in occupational participation but not in QOL. The MOHOST was implemented as an observational tool by the occupational therapist and the LyQoLI a self-report of the participant, indicating incongruence between the perspectives of the provider of occupational therapy and recipient of occupational therapy. A future study should further investigate the similarities and differences in the perspective of the occupational therapist and the participant regarding BCRL and the performance of the SMP.



- A retrospective inquiry can articulate the unique meaning of personal causation to each participant. The study should also expand the other factors that affected each participant's personal causation and volitional cycle. An in-depth analysis of the study findings must also explicate the active ingredients of the Remotivation Process that influences the volitional cycle.

### **Conclusion**

This study aimed to provide evidence for the possible use of the Remotivation Process to enhance motivation and engagement in SMP in women who developed lymphedema of the upper extremity due to breast cancer. The study showed that the Remotivation Process can motivate a client to adhere to the SMP, facilitate positive change in the physical appearance of their affected extremity, and become more aware of lymphedema. The Remotivation Process can also facilitate an improvement in occupational participation.

The study was not able to report a statistically significant change in the frequency of performance of SMP nor a change in the quality of life. However, it did highlight the positive impact of the Remotivation Process through the perspectives of the participants.

The study also aimed to investigate the practical use of the Remotivation Process in oncology, specifically with BCRL. The Remotivation Process was combined with the occupational therapy program that was customary for women with BCRL. The findings of the study can be the first step in providing evidence that the Remotivation Process is a valuable tool that can be integrated into an occupational therapy program for BCRL.

## REFERENCES

- Abou-Elenein, M., Makar, W., Abdel-Azim, H., & Alsirafy, S. (2016). The relation between the severity of breast cancer-related lymphedema and quality-of-life. *Annals of Oncology*, 27 (Suppl6), 6.
- Agren, K. A., & Kjellberg, A. (2008). Utilization and content validity of the Swedish version of the volitional questionnaire (VQ-S). *Occupational Therapy in Health Care*, 22(2-3), 163-176. doi:10.1080/07380570802135456
- American Cancer Society. (2016a). Breast cancer survival rates. Retrieved from <https://www.cancer.org/cancer/breast-cancer/understanding-a-breast-cancer-diagnosis/breast-cancer-survival-rates.html>
- American Cancer Society. (2016b). Surgery for breast cancer. Retrieved from <https://www.cancer.org/cancer/breast-cancer/treatment/surgery-for-breast-cancer/lymph-node-surgery-for-breast-cancer.html>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl.1), S1-S48.
- Armer, J. M., Brooks, C. W., & Stewart, B. (2011). Limitations of self-care in reducing the risk of lymphedema: Supportive-educative systems. *Nursing Science Quarterly*, 24(1), 57-63. doi:10.1177/0894318410389058
- Berger, S., Escher, A., Mengle, E., & Sullivan, N. (2018). Effectiveness of health promotion, management, and maintenance interventions within the scope of occupational therapy for community-dwelling older adults: A systematic

- review. *The American Journal of Occupational Therapy : Official Publication of the American Occupational Therapy Association*, 72(4), 1-10.
- Bloomquist, K., Oturai, P., Steele, M., Adamsen, L., Møller, T., Christensen, K., . . .
- Hayes, S. (2018). Heavy-load lifting: Acute response in breast cancer survivors at risk for lymphedema. *Medicine and Science in Sports and Exercise*, 50(2), 187-195.
- Bogan, L. K., Powell, J. M., & Dudgeon, B. J. (2007). Experiences of living with non-cancer-related lymphedema: Implications for clinical practice. *Qualitative Health Research*, 17(2), 213-224. doi:10.1177/1049732306297660
- Bojinović –Rodić, D., Popović–Petrovic, S., Sanja Tomić, S., Markez, S., & Živanić, D. (2016). Upper extremity function and quality of life in patients with breast cancer related lymphedema. *Vojnosanitetski Pregled*, 73(9), 831-837.
- Breastcancer.org. (2020). U.S. breast cancer statistics. Retrieved from [http://www.breastcancer.org/symptoms/understand\\_bc/statistics](http://www.breastcancer.org/symptoms/understand_bc/statistics)
- Bulley, C., Coutts, F., Blyth, C., Jack, W., Chetty, U., Barber, M., & Tan, C. (2014). A Morbidity Screening Tool for identifying fatigue, pain, upper limb dysfunction and lymphedema after breast cancer treatment: A validity study. *European Journal of Oncology Nursing*, 18(2), 218-227.
- Burckhardt, M., Belzner, M., Berg, A., & Fleischer, S. (2014). Living with breast cancer-related lymphedema: A synthesis of qualitative research. *Oncology Nursing Forum*, 41(4), E220-37. doi:10.1188/14.ONF.E220-E237

- Cal, A. & Bahar, Z. (2016). Women's barriers to prevention of lymphedema after breast surgery and home care needs: A qualitative study. *Cancer Nursing*, 39(6), E17-E25.
- Campbell, C. & Munoz, L. (2016). Online course: AOTA cancer series - module 2: Lymphedema and breast cancer for OT practitioners. Retrieved from <https://learn.aota.org>
- Carpenter, R., Dichiacchio, T., & Barker, K. (2019). Interventions for self-management of type 2 diabetes: An integrative review. *International Journal of Nursing Sciences*, 6(1), 70-91.
- Chang, S., Choi, S., Kim, S., & Song, M. (2014). Intervention strategies based on information-motivation-behavioral skills model for health behavior change: A systematic review. *Asian Nursing Research*, 8(3), 172-181.
- Chern, J., Kielhofner, G., de las Heras, G., & Magalhaes, L. C. (1996). The volitional questionnaire: Psychometric development and practical use. *American Journal of Occupational Therapy*, 50(7), 516-525.
- Christensen, A. H. (2004). *Patient adherence to medical treatment regimens*. New Haven, CT: Yale University Press.
- Cohen, M., D. (2011). Complete decongestive physical therapy in a patient with secondary lymphedema due to orthopedic trauma and surgery of the lower extremity. *Physical Therapy*, 91(11), 1618-1626. doi:10.2522/ptj.20100101

- Connors, B. P., McGlamery, J. N., & Stern, B. Z. (2019). Brief motivational interviewing: A tool for occupational therapy practitioners to support self-management. *SIS Quarterly Practice Connections*, 4(3), 16–18.
- Corby, D., Taggart, L., & Cousins, W. (2015). People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities*, 47, 451-465.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Cuevas, B. T., Hughes, D. C., Parma, D. L., Trevino-Whitaker, R. A., Ghosh, S., Li, R., & Ramirez, A. G. (2014). Motivation, exercise, and stress in breast cancer survivors. *Support Care Cancer*, 22, 911-917. doi:10.1007/s00520-013-2038-6
- Davies, C., Ryans, K., Levenhagen, K., & Pardomo, M. (2014). Quality of life and functional outcome measures for secondary lymphedema in breast cancer survivors. *Rehabilitation Oncology*, 32(1), 7-12.
- de las Heras, C. G., Geist, R., Kielhofner, G., & Li, Y. (2007). *The volitional questionnaire (VQ) [version 4.1]*. Chicago, IL: University of Illinois.
- de las Heras, C. G., Llerena, V., & Kielhofner, G. (2003). *A user's manual for remotivation process: Progressive intervention for individuals with severe volitional challenges*. Chicago, IL: University of Illinois at Chicago.

de las Heras de Pablo, C. G., Parkinson, S., Pepin, G., & Kielhofner, G. (2017).

Intervention process: Enabling occupational change. In R. Taylor  
(Ed.), *Kielhofner's model of human occupation* (5th ed., pp. 195-221).

Philadelphia, PA: Lippincott Williams & Wilkins.

De Brucker, B., Zeltzer, A., Seidenstuecker, K., Hendrickx, B., Adriaenssens, N., &

Hamdi, M. (2016). Breast cancer-related lymphedema: Quality of life after  
lymph node transfer. *Plastic and Reconstructive Surgery*, 137(6), 1673-1680.

Dennis, B. (1993). Acquired lymphedema: A chart review of nine women's responses to  
intervention. *American Journal of Occupational Therapy*, 47(10), 891-899.

Devoogdt, N., Van Kampen, M., Geraerts, I., Coremans, T., & Christiaens, M. (2011).

Lymphoedema functioning, disability and health questionnaire (lymph-  
ICF): Reliability and validity.(research report)(survey). *Physical Therapy*,  
91(6), 944.

Dominick, S. A., Natarajan, L., Pierce, J. P., Madanat, H., & Madlensky, L. (2014).

Patient compliance with a health care provider referral for an occupational  
therapy lymphedema consult. *Support.Care Cancer*, 22, 1781-1787.

doi:10.1007/s00520-014-2145-z.

Falout, J. (2012). Coping with demotivation: EFL learners' remotivation process. *The*

*Electronic Journal for English as a Second Language*, 16(3), 29.

Fangel, L. M. V., Panobianco, M. S., Kebbe, L. M., de Almeida, A. M., & Gozzo, T. d.

O. (2013). Qualify of life and daily activities performance after breast  
cancer treatment/Qualidade de vida e desempenho de atividades cotidianas

- após tratamento das neoplasias mamárias. *Acta Paulista De Enfermagem*, 26(1), 93-100. Retrieved from <http://ezproxy.twu.edu:2092/docview/1446973681?accountid=7102>
- Faul, F., Erdfelder, E., Lang, A., & Buchner, A. (2007). G\* power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39(2), 175-191. doi:10.3758/BF03193146
- Ferketich, S. (1991). Focus on psychometrics: Aspects of item analysis. *Research in Nursing & Health*, 14, 165-168.
- Fisher, G., Parkinson, S., & Haglund, L. (2017). The environment and human occupation. In Taylor, R.R. (Ed.), *Kielhofner's Model of Human Occupation* (pp. 91-106). Philadelphia: Wolters Kluwer Health.
- Flood, A. (2010). Understanding phenomenology. *Nurse Researcher*, 17(2), 7-15.
- Foldi, M. (2006). *Foldi's textbook of lymphology for physicians and lymphedema therapists* (2nd ed.). Munich: Elsevier GmbH.
- Forsyth, K., Parkinson, S., Kielhofner, G., Kramer, J., Mann, L. S., & Duncan, E. (2011). The measurement properties of the model of human occupation screening tool and implications for practice. *New Zealand Journal of Occupational Therapy*, 58(2), 5-13.
- Friedman, L. C., Kalidas, M., Elledge, R., Chang, J., Romero, C., Husain, I., . . . Liscum, K. R. (2006). Optimism, social support and psychosocial functioning among women with breast cancer. *Psycho-Oncology*, 15(7), 595-603.

- Fu, M. R. (2005). Breast cancer survivors' intentions of managing lymphedema. *Cancer Nursing*, 28(6), 446-457.
- Giorgi, A. (2009). *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. Philadelphia, PA: Duquesne University Press.
- Grada, A., & Phillips, T. (2017). Lymphedema. *Journal of the American Academy of Dermatology*, 77(6), 995-1006.
- Grady, P. A., & Gough, L. L. (2014). Self-management: A comprehensive approach to management of chronic conditions. *American Journal of Public Health*, 104(8), e25-e31.
- Hidding, J., Beurskens, C., Wees, J., Laarhoven, W., & Sanden, G. (2014). Treatment related impairments in arm and shoulder in patients with breast cancer: A systematic review. *PLoS ONE*, 9(5), E96748. doi.10.2522/ptj.20150412
- Hidding, J. T., Viehoff, P. B., Beurskens, C. H. G., van Laarhoven, Hanneke W. M., Nijhuis-van, d. S., & van, d. W. (2016). Measurement properties of instruments for measuring of lymphedema: Systematic review. *Physical Therapy*, 96(12), 1965-1981.
- Holmes, E.A.F., Hughes, D.A., Valerie L.Morrison, V.L. (2014). Predicting adherence to medications using health psychology theories: A systematic review of 20 years of empirical research. *Value in Health*, 17, 863 – 876.
- Johnstone, P. A. S., Hawkins, K., & Hood, S. (2006). Role of patient adherence in maintenance of results after manipulative therapy for lymphedema. *Journal of the Society for Integrative Oncology*, 4, 125-129.



- Kielhofner, G. (2005). Research concepts in clinical scholarship - scholarship and practice: Bridging the divide. *American Journal of Occupational Therapy*, 59, 231-239.
- Kielhofner, G. (2006). *Research in occupational therapy methods of inquiry for enhancing practice*. Philadelphia, PA: F.A. Davis Company.
- Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4th ed.). Baltimore, MD: Lippincott, Williams & Wilkins.
- Kielhofner, G., Fan, C., Morley, M., Garnham, M., Heasman, D., Forsyth, K., Lee, S. W. & Taylor, R. R. (2010). A psychometric study of the model of human occupation screening tool (MOHOST). *Hongkong Journal of Occupational Therapy*, 20(2), 63-70. doi:10.1016/S1569-1861(11)70005-5
- Klernas, P., Johnsson, A., Horstmann, V., Kristjanson, L. J., & Johansson, K. (2015). Lymphedema quality of life inventory (LyQLI)-development and investigation of validity and reliability. *Quality of Life Research*, 24, 427-439.
- Kramer, J., Kielhofner, G., Lee, S. W., Ashpole, E., & Castle, L. (2009). Utility of the model of human occupation screening tool for detecting client change. *Occupational Therapy in Mental Health*, 25(2), 181-191. doi:10.1080/01642120902859261
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3), 214-222.

- Kulesza-Bronczyk, B., Dobrzycka, B., Chrzanowska, M., Terlikowski, R., Mackowiak-Matejczyk, B., Stadnicka, G., & Terlikowski, S. (2014). Quality of life and the level of knowledge and utilization of lymphedema prevention principles among mastectomized patients. *Progress in Health Sciences*, 4(1), 110-117.
- Lashinski, B. B., Thrift, K. M., Squire, D., Austin, M. K., Smith, K. M., Wanchai, A., . . . Armer, J. M. (2012). A systematic review of the evidence for complete decongestive therapy in the treatment of lymphedema from 2004 to 2011. *Pm&r*, 4(8), 580-601.
- Lee, S. W., Forsyth, K., Morley, M., Garnham, M., Heasman, D., & Taylor, R. (2013). Mental health payment-by-results clusters and model of human occupation screening tool. *OTJR: Occupation, Participation & Health*, 33(1), 40-49. doi:10.3928/15394492-20120426-01
- Lee, S. W., & Kielhofner, G. (2017). Volition. In Taylor, R.R. (Ed.), *Kielhofner's model of human occupation* (pp. 38-56). Philadelphia, PA: Wolters Kluwer Health.
- Leland, N. E., Fogelberg, D. J., Halle, A. D., & Mroz, T. M. (2017). Health policy perspectives—occupational therapy and management of multiple chronic conditions in the context of health care reform. *American Journal of Occupational Therapy*, 71, doi:10.5014/ajot.2017.711001.

- Li, Y., & Kielhofner, G. (2004). Psychometric properties of the volitional questionnaire. *The Israeli Journal of Occupational Therapy*, 3(13), E85-E98.
- Lindquist, H., Enblom, A., & Bergmark, K. (2015). Self-care among female cancer survivors with secondary lymphedema: A qualitative study. *Rehabilitation Oncology*, 33(1), 51-57.
- Loh, S. Y., & Musa, A. N. (2015). Methods to improve rehabilitation of patients following breast cancer surgery: A review of systematic reviews. *Breast Cancer: Targets and Therapy*, 7, 81-98. doi:10.2147/BCTT.S47012
- Lorig, K. R., & Holman, H. R. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1-7.
- Mapp, T. (2008). Understanding phenomenology: The lived experience. *British Journal of Midwifery*, 16(5), 308-311.
- Martínez, G., & Martínez, M. (2018). Nursing intervention in women who developed lymphedema after undergoing a modified radical mastectomy: A pre-experimental study. *Ecancermedicalscience*, 12, 827.
- Matthews, E. E., & Cook, P. F. (2009). Relationships among optimism, well-being, self-transcendence, coping, and social support in women during treatment for breast cancer. *Psycho-Oncology*, 18(7), 716-726. doi:10.1002/pon.1461
- McGrath, T. (2013). Irish insights into the lived experience of breast cancer related lymphoedema: Implications for occupation focused practice. *WFOT Bulletin*, 68, 44-50.

- Meiklejohn, J., Heesch, K., Janda, M., & Hayes, S. (2013). How people construct their experience of living with secondary lymphoedema in the context of their everyday lives in australia. *Supportive Care in Cancer*, 21(2), 459-466. doi:10.1007/s00520-012-1534-4
- Miller, W. R., & Rollnick, S. (2013). *Motivational interviewing : Helping people change* (3rd ed.). New York, NY: Guilford Press.
- Mortimer, P. S., & Rockson, S. G. (2014). New developments in clinical aspects of lymphatic disease. *Journal of Clinical Investigation*, 124(3), 915-21.
- Muraca, L., Leuung, D., Clark, A., Beduz, M.A. & Goodwin, P. (2011). Breast cancer survivors: Taking charge of lifestyle choices after treatment. *European Journal of Oncology Nursing*, 15, 250-253. doi:10.1016/j.ejon.2009.12.001
- Myford, C. M., & Wolfe, E. W. (2004). Detecting and measuring rater effects using many-facet rasch measurement. *Journal of Applied Measurement*, 5(2), 189–227.
- National Institutes of Health. (2020). *Self-management* [fact sheet}. Retrieved from <http://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=70>
- National Lymphedema Network. (2011a). NLN position paper: screening and measurement for early detection of breast cancer-related lymphedema . Retrieved from <https://www.lymphnet.org/resources/position-paper-screening-and-measurement-for-early-detection-of-breast-cancer-related>
- National Lymphedema Network. (2011b). NLN position paper: The diagnosis and treatment of lymphedema . Retrieved from

<https://www.lymphnet.org/resources/nln-position-paper-the-diagnosis-and-treatment-of-lymphedema>

- O'Brien, J. C., & Kielhofner, G. (2017). The interaction between the person and the environment. In R.R. Taylor (Ed.), *Kielhofner's Model of Human Occupation* (pp. 24 – 37). Philadelphia, PA: Wolters Kluwer Health.
- Palmadottir, G. (2010). The role of occupational participation and environment among Icelandic women with breast cancer: A qualitative study. *Scandinavian Journal of Occupational Therapy*, 17(4), 299-307.  
doi:10.3109/11038120903302874
- Parkinson, S., Forsyth, K., Kielhofner, G. (2006). *The model of human occupation screening tool (MOHOST; version 2.0)*. Chicago, IL: University of Illinois.
- Parmenter, V., Fieldhouse, J., & Barham, R. (2013). An occupational therapy intervention service to hostels for homeless people: An overview. *British Journal of Occupational Therapy*, 76(5), 242-245.  
doi:10.4276/030802213X13679275042807
- Patton, M. Q. (2015). *Qualitative research & evaluation methods* (4th ed.). Thousand Oaks, CA: Sage.
- Pepin, G. (2017). Occupational engagement: how clients achieve change. In R.R. Taylor (Ed.), *Kielhofner's Model of Human Occupation, 7th Ed.* (pp. 187–194). Philadelphia, PA: Wolters Kluwer Health.

- Pépin, G., Guérette, F., Lefebvre, B., & Jacques, P. (2008). Canadian therapists' experiences while implementing the model of human occupation remotivation process. *Occupational Therapy in Health Care*, 22(2), 115-124.
- Prochaska, J., Redding, C., Harlow, L., Rossi, J., & Velicer, W. (1994). The transtheoretical model of change and HIV prevention: A review. *Health Education Quarterly*, 21 (4), 471-486.
- Pullinger, W. F. (1960). Remotivation. *The American Journal of Nursing*, 60(5), 682-685. doi:10.2307/3418168
- Raber, C., Purdin, S., Hupp, A. & Stephenson, B. (2016). Occupational therapists' perspectives on using the remotivation process with clients experiencing dementia. *British Journal of Occupational Therapy*, 79, 92-101. doi:10.1177/0308022615615892
- Radina, E. M., Armer, J. M., & Stewart, B. (2014). Making self-care a priority for women at risk of breast cancer-related lymphedema. *Journal of Family Nursing*, 20(2), 226-249. doi:10.1177/1074840714520716
- Radina, M. E. (2009). Breast cancer-related lymphedema: Implications for family leisure participation. *Family Relations*, 58(4), 445-459.
- Radomski, M. V. (2011). More than good intentions: Advancing adherence to therapy recommendations. *The American Journal of Occupational Therapy*, 65(4), 471-477.

- Ridner, S. H., Murphy, B., Deng, J., Kidd, N., Galford, E., Bonner, C., . . . Dietrich, M. S. (2012a). A randomized clinical trial comparing advanced pneumatic truncal, chest, and arm treatment to arm treatment only in self-care of arm lymphedema. *Breast Cancer Research and Treatment, 131*(1), 147-158. doi:10.1007/s10549-011-1795-5.
- Ridner, S. H., Sinclair, V., Deng, J., Bonner, C. M., Kidd, N., & Dietrich, M. S. (2012b). Breast cancer survivors with lymphedema. *Clinical Journal of Oncology Nursing, 16*(6), 609-614. doi:10.1188/12.CJON.609-614
- Ridner, S., Dietrich, M., & Kidd, N. (2011). Breast cancer treatment- related lymphedema self- care: Education, practices, symptoms, and quality of life. *Supportive Care in Cancer, 19*(5), 631-637. doi:10.1007/s00520-010-0870-5
- Riegel, B., Dickson, V.V., Hoke, L., McMahon, J.P., Reis, B.F., & Sayers, S. (2006). A motivational counseling approach to improving heart failure self-care. *Journal of Cardiovascular Nursing, 21*(3), 232-241.
- Rubio, L. K. (2016). *Phenomenological study of breast cancer-related lymphedema*. Unpublished manuscript.
- Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook, 57* (2), 217-225. Doi:10.1016/j.outlook.2008.10.004
- Sander, A. P., Hajer, N. M., Hemenway, K., & Miller, A. C. (2002). Upper-extremity volume measurements in women with lymphedema: A comparison of

- measurements obtained via water displacement with geometrically determined volume. *Physical Therapy*, 82(12), 1201-1211.
- Shih, Y. T., Ying Xu, Y., Cormier, J.N., Giordano, S., Ridner, S.H., Buchholz, T.A., Perkins, G.H., & Elting, L.S. (2009). Incidence, treatment costs, and complications of lymphedema after breast cancer among women of working age: A 2-year follow-up study. *Journal of Clinical Oncology*, 27(12), 2007-2014.
- Taylor, R. (2017). *Model of human occupation: Theory and application* (5th ed.). USA: Lippincott Williams and Wilkins.
- Taylor, R. R., Pan, A., & Kielhofner, G. (2017). Doing and becoming: occupational change and development. In Taylor, R. R. (Ed.), *Kielhofner's Model of Human Occupation* (pp.140-156). Philadelphia, PA: Wolters Kluwer Health.
- Taghian, N. R., Miller, C. L., Jammallo, L. S., O'Toole, J., & Skolny, M. N. (2014). Lymphedema following breast cancer treatment and impact on quality of life: A review. *Critical Reviews in oncology/hematology*, 92(3), 227-234. doi:10.1016/j.critrevonc.2014.06.004.
- Tahan, G., Johnson, R., Mager, L., & Soran, A. (2010). The role of occupational upper extremity use in breast cancer related upper extremity lymphedema. *Journal of Cancer Survivorship*, 4(1), 15-9. doi:10.1007/s11764-009-0103-4



- Teo, I., Fingeret, M.C., Liu, J., & Chang, D.W. (2015). Coping and quality of life of patients following microsurgical treatment for breast cancer-related lymphedema. *Journal of Health Psychology, 1*(11), 2983-2993. doi:10.1177/1359105315589801
- The American Occupational Therapy Association. (2012). *Occupational therapy's role in chronic disease management* [fact sheet]. Retrieved from [https://www.aota.org/~media/Corporate/Files/AboutOT/Professionals/WhatIsOT/HW/Facts/FactSheet\\_ChronicDiseaseManagement.pdf](https://www.aota.org/~media/Corporate/Files/AboutOT/Professionals/WhatIsOT/HW/Facts/FactSheet_ChronicDiseaseManagement.pdf).
- Tomlin, G. & Borgetto, B. (2011). Research pyramid: A new evidence-based practice model for occupational therapy. *American Journal of Occupational Therapy, 65*, 189-196. doi:10.5014/ajot.2011.000828
- Trinh, L., Mutrie, N., Campbell, A. M., Crawford, J. J., & Courneya, K. S. (2014). Effects of supervised exercise on motivational outcomes in breast cancer survivors at 5-year follow up. *European Journal of Oncology Nursing, 18*, 557-563. doi:10.1010/j.ejon.2014.07.004
- Trudeau, K. J., Pujol, L. A., DasMahapatra, P., Wall, R., Black, R. A., & Zacharoff, K. (2015). A randomized controlled trial of an online self-management program for adults with arthritis pain. *Journal of Behavioral Medicine, 38*(3), 483-496. doi:10.1007/s10865-015-9622-9
- Turner, A., Anderson, J. K., Wallace, L. M., & Bourne, C. (2015). An evaluation of a self-management program for patients with long-term conditions. *Patient Education and Counseling, 98*(2), 213-219. doi:10.1016/j.pec.201.08.022

Upton, D., & Solowiej, K. (2011). Psychosocial aspects of living with non-cancer-related lymphoedema. *Nursing Standard*, 25(33), 51.

Yamada, T., Taylor, R. R., & Kielhofner, G. (2017). The person-specific concepts of human occupation. In R.R. Taylor (Ed.), *Kielhofner's Model of Human Occupation* (pp.11-23). Philadelphia, PA: Wolters Kluwer Health.

## APPENDIX A

Collaborative Institutional Training Initiative (CITI) Training Certificate of Onsite Collaborator



This is to certify that:

**Sherry Hite**

Has completed the following CITI Program course:

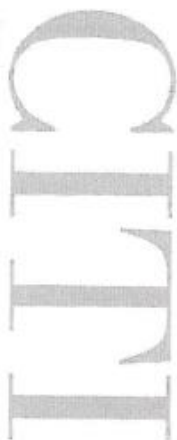
**Both Biomedical and SBR** (Curriculum Group)  
**Both Biomedical and SBR** (Course Learner Group)  
**1 - Basic Course** (Stage)

Under requirements set by:

**City of Hope National Medical Center**



Completion Date 22-Jun-2016  
Expiration Date 22-Jun-2019  
Record ID 19799553



Collaborative Institutional Training Initiative

Verify at [www.citiprogram.org/verify?w31020a8e-02fb-4a0d-8ccb-96e05a7cf274-19799553](http://www.citiprogram.org/verify?w31020a8e-02fb-4a0d-8ccb-96e05a7cf274-19799553)



This is to certify that:

**Sherry Hite**

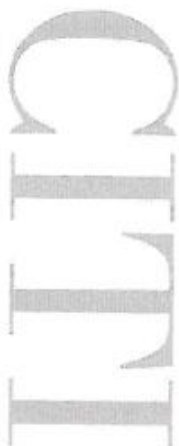
Has completed the following CITI Program course:

CITI Health Information Privacy and Security (HIPS) (Curriculum Group)  
CITI Health Information Privacy and Security (HIPS) (Course Learner Group)  
1 - HIPS (Stage)

Under requirements set by:

**City of Hope National Medical Center**

Completion Date 23-Jun-2016  
Expiration Date 23-Jun-2019  
Record ID 19799552



Collaborative Institutional Training Initiative

Verify at [www.citiprogram.org/verify/?wa1a05bc4-e41c-4100-88db-a86a419dc8ce-19799552](http://www.citiprogram.org/verify/?wa1a05bc4-e41c-4100-88db-a86a419dc8ce-19799552)

## APPENDIX B

### City of Hope Study Protocol

**CITY OF HOPE NATIONAL MEDICAL CENTER  
1500 E. DUARTE ROAD  
DUARTE, CA 91010**

**DEPARTMENT OF OCCUPATIONAL THERAPY**

**TITLE:** THE USE OF THE REMOTIVATION PROCESS IN AN OCCUPATIONAL  
THERAPY PROGRAM FOR BREAST CANCER-RELATED LYMPHEDEMA

**CITY OF HOPE PROTOCOL NUMBER:** 18549 **VERSION:** 03

DATE(S) OF COH Amendment 02 Dated April 03, 2019  
AMENDMENT(S)/REVISION(S):

**SPONSOR/IND NUMBER:** Exempt from IND, the study does not involve an investigational  
drug

**DISEASE SITE:** COH

**STAGE (if applicable):** N/A

**MODALITY:** Discussion and interview

**PHASE/TYPE:** Interventional / Feasibility study of an occupational therapy  
intervention

**PRINCIPAL INVESTIGATOR:**

*Designs protocol, responsible for study conduct and  
data analysis*

Sherry Hite, OTR/L

COH Department of Occupational  
Therapy

Lester Kaye Rubio, OTR, MHS, CLT  
Texas Woman's University

**COLLABORATING INVESTIGATOR(S):**

*Key individual(s); Assist in study design and  
development;*

*May be involved in analysis of data*

***Texas Woman's University***

Patricia/Bowyer EdD, MS, OTR

Lester Kaye/Rubio

**PARTICIPATING CLINICIANS:**

*Enrolls and follows eligible patients on study;*

*Not involved in study development or data analysis  
(Physician or research support staff)*

N/A

**STUDY STATISTICIAN:**

Texas Woman's University Center for  
Research Design and Analysis

**PARTICIPATING SITES:**

COH Department of Occupational  
Therapy  
Texas Woman's University

**STUDY SPONSOR AND MONITOR:**

N/A



**Investigators N/A**

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**PRINCIPAL INVESTIGATOR:**

{Insert PI Name and Personal Title}  
{Department/Division}  
{Address}  
{City, State}  
Phone: {insert phone number}  
Fax: {insert fax number}  
e-mail: {insert email address}

**STUDY STATISTICIAN:**

{Insert Statistician Name and Personal Title}  
{Department/Division}  
{Address}  
{City, State}  
Phone: {insert phone number}  
Fax: {insert fax number}  
e-mail: {insert email address}

**COLLABORATING INVESTIGATORS:**

{Insert Name and Personal Title}  
{Department/Division}  
{Address}  
{City, State}  
Phone: {insert phone number}  
Fax: {insert fax number}  
e-mail: {insert email address}

{Insert Name and Personal Title}  
{Department/Division}  
{Address}  
{City, State}  
Phone: {insert phone number}  
Fax: {insert fax number}  
e-mail: {insert email address}

{Insert Name and Degrees}  
{Department/Division}  
{Address}  
{City, State}  
Phone: {insert phone number}  
Fax: {insert fax number}  
e-mail: {insert email address}

{Insert Name and Degrees}  
{Department/Division}  
{Address}  
{City, State}  
Phone: {insert phone number}  
Fax: {insert fax number}  
e-mail: {insert email address}

**AGENT NSC# AND IND#:**

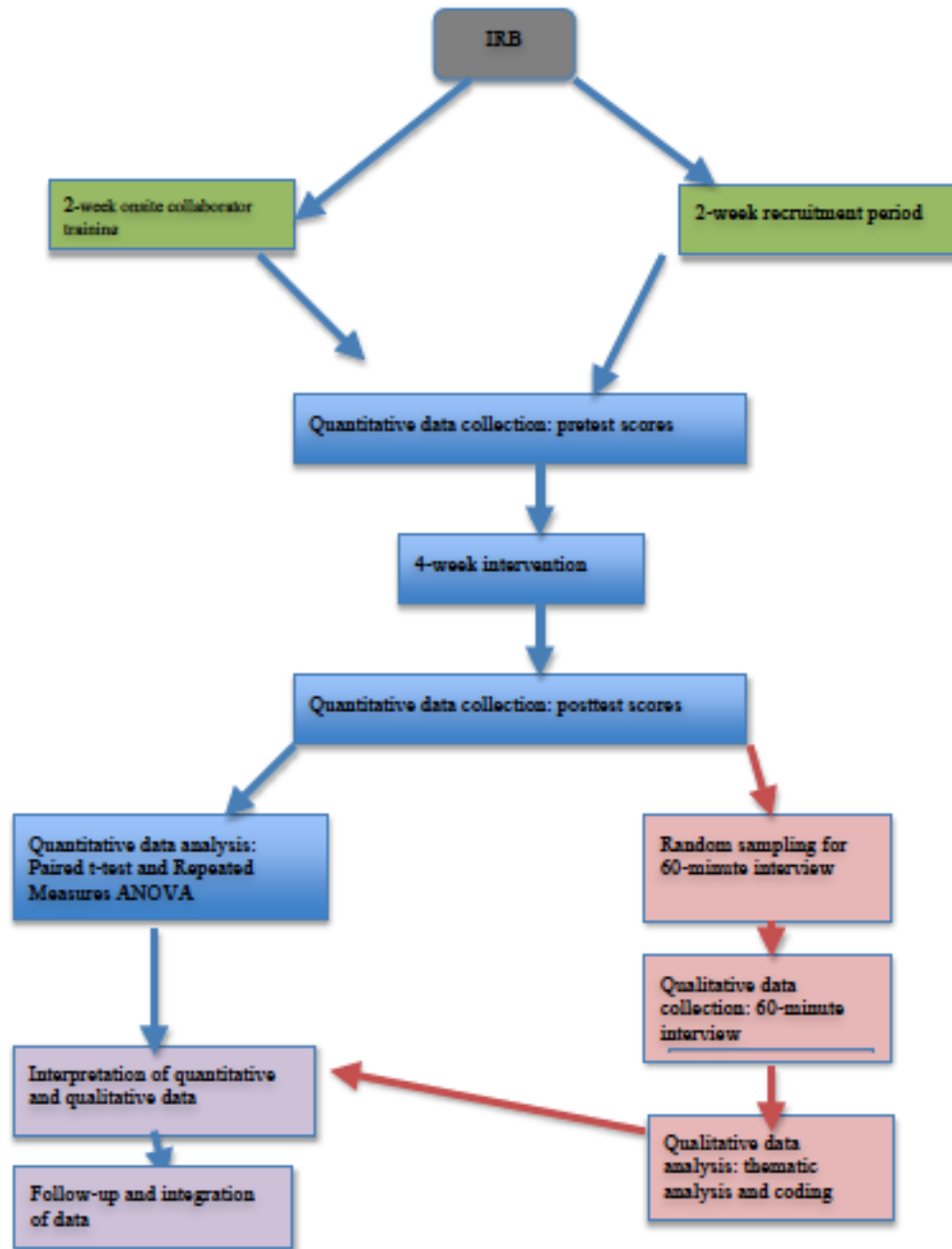
{If applicable}

**COORDINATING CENTER:**

{For multicenter trials only}

## Experimental Design Schema

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## Protocol Synopsis

<b>Protocol Title:</b>
THE USE OF THE REMOTIVATION PROCESS IN AN OCCUPATIONAL THERAPY PROGRAM FOR BREAST CANCER-RELATED LYMPHEDEMA
<b>Brief Protocol Title for the Lay Public (if applicable):</b>
N/A
<b>Study Phase:</b>
Interventional / Feasibility study of an occupational therapy intervention
<b>Participating Sites:</b>
COH Department of Occupational Therapy Texas Woman's University
<b>Rationale for this Study:</b>
The proposed study aims to explore the use of the Remotivation Process to increase motivation and facilitate an increase a woman's daily performance of the self-management program (SMP) for lymphedema. Breast Cancer-Related Lymphedema (BCRL) affects a significant number of women with breast cancer. It is a chronic condition, which is a potential side effect of breast cancer treatment. Women with this condition experience physical changes such as increased girth in the arm and hand. These affect occupational performance, occupational adaptation, and quality of life. SMPs are necessary for long-term management of BCRL. Research has found that women who do not continue to perform the SMP after lymphedema therapy experience a reoccurrence of the condition. However, most women with lymphedema do not perform SMP on a daily basis. Literature has indicated that a woman's motivation may have an impact on the incorporation of the program in her daily routine.
<b>Objectives:</b>
The proposed mixed methods using a concurrent triangulation design study aims to explore if the Remotivation Process leads to an improvement in the adherence to the SMP, girth reduction, occupational performance, self-perception, and quality of life when added to a customary occupational therapy program for BCRL.
<b>Study Design:</b>
This is a feasibility study of an occupational therapy intervention involving a single group of participants, using a mixed methods concurrent triangulation design. It only involves one site, which is the department of occupational therapy at COH.
<b>Endpoints:</b>
The primary end points will be the girth measurement of each participant's arm and the number of times each participant performed the self-management program during the end of the study compared with the girth measurement and daily performance at the self-management program at the beginning of the study. The secondary end points are the Lymphedema Quality of Life Inventory and Model of Human Occupation Screening Tool pretest and post test scores. These measures quality of life and occupational performance.
<b>Sample Size:</b>

A single **treatment** group of 42 participants will be recruited for the study.

<b>Estimated Duration of the Study</b>
The study is expected to close after 12 months.
<b>Summary of Subject Eligibility Criteria:</b>
<u>Inclusion Criteria:</u>

#### 1.1.1 Disease Status

Inclusion criteria will be females with unilateral upper extremity lymphedema following procedures to address breast cancer, able to communicate in English and participate in discussion sessions for the duration of the study of eight weeks.

#### 1.1.2 Age Criteria, Performance Status and Life Expectancy

The study will recruit females 21 years or older. Women in this age-range will be able to participate in work, household responsibilities, and possible child-rearing responsibilities. These are necessary components of quality of life and occupation, which are the primary concepts of interest of the study. The study will include women with vary level of functional performance status and life expectancy as long as they are willing to participate in a 15-minute discussion once a week in addition to their scheduled occupational therapy sessions at COH.

#### 1.1.3 Child Bearing Potential

**The effects of Remotivation Process on the developing fetus are unknown. For this reason, women of child-bearing potential and men must agree to use adequate contraception (hormonal or barrier method of birth control or abstinence) prior to study entry and for six months following duration of study participation. Should a woman become pregnant or suspect that she is pregnant while participating on the trial, she should inform her treating physician immediately.**

#### 1.1.4 Protocol-Specific Criteria

The study will only recruit female participants. The primary purpose of the study involves women breast cancer-survivors. It is necessary to restrict the recruitment based on gender since women's experience of BCRL, psychosocial being, and patterns of participation in work, household responsibilities, and possible child-rearing responsibilities are different from their male counterparts. These are necessary components of quality of life and occupation, which are the primary concepts of interest of the study. The literature reviewed to support the study also focused on women's experience of BCRL.

#### 1.1.5 Informed Consent/Assent

All subjects must have the ability to understand and the willingness to sign a written informed consent.

#### 1.1.6 Prior Therapy

The participant should also be receiving occupational therapy services at COH for BCRL during the first week of the study. The participant can be an on-going patient receiving customary occupational therapy services, or a new patient who will be seen for occupational therapy initial evaluation. The study will include patients with BCRL regardless of any other medical treatment they are receiving in addition to occupational therapy. Some participants may only need less than 4 weeks of customary occupational therapy in order to meet their intervention goals. In this case, the participant will still be asked to return at the end of the fourth week for follow up. Data obtained from the outcome measures will be included in quantitative analysis. The participant will also be included in the list of names that will be randomly selected for the 60-minute interview.

#### Exclusion Criteria:

The study cannot include male participants

<b>Investigational Product Dosage and Administration:</b>
The Remotivation Process is not a drug but a continuum of techniques based on the concept of volition. It will be implemented in the form of a 15-minute discussion session once a week for four weeks.
<b>Clinical Observations and Tests to be Performed:</b>
Laboratory studies, DLT, and correlative studies are not applicable.
<b>Statistical Considerations:</b>
<p>In the quantitative phase, the independent variable will be the time between prettest and post test. Dependent variables will be the data from the outcomes measures, which are girth measurement, frequency of the performance of the self-management program, the score from the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory. Repeated measures ANOVA is used since the study will compare the prettest and posttest girth of the affected arm as well as compare the difference between the affected and non-affected arm at prettest and post test. Paired t-test, will compare the number of times the participant performs the self-management program at prettest and post test. Paired t-test will also be used to compare the scores of the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory. Pearson correlation will be used to determine the correlation between the score from the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory.</p> <p>Non- parametric tests, will be used should the study does not meet the assumptions of parametric test. For non-parametric tests in this case, Friedman's ANOVA will be used to compare girth, and Wilcoxon signed-ranks test will be used to compare the prettest and post test scores of the the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory. The Spearman's ranks tests will be used to determine the correlation between the score from the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory. The qualitative phase follows a descriptive phenomenological design. Thematic analysis will be used to analyze data. The breast cancer disease team of COH agreed that all statistical work will be completed by TWU.</p>
<b>Sponsor/Licensee:</b>
Exempt from IND, the study does not involve an investigational drug
<b>Case Report Forms</b>
N/A, the study does not involve an investigational drug



## Table of Contents

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<b>SECTION</b> .....	<b>PAGE</b>
<b>1.0 Goals and Objectives (Scientific Aims)</b>	<b>269</b>
<b>2.0 Background</b>	<b>269</b>
<b>2.1 Introduction/Rationale for Development</b>	<b>269</b>
<b>2.2 Overview of Proposed Study</b>	<b>269</b>
<b>2.3 Preclinical Studies</b>	<b>271</b>
2.3.1 [Name of Agent]	
<b>2.4 Human Studies</b>	<b>271</b>
2.4.1 [Name of Agent]	
<b>3.0 Patient Eligibility</b>	<b>272</b>
<b>3.1 Inclusion Criteria</b>	<b>272</b>
3.1.1 Disease Status	272
3.1.2 Age Criteria, Performance Status and Life Expectancy	272
3.1.3 Child Bearing Potential	272
3.1.4 Protocol-Specific Criteria	272
3.1.5 Informed Consent/Assent	272
3.1.6 Prior Therapy	272
<b>3.2 Exclusion Criteria</b>	<b>273</b>
3.2.1 Study-Specific Exclusions	273
3.2.2 Non-Compliance	273
<b>3.3 Inclusion of Women and Minorities</b>	<b>273</b>
<b>4.0 Screening and Registration Procedures</b>	<b>273</b>
<b>4.1 Screening Procedures</b>	<b>273</b>
<b>4.2 Informed Consent</b>	<b>273</b>
<b>4.3 Registration Requirements/Process</b>	<b>273</b>
<b>4.4 Randomization and/or Dose Level Assignment</b>	<b>273</b>
<b>5.0 Treatment Program</b>	<b>271</b>
<b>5.1 Treatment Overview</b>	<b>275</b>
5.1.1 Schedule	275
<b>5.2 Planned Duration of Therapy</b>	<b>277</b>
<b>5.3 Criteria for Removal from Treatment</b>	<b>277</b>
<b>5.4 Subject Follow-Up</b>	<b>277</b>
<b>5.5 Supportive Care, Other Concomitant Therapy, Prohibited Medications</b>	<b>277</b>
<b>5.6 Additional Studies</b>	<b>277</b>
5.6.1 Laboratory Studies	277
<b>5.7 Definition of Dose-Limiting Toxicity (DLT)</b>	<b>277</b>
<b>6.0 Dose Delays/Modifications for Adverse Events</b>	<b>277</b>
<b>7.0 Data and Safety Monitoring, Unanticipated Problems and Adverse Event Reporting</b>	<b>278</b>
<b>8.0 Agent Information and Risks</b>	<b>278</b>

<b>9.0</b>	<b>Correlative/Special Studies</b>	<b>279</b>
<b>10.0</b>	<b>Study Calendar</b>	<b>280</b>
<b>11.0</b>	<b>Endpoint Evaluation Criteria/Measurement of Effect</b>	<b>282</b>
<b>11.1</b>	<b>Response Criteria</b>	<b>282</b>
<b>12.0</b>	<b>Data Reporting/Protocol Deviations</b>	<b>282</b>
<b>12.1</b>	<b>Data Reporting</b>	<b>282</b>
12.1.1	Confidentiality and Storage of Records	282
12.1.2	Subject Consent Form	283
12.1.3	Data Collection Forms and Submission Schedule	283
<b>12.2</b>	<b>Protocol Deviations</b>	<b>284</b>
12.2.1	Deviation Policy	284
12.2.2	Reporting of Deviations	284
12.2.3	Resolving Disputes	284
<b>13.0</b>	<b>Statistical Considerations</b>	<b>284</b>
<b>13.1</b>	<b>Study Design</b>	<b>284</b>
<b>13.2</b>	<b>Sample Size Accrual Rate</b>	<b>284</b>
<b>13.3</b>	<b>Statistical Analysis Plan</b>	<b>293</b>
<b>14.0</b>	<b>Human Subject Issues</b>	
<b>14.1</b>	<b>Institutional Review Board</b>	<b>294</b>
<b>14.2</b>	<b>Recruitment of Subjects</b>	<b>294</b>
<b>14.3</b>	<b>Advertisements</b>	<b>294</b>
<b>14.4</b>	<b>Study location and Performance Sites</b>	<b>295</b>
<b>14.5</b>	<b>Confidentiality</b>	<b>295</b>
<b>14.6</b>	<b>Financial Obligations and Compensation</b>	<b>295</b>
<b>14.7</b>	<b>Informed Consent Processes</b>	<b>295</b>
<b>15.0</b>	<b>References</b>	<b>297</b>

<b>Attachments:</b>	<b>Page</b>
<b>Numbers</b>	
B.1 The Remotivation Process and Planned Discussion Guide .....	300 - 303
B.2 COH Data Collection Form .....	304 - 306
B.3 Model of Human Occupation Screening Tool .....	307 - 308
B.4 Lymphedema Quality of Life Inventory .....	309 - 314
B.5 Field NotE Used by the PI .....	315 - 316
B.6 Interview Guide for Qualitative Data Collection .....	317 - 320
B.7 Recruitment Brochure .....	321 - 323
B.8 Informed Consent Form for Study Participants .....	324 - 327

## Abbreviations

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Abbreviation	Meaning
AE	Adverse Event
BCRL	Breast Cancer-Related Lymphedema
CFR	Code of Federal Regulations
COH	City of Hope
DLT	Dose Limiting Toxicity
DSMC	Data Safety Monitoring Committee
FDA	Food and Drug Administration
GCP	Good Clinical Practice
IB	Investigator Brochure
IDS	Investigational Drug Services
IND	Investigational New Drug
IRB	Institutional Review Board
LyQoLI	Lymphedema Quality of Life Inventory
MOHO	Model of Human Occupation
MOHOST	Model of Human Occupation Screening Tool
NCI	National Cancer Institute
NMU	Natural Meaning Unit
PI	Principal Investigator
SMP	Self Management Program
TWU	Texas Woman's University
TWU CRDA	Texas Woman's University Center for Research Design and Analysis

## 2.0 Goals and Objectives (Scientific Aims)

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The research questions for the quantitative study are:

4. How does remotivation process change daily performance of the lymphedema management techniques
5. How does the Remotivation Process affect the client's manifestation of BCRL?
6. How does the Remotivation Process affect the client's occupational participation and quality of life?

The research questions for the qualitative study are:

1. What are the perspectives of patients with BCRL about the self-management program after participating in an occupational therapy using the Remotivation Process?
2. What are the perspectives of patients with BCRL about their arm after the occupational therapy program?
3. How do patients with BCRL describe their daily life after occupational therapy?

## 3.0 Background

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### 3.1 Introduction/Rationale for Development

The Remotivation Process is a continuum of interventions based on the Model of Human Occupation (MOHO) (Taylor, 2017; Kielhofner, 2008) concept of volition (de las Heras, Llerena & Kielhofner, 2003). It is used by occupational therapists to guide their discussions and interactions with their clients based on their level of motivation. The authors of the process state that motivation is affected by illness or life events (de las Heras et al., 2003). The Remotivation

Process can be used as an occupational therapy program to facilitate the return of motivation in clients with motivational problems. Breast Cancer Related Lymphedema (BCRL) is the swelling of the arm and it affects a significant number of women with breast cancer. The proposed study aims to explore the use of the Remotivation Process (de las Heras et al., 2003) in an occupational therapy program to facilitate motivation in women with BCRL using a mixed methods design. The overarching research question for this study is “What are the experiences of facilitating motivation in women using the Remotivation Process in an occupational therapy program?”. As mentioned in the previous section, the research questions for the quantitative study are:

1. How does remotivation process change daily performance of the lymphedema management techniques
2. How does the Remotivation Process affect the client’s manifestation of BCRL?
3. How does the Remotivation Process affect the client’s occupational participation and quality of life?

The research questions for the qualitative study are:

1. What are the perspectives of patients with BCRL about the SMP after participating in an occupational therapy using the Remotivation Process?
2. What are the perspectives of patients with BCRL about their arm after the occupational therapy program?
3. How do patients with BCRL describe their daily life after occupational therapy?

These questions need to be addressed since research has found that women who do not continue to perform the SMP after lymphedema therapy experience a reoccurrence of the condition (Loh & Musa, 2015; Lashinski et al., 2012). Furthermore, while the effectiveness of the Remotivation Process has been demonstrated in the homeless (Parmenter, Fieldhouse, & Barham, 2013), in clients with dementia (Raber, Purdin, Hupp & Stephenson, 2016), and clients with depression (Pepin, Guerette, Lefebvre & Jaques, 2008), research on the effectiveness of the Remotivation Process on SMP and lymphedema has not been conducted.

### **3.2 Overview of Proposed Study**

The proposed study will involve cohorts. Each cohort will participate in a 4-week intervention period with a follow up after one month. It aims to determine if including the Remotivation Process to an occupational therapist’s interaction with a client will improve the client’s adherence to the SMP for breast cancer-related lymphedema. This is a mixed methods research design, which involves a pretest-posttest single group design and a qualitative study that follows the phenomenological tradition. Four outcome measures will be used for quantitative data gathering to determine the change in the client’s lymphedema, functional participation, weekly performance of SMP, and quality of life after 4 weeks. Ms. Hite, from COH, will administer the outcome measures. The collaborating investigator from Texas Woman’s University (TWU), Ms. Rubio, will meet with the study participants to complete a 15-minute discussion session once a week for 4 weeks. The study aims to recruit 42 participants with BCRL. Six participants will be randomly selected for a 60-minute interview with Ms. Rubio for qualitative data gathering. A follow up interview will be conducted on the 8<sup>th</sup> week. Ms. Rubio will triangulate quantitative and qualitative data with the assistance of TWU Center for Research Design and Analysis (TWU CDRA). This process will be repeated with subsequent cohorts.

**The Remotivation Process is a continuum of techniques based on the concept of volition (de las Heras, et al., 2003) (see Appendix 1). It is used by occupational therapists to guide their discussions and interactions with their clients based on their level of motivation.**

**It is not a drug or equipment, but a therapeutic use of self-implemented by occupational therapists during their interactions with their patients.**

This study will be conducted in compliance with the protocol, Good Clinical Practice (GCP) and the applicable regulatory requirements.

### **3.3 Preclinical Studies**

3.3.1 **N/A, this study does not involve the use or administration of a drug or equipment. It only involves a discussion guide for the occupational therapist to use during an interaction with the participant.**

### **3.4 Human Studies**

3.4.1 **N/A, this study does not involve the use or administration of a drug or equipment. It only involves a discussion guide for the occupational therapist to use during an interaction with the participant.**

However, Ms. Rubio completed an interview with a patient with BCRL as part of her PhD program at TWU (Rubio, 2016). The phenomenological study explored the client's perception of the occupational therapy service she received. The study asked, "What are the perspectives of patients with BCRL about their occupational therapy experience?" Subsidiary questions were (1) how does the patient describe the experience of living with breast cancer-related lymphedema? (2) What are the client's perspectives of the occupational therapy program they received? (3) What motivates a person with BCRL to remain committed to the self-management program? The study applied the phenomenological approach to explore the experience of a client with BCRL as she lived through the condition and received occupational therapy services. Participant observation and data analysis revealed that breast cancer survivors with BCRL experience limitations in daily life due to the signs and symptoms of the condition. The personal value of independence provides the motivation to commit to the long-term daily self-management of BCRL. They need to have the knowledge and skills to commit to self-management. Clients need timely therapy services that address the manifestation of BCRL. A program that is perceived as helpful provides patient education in a manner specific to their roles, daily occupations and performance skills. Occupational therapy plays an important role in enabling survivors to adapt to the lifelong condition of BCRL. Clients with BCRL will benefit from a practice framework that combines factors of lymphedema therapy and occupational therapy. A program that is unique to occupational therapy addresses the presentation and effects of BCRL, the client's motivation, level of understanding, occupational roles, daily habits and performance skills. The theme *Independence motivates you. It is a commitment* was the inspiration behind the proposed study. The self-management routine adds 15 minutes up to 2 hours to a person's daily routine. Only 65% were able to perform the routine independently while the rest required assistance from others. The client performs her self-management routine and monitors her arms for signs of lymphedema every day even with the amount of time that was added to her routine. This was different from the majority of the findings in both quantitative and qualitative studies. The daily self-management routine for BCRL takes time. Literature suggests that only 49% of participants performed the routine on a daily basis since they prefer to use this time to fulfill occupational roles. They also try to cope in different ways. Some became motivated to stay active and healthy and refuse to let lymphedema control their lives. Others were unable to do so. The client's commitment comes from the value she places on her independence and ability to be in charge of her well-being.

## 4.0 Patient Eligibility

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### 4.1 Inclusion Criteria

#### 4.1.1 Disease Status

Inclusion criteria will be females with unilateral upper extremity lymphedema following procedures to address breast cancer, able to communicate in English and participate in discussion sessions and follow up for the duration of the study of eight weeks.

#### 4.1.2 Age Criteria, Performance Status and Life Expectancy

The study will recruit females 21 years or older. Women in this age-range will be able to participate in work, household responsibilities, and possible child-rearing responsibilities. These are necessary components of quality of life and occupation, which are the primary concepts of interest of the study. The study will include women with vary level of functional performance status and life expectancy as long as they are willing to participate in a 15-minute discussion once a week in addition to their scheduled occupational therapy sessions at COH.

#### 4.1.3 Child Bearing Potential

**The effects of Remotivation Process on the developing fetus are unknown. For this reason, women of child-bearing potential and men must agree to use adequate contraception (hormonal or barrier method of birth control or abstinence) prior to study entry and for six months following duration of study participation. Should a woman become pregnant or suspect that she is pregnant while participating on the trial, she should inform her treating physician immediately.**

#### 4.1.4 Protocol-Specific Criteria

The study will only recruit female participants. The primary purpose of the study involves women breast cancer-survivors. It is necessary to restrict the recruitment based on gender since women's experience of BCRL, psychosocial being, and patterns of participation in work, household responsibilities, and possible child-rearing responsibilities are different from their male counterparts. These are necessary components of quality of life and occupation, which are the primary concepts of interest of the study. The literature reviewed to support the study also focused on women's experience of BCRL.

#### 4.1.5 Informed Consent/Assent

All subjects must have the ability to understand and the willingness to sign a written informed consent.

#### 4.1.6 Prior Therapy

The participant should also be receiving occupational therapy services at COH for BCRL during the first week of the study. The participant can be an on-going patient receiving customary occupational therapy services, or a new patient who will be seen for occupational therapy initial evaluation. The study will include patients with BCRL regardless of any other medical treatment they are receiving in addition to occupational therapy. Some participants may only need less than 4 weeks of customary occupational therapy in order to meet their intervention goals. In this case, the participant will still be asked to return at the end of the fourth week for follow up. Data obtained from the outcome measures will be included in quantitative analysis.

The participant will also be included in the list of names that will be randomly selected for the 60-minute interview.

## **4.2 Exclusion Criteria**

- Patients should not have any uncontrolled illness including ongoing or active infection such as cellulitis.

### **4.2.1 Study-Specific Exclusions**

The study cannot include male patients with BCRL. It is necessary to restrict the recruitment based on gender since women's experience of BCRL, psychosocial being, and patterns of participation in work, household responsibilities, and possible child-rearing responsibilities are different from their male counterparts.

### **4.2.2 Non-Compliance**

Subjects, who in the opinion of the investigator, may not be able to comply with the safety monitoring requirements of the study.

## **4.3 Inclusion of Women and Minorities**

The study is open anyone regardless of gender or ethnicity. Efforts will be made to extend the accrual to a representative population, but in a trial which will accrue approximately 42 subjects, a balance must be struck between subject safety considerations and limitations on the number of individuals exposed to potentially toxic or ineffective treatments on the one hand and the need to explore gender, racial, and ethnic aspects of clinical research on the other. If differences in outcome that correlate to gender, racial, or ethnic identity are noted, accrual may be expanded or additional studies may be performed to investigate those differences more fully.

## **5.0 Screening and Registration Procedures**

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### **5.1 Screening Procedures**

Diagnostic or laboratory studies performed exclusively to determine eligibility for this trial will be done only after obtaining written informed consent. Studies or procedures that were for clinical indications (not exclusively to determine study eligibility) may be used for baseline values, even if the studies were done before informed consent was obtained. Reference is made to Section 10.0 – Study Calendar.

### **5.2 Informed Consent**

The investigational nature and objectives of the trial, the procedures and treatments involved and their attendant risks and discomforts, and potential alternative therapies will be carefully explained to the subject and a signed informed consent will be obtained. Documentation of informed consent for screening will be maintained in the subject's research chart and medical record.

### **5.3 Registration Requirements/Process**

- 1.0 **Ms. Hite will invite potential participants with a brochure as an invitation to participate in the study.**
- 2.0 **Ms. Rubio will then meet with the potential participant remotely through Zoom, a secure videoconferencing program, that is HIPAA certified, and used by COH to communicate with their clients. Participants will also be informed that they should**

**be able to participate in a 15 minutes once a week for 4 weeks with a follow-up discussion a month later. They will also be informed that they can be asked to participate in a 60-minute interview through Zoom after 4 weeks and will have the opportunity for a follow-up visit after 1 month, which is the 8<sup>th</sup> week of the study.**

- 3.0 Informed consent will be obtained from participants prior to the commencement of the study**
  - 4.0 The participant will be assigned a unique number, which will be used to label their data collection sheets and transcription of the interview**
  - 5.0 Ms. Hite will complete the COH Data Collection Form (see Appendix 2), which includes participant demographics.**
- 

#### **5.4 Randomization and/or Dose Level Assignment**

The pretest-post test study will only involve one group and will not involve randomization. 6 participants from each cohort will be invited for a 60-minute interview. They will be randomly selected using an online research randomizer. The participant's unique number will be used instead of their names to protect their identity.



## **6.0 Treatment Program**

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### **6.1 Treatment Overview**

#### **6.1.1 Schedule**

For a tabular view of the treatment, monitoring, and follow-up schedule, see study calendar in Section 10.

2 weeks before the study for each cohort	<ul style="list-style-type: none"> <li>• Recruitment of participants</li> <li>• Participants will speak with Ms. Rubio for any questions regarding the study</li> <li>• Participants will sign the informed consent</li> <li>• Ms. Hite and Ms. Rubio will meet through Zoom to discuss the recruitment outcome</li> </ul>
Week 1	<ul style="list-style-type: none"> <li>• Pretest data collection</li> <li>• 15-minute discussion with Ms. Rubio through Zoom</li> <li>• <i>The participant will continue with customary occupational therapy based on their plan of care. Customary therapy can be through in-patient or outpatient, depending on their occupational therapy plan of care. Note that customary occupational therapy is not included in the study</i></li> <li>• Ms. Hite and Ms. Rubio will meet through Zoom to discuss the study</li> </ul>
Week 2	<ul style="list-style-type: none"> <li>• 15-minute discussion with Ms. Rubio through Zoom</li> <li>• <i>The participant will continue with customary occupational therapy based on their plan of care. Customary therapy can be through in-patient or outpatient, depending on their occupational therapy plan of care. Note that customary occupational therapy is not included in the study</i></li> <li>• Ms. Hite and Ms. Rubio will meet through Zoom to discuss the study if needed</li> </ul>
Week 3	<ul style="list-style-type: none"> <li>• Ms. Rubio will randomly select 6 participants for the 60-minute interview. Ms. Rubio will inform the participant at the end of the 15-minute discussion if they are selected.</li> <li>• 15-minute discussion with Ms. Rubio through Zoom</li> <li>• <i>The participant will continue with customary occupational therapy based on their plan of care. Customary therapy can be through in-patient or outpatient, depending on their occupational therapy plan of care. Note that customary occupational therapy is not included in the study</i></li> <li>• Ms. Hite and Ms. Rubio will meet through Zoom to discuss the study if needed</li> </ul>
Week 4	<ul style="list-style-type: none"> <li>• Post test data collection</li> <li>• Participants who were not selected will participate 15-minute discussion with Ms. Rubio through Zoom</li> <li>• Participants who were selected will participate 60-minute interview with Ms. Rubio through Zoom</li> <li>• Ms. Hite and Ms. Rubio will meet through Zoom to discuss the study outcomes</li> </ul>
Week 5	<ul style="list-style-type: none"> <li>• Ms. Rubio will transcribe the 60-minute interview and will send a copy of the transcript to Ms. Hite</li> <li>• Ms. Hite will give the transcription to the participant for their review</li> <li>• Ms. Rubio will meet with the 6 participants to verify the accuracy of the transcript via Zoom</li> </ul>

Week 6	<ul style="list-style-type: none"> <li>Quantitative data analysis by Ms. Rubio and TWU CRDA</li> <li>Ms. Rubio will meet with the 6 participants to verify the accuracy of the thematic analysis used in qualitative data analysis via Zoom</li> </ul>
Week 7	<ul style="list-style-type: none"> <li>Qualitative data analysis by Ms. Rubio with the CRDA</li> </ul>
Week 8	<ul style="list-style-type: none"> <li>Follow up 15-minute discussion with the study participants (<i>final point of contact with the participant</i>)</li> <li>Ms. Hite will re-administer the outcome measures to the participants who can be at COH during the week.</li> <li>Ms. Hite and Ms. Rubio will meet through Zoom to discuss the outcomes of the study</li> </ul>

This schedule will be replicated in the subsequent cohorts

## 6.2 Planned Duration of Therapy

Participants will meet with Ms. Rubio via Zoom 15 minutes once a week for 4 weeks. Six participants will meet with Ms. Rubio for 60 minutes during the 4<sup>th</sup> week. Participants will be invited once again for a follow-up 15-minute discussion after one month, which is the 8<sup>th</sup> week of the study.

## 6.3 Criteria for Removal from Treatment

Participation in the study is voluntary. The participant may withdraw at anytime.

## 6.4 Subject Follow-Up

- |        |   |
|--------|---|
| Week 5 | <ul style="list-style-type: none"> <li>Ms. Rubio will transcribe the 60-minute interview and will send a copy of the transcript to Ms. Hite</li> </ul>  |
| Week 6 | <ul style="list-style-type: none"> <li>Ms. Hite will give the transcription to the participant for their review</li> <li>Quantitative data analysis by Ms. Rubio and TWU CRDA</li> <li>Ms. Rubio will meet with the 6 participants to verify the accuracy of the transcript via Zoom</li> </ul> |
| Week 8 | <ul style="list-style-type: none"> <li>Follow up 15-minute discussion with the study participants</li> <li>Ms. Hite and Ms. Rubio will meet through Zoom to discuss the outcomes of the study</li> </ul>  |

## 6.5 Supportive Care, Other Concomitant Therapy, Prohibited Medications

The participant should also be receiving occupational therapy services at COH for BCRL during the first week of the study. The participant can be an on-going patient receiving customary occupational therapy services, or a new patient who will be seen for occupational therapy initial evaluation. The study will include patients with BCRL regardless of any other medical treatment they are receiving in addition to occupational therapy.

### Additional Studies

Not Applicable

### 6.5.1 Laboratory Studies

**Laboratory studies and DLT are Not Applicable**

## 7.0 Dose Delays/Modifications for Adverse Events

The study does not involve the administration of drugs or the use of equipment. However, some participants may experience emotional discomfort relating to not being able to perform the self-

management strategies at home. Ms. Hite and Ms. Rubio will provide a positive environment and constant reassurance during the sessions.

## **8.0 Data and Safety Monitoring, Unanticipated Problems and Adverse Event Reporting**

### **TEMPLATE FOR DATA AND SAFETY MONITORING PLAN Risk Level 1 or 2 Single Site Studies**

#### **Definition of Risk Level**

This is a Risk Level 1 study, as defined in the City of Hope Institutional Data and Safety Monitoring Plan [policy effective date: 07/09/14], because it involves Low to minimal risk. The study involves the use of a discussion guide and gathers data regarding the participant's perception of quality of life and adherence to a home program, which is standard to the existing occupational therapy programs for breast cancer survivors with lymphedema. The outcome measures that will be used are in the form of questionnaires that gather data that is non-sensitive in nature. For example, the questionnaires ask the participant regarding her perception of quality of life, habits, roles, and routines. A tape measure will be used to measure the girth of the arm, which is non-invasive. It does not involve administration of chemicals or substances, does not use imaging, does not collect a specimen, nor involves electrophysiological studies or genomic studies. The participants may experience discomfort during the discussions, which is not greater than those ordinarily encountered in daily life or during the performance of routine physical and psychological testing. Each participant's confidentiality is adequately protected

#### **Monitoring and Personnel Responsible for Monitoring**

*The Principal Investigator (PI) is responsible for monitoring protocol conduct and reporting to the City of Hope (COH) Data and Safety Monitoring Committee (DSMC) and Institutional Review Board (IRB) as indicated in the sections below.*

#### **Unanticipated Problems (UP) Involving Risks to Subjects or Others**

An unanticipated problem is any incident, experience or outcome that **meets all three** of the following criteria:

1. Unexpected (in terms of nature, severity, or frequency) given the following: a) the research procedures that are described in the protocol-related documents such as the IRB approved research protocol, informed consent document or Investigator Brochure (IB); and b) the characteristics of the subject population being studied; **AND**
2. Related or possibly related to participation in the research (possibly related means there is a reasonable possibility that the incident, experience, or outcomes may have been caused by the procedures involved in the research); **AND**
3. Suggests that the research places participants or others at greater risk of harm (including physical, psychological, economic, or social harm) than previously known or recognized.

Any UP that occurs during the study conduct will be reported to the DSMC and IRB in accordance with the City of Hope's Institutional policy [policy effective date: 05/14/14] using the electronic submission system, iRIS.

#### **Deviations**

A deviation is a divergence from a specific element of a protocol and that occurred without prior IRB approval. Deviations from the approved protocol should be avoided, except when necessary to eliminate an immediate hazard to a research participant. A Corrective and Preventative Action (CAPA) plan should be developed by the study staff and implemented promptly to avoid similar issues in the future. All deviations from the protocol must be documented in study source documents and promptly reported to the DSMC and IRB.

### **Reporting Deviations**

Investigators may deviate from the protocol to eliminate immediate hazards for the protection, safety, and well-being of the study subjects without prior IRB approval. For any such deviation, the PI will notify the DSMC and IRB, within 5 calendar days of its occurrence by electronic submission of a Deviation Notice via [iRIS](#).

### **Single Subject Exception (SSE) Amendment Request**

Deviations from the written protocol that are not done to eliminate an immediate hazard(s) for the protection, safety, and well-being of study subjects but may increase risk and/or alter the protocol integrity require prior IRB approval. The deviation is submitted as a Single Subject Exception (SSE) amendment request. An IRB approved SSE does not need to be submitted as a protocol deviation to the DSMC. The SSE should be submitted according to the IRB guidelines and [Clinical Research Protocol Deviation policy](#) [policy effective date: 11/07/11] and submitted via [iRIS](#).

A deviation that is not an SSE (i.e., discovered after the occurrence) must be reported to the COH DSMC and IRB according to the [Clinical Research Protocol Deviation policy](#) [policy effective date: 11/07/11] and submitted via [iRIS](#).

## **9.0 Agent Information and Risks**

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### **9.1 The Remotivation Process**

**The Remotivation Process is a continuum of techniques based on the concept of volition (de las Heras, et al., 2003) (see Appendix 1). It is used by occupational therapists to guide their discussions and interactions with their clients based on their level of motivation. It is not a drug or equipment, but a therapeutic use of self-implemented by occupational therapists during their interactions with their patients.**

## **10.0 Correlative/Special Studies**

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No correlative studies will be performed during this trial

## 11.0 Study Calendar

{

This calendar shows the schedule for each cohort.	Week													
	Pre-Study 2 weeks	1	2	3	4	5	6	7	8	9	10	11	12	
Study/15-minute discussion using the Remotivation Process		R	R	R	R									
Informed consent	R													
Demographics		R												
Medical history		R												
Outcome measures: <ul style="list-style-type: none"> <li>• Girth Measurement</li> <li>• Self report of frequency of performance of SMP</li> <li>• Lymphedema Quality of Life Inventory</li> <li>• Model of Human Occupation Screening Tool</li> </ul>		R			R									
Random selection of 6 participants for the interview				R										
60-minute interview					R									
Verify transcription of interview for accuracy						R	R							
Follow-up 15-minute discussion									R					

Communication between Ms. Hite and Ms. Rubio regarding the study	R	R	R	R	R	R	R	R	R	R				
Adverse event evaluation		R	R	R	R	R	R	R	R					
Data Analysis by Ms. Rubio (does not involve the participants)						R	R	R	R	R	R			

a: 15-minute discussion guided by the Remotivation Process

b: Albumin, alkaline phosphatase, total bilirubin, bicarbonate, BUN, calcium, chloride, creatinine, glucose, LDH, phosphorus, potassium, total protein, SGOT[AST], SGPT[ALT], sodium

c: Serum pregnancy test (women of childbearing potential)

d: Outcome measures:

- Girth Measurement
- Self report of frequency of performance of SMP
- Lymphedema Quality of Life Inventory
- Model of Human Occupation Screening Tool

## 12.0 Endpoint Evaluation Criteria/Measurement of Effect

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### 12.1 Response Criteria

The quantitative phase of the study will involve a pretest-posttest design. Pretest data will be collected during the first week of the study. Posttest data will be collected during the fourth week of the study. Four outcome measures will be used to answer the research questions.

The primary endpoints of the study are as follows: The question, *How does remotivation process change daily performance of the lymphedema management techniques?* Will be answered by frequency count that records the number of times the participant performed the SMP during the first and fourth week of the study, which is a 7-day period. The question, *How does the Remotivation Process affect the manifestation of the client's upper extremity lymphedema?* Will be answered through girth measurement. A difference of 2 centimeters between the affected and non-affected extremity is significant and indicative of lymphedema (Taghian, 2014; McGrath, 2013). A girth difference of 2 centimeters in the affected extremity before and after treatment is also considered clinically significant (Taghian, 2014). However, repeated measures ANOVA will be used to establish statistical significance. Repeated measures ANOVA is used since the study will compare the pretest and posttest girth of the affected arm as well as compare the difference between the affected and non-affected arm at pretest and post test.

The secondary endpoints of the study are as follows: The question, *How does the Remotivation Process affect the client's occupational participation and quality of life?* will be answered through the outcome measures Lymphedema Quality of Life Inventory (LyQoLI) (Klernas, Johnsson, Horstmann, & Kristjanson, 2015) and Model of Human Occupation Screening Tool (MOHOST) (Parkinson, Forsyth, & Kielhofner, 2006).

The qualitative phase aims explore the lived experience of the participants after occupational therapy. It will compare the experiences of participants after the intervention period. The perspectives of the participants will be compared with the quantitative data. The study will follow the tradition of phenomenology. It seeks to understand the participant's perspective of a phenomenon and the effect of that perspective on the participant's life through her own personal accounts. Qualitative data will be collected during the fourth week of the study through an interview of six participants. Individual member checking through Zoom during the 6<sup>th</sup> and 8<sup>th</sup> week of the study will verify the final qualitative data with the participants of the study.

## 13.0 Data Reporting/Protocol Deviations

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### 13.1 Data Reporting

#### 13.1.1 Confidentiality and Storage of Records

The original data collection forms will be sent to the COH Occupational Therapy Department and stored in a locked area in the main medical building, room 1024. The protocol uses Electronic Data Collection. The data will be stored in encrypted, password protected, secure computers that meet all HIPAA requirements.

Medical Records: Ms. Hite will fill out a COH Data Collection Form that will contain the patient's medical history, age, diagnosis, surgical report, and occupational therapy documentation, which includes girth measurements taken at 4 cm from the wrist. These forms will not contain the participant's names and will instead use a unique identifier. The forms will follow the format used



by COH and will be sent to Ms. Rubio using encrypted email.

**Audio recording:** An audio recording will be used to accurately transcribe the interview. It will only be used during the 60-minute interview. The interview will be conducted in Ms. Rubio's private office with no other people present. The participant will be instructed not to use her name to protect her identity. Ms. Rubio will use "ma'am" or a pseudonym instead to address the participant. Only Ms. Rubio will have access to the recording. Ms. Rubio will be the only person to transcribe the interview. Audio recordings will be stored in a dedicated and encrypted USB Flash Drive labeled with the participant's unique ID number.

**Data storage and disposal:** Data will be sorted using unique ID numbers and will be stored in a dedicated external hard drive. The audio recording will be stored in a dedicated USB Flash drive. These external storage devices will be encrypted and kept in a locked cabinet or drawer at Ms. Rubio work office and only accessible to Ms. Rubio. All files used in the data collection will be submitted to TWU IRB upon study closure. The data in the laptop computer, USB Flash Drives and removable hard drives will be removed and destroyed after the final write up of the study is submitted by Ms. Rubio to Texas Woman's University after the study manuscript is accepted by the graduate school of TWU, approximately two years after data collection. Emails will be deleted and the "Trash" and "Sent" folder will also be emptied. Ms. Rubio will coordinate with the TWU service desk to remove the data from the USB flash drive and removable hard drives.

When results of this study are reported in medical journals or at meetings, identification of those taking part will not be disclosed. Medical records of subjects will be securely maintained in the strictest confidence, according to current legal requirements. They will be made available for review, as required by the FDA, HHS, or other authorized users such as the NCI, under the guidelines established by the Federal Privacy Act and rules for the protection of human subjects.

### **13.1.2 Subject Consent Form**

At the time of registration, the original signed and dated Informed Consent form, HIPAA research authorization form, and the California Experimental Subject's Bill of Rights (for the medical record) and three copies (for the subject, the research record, and the Coordinating Center) must be available. All Institutional, NCI, Federal, and State of California requirements will be fulfilled.

### **13.1.3 Data Collection Forms and Submission Schedule**

All data will be collected during the 4 weeks of the study and a follow-up discussion after one month using a COH Data collection form, which will be completed by Ms. Hite and a discussion with Ms. Rubio through Zoom. Ms. Rubio will also use Zoom for the 60-minute interview. The interview will be audio recorded. Video recording will not be used to protect the participant's identity. Data will be sent to the location identified in Section 12.1.1 and stored in a secure location.

#### **13.1.3.1 Eligibility Checklist**

The Eligibility Checklist must be completed by a protocol nurse or clinical research associate and signed by an authorized investigator prior to registering the subject. See Section 4.3 for the registration procedure.

#### **13.1.3.2 Prior Therapy Forms and On-Study Forms**

Within 8 weeks of registration, the clinical research associate will submit the COH Data Collection Form, MOHOST Score Sheet, LyQoLI, interview transcription of each cohort.

## **13.2 Protocol Deviations**

### **13.2.1 Deviation Policy**

This protocol will be conducted in accordance with COH's "Clinical Research Protocol Deviation Policy" located at

<http://www.coh.org/dsmc/Documents/Institutional%20Deviation%20Policy.pdf>.

Deviations from the written protocol that could increase patient risk or alter protocol integrity require prior IRB approval of a single subject exception (SSE) request. In addition, if contractually obligated, the sponsor must also approve the deviation. IRB pre-approved SSE protocol modifications are considered an amendment to the protocol and not a deviation. The submission of a deviation report is not required.

Brief interruptions and delays may occasionally be required due to travel delays, airport closure, inclement weather, family responsibilities, security alerts, government holidays, etc. This can also extend to complications of disease or unrelated medical illnesses not related to disease progression. The PI has the discretion to deviate from the protocol when necessary so long as such deviation does not threaten patient safety or protocol scientific integrity. Examples include, but are not limited to: a) dose adjustments based on excessive patient weight; b) alteration in treatment schedule due to non-availability of the research participant for treatment; c) laboratory test results which are slightly outside the protocol requirements but at levels that do not affect participant safety. These instances are considered to be deviations from the protocol. A deviation report will be submitted to the DSMC/IRB within five days.

### **13.2.2 Reporting of Deviations**

All deviations will be reported to the COH DSMC within five days. The DSMC will forward to report to the IRB following review.

### **13.2.3 Resolving Disputes**

The COH Investigational Drug Service (IDS) cannot release a research agent that would cause a protocol deviation without approval by the PI. Whenever the protocol is ambiguous on a key point, the IDS should rely on the PI to clarify the issue.

In situations where there is misperception or dispute regarding a protocol deviation among the persons involved in implementing the protocol, it is the responsibility of the PI to resolve the dispute and the PI may consult with the DSMC chair (or designee) to arrive at resolution.

## **14.0 Statistical Considerations**

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### **14.1 Study Design**

It was agreed upon by the Breast Disease Team that all statistical work will be completed by TWU. Ms. Rubio completed the study design with the assistance of TWU CDRA and her dissertation committee.

The study follows a concurrent triangulation design. Data from the quantitative and qualitative studies are gathered separately then combined during analysis (Creswell, 2005). Results from the quantitative study will be compared with the themes gathered from the qualitative study. Data gathered to answer the research question of quantitative study will be combined with the corresponding themes that answered the questions for the qualitative study. The research questions will be answered through a combined analysis of quantitative and qualitative data, which is described in table below.

<b>Quantitative Data Gathering</b>	
<b>Research Question</b>	<b>Outcome Measures</b>
How does remotivation process change daily performance of the lymphedema management techniques	Average number of days each participant completed the SMP during the first week and fourth week (x/ 7 days) as reported by the participant
How does the Remotivation Process affect the client's manifestation of upper extremity lymphedema?	<ul style="list-style-type: none"> <li>• Physical domain of the LyQoLI</li> <li>• Girth measurement</li> </ul>
How does the Remotivation Process affect the client's occupational participation and quality of life?	<ul style="list-style-type: none"> <li>• MOHOST</li> <li>• LyQoLI</li> </ul>
<b>Qualitative Data Gathering</b>	
<b>Qualitative Research Question</b>	<b>Interview Question</b>
What are the perspectives of patients with BCRL about the self-management program after participating in an occupational therapy program using the Remotivation Process?	<p><i>What are your thoughts on the lymphedema home program?</i></p> <p><i>Sample questions:</i></p> <ol style="list-style-type: none"> <li>4. <i>What do you understand about lymphedema?</i></li> <li>5. <i>If there were challenges in doing the home program, how were these problems handled?</i></li> <li>6. <i>What has helped you do the home program?</i></li> </ol>
What are the perspectives of patients with BCRL about physical appearance their arm after the occupational therapy program?	<p><i>How do you feel about your body after spending some time with occupational therapy?</i></p> <p><i>Sample questions:</i></p> <ol style="list-style-type: none"> <li>4. <i>What have you noticed in your arm in the past four weeks?</i></li> <li>5. <i>How do you feel about lymphedema when you first noticed changes in your arm?</i></li> <li>6. <i>How do you feel about lymphedema after receiving occupational therapy?</i></li> </ol>
How do patients with BCRL describe their daily life after occupational therapy?	<p><i>How do you feel about your everyday life &amp; what you understand about lymphedema?</i></p> <p><i>Sample questions:</i></p>

- 
6. *What are some of the things that you engaged in before lymphedema?*
  7. *What are some of the things that you engage in at this point after occupational therapy?*
  8. *What are some of the activities that you were doing before lymphedema?*
  9. *What are some of the activities that you were doing after lymphedema?*
  10. *What are some activity limitations, if any, have you experienced?*
- 

#### **Planned implementation of the quantitative study.**

Each participant will receive lymphedema therapy that consistent with the plan of care designed by their respective occupational therapists and will follow the existing lymphedema therapy program of COH. The occupational therapists will provide evaluation and intervention services that are customary for BCRL and will not be involved in the study.

**Study week 1.** The participants will either be evaluated or receive customary lymphedema therapy intervention from the staff occupational therapist, which ever is scheduled for the week. The evaluation or treatment session is part of the staff occupational therapists' role in the department and not a part of the study. The following section clarifies the role of the Ms. Hite and Ms. Rubio.

*Ms. Hite.* Ms. Hite will gather the signed consent forms during the prestudy. During week 1, she will also gather pretest data. Ms. Hite will complete the COH Data Collection Form (see Appendix 2), administer the MOHOST (see Appendix 3) and LyQoLI (see Appendix 4) to participants during the first week. Ms. Hite also reminds the participants of the scheduled 15-minute session with the PI. Ms. Hite meets with the PI at the end of the week to discuss any issues that occurred during the sessions.

*Ms. Rubio.* Ms. Rubio will receive an electronic copy of the COH Data Collection Form, MOHOST, and LyQoLI through encrypted email. She will then meet with the participants individually for 15 minutes through Zoom. The PI will ask each participant how often she performs the SMP and then proceed to implement the planned discussion sessions, which will follow the Remotivation Process (see Appendix 1). Ms. Rubio will record these weekly discussions using field notes (see Appendix 5).

**Study week 2 and 3.** The participants will continue with their occupational therapy program with their respective therapists following their individual plan of care. These sessions are not part of the study. The following section once again clarifies the role of the Ms. Hite and Ms. Rubio.

*Ms. Hite.* Ms. Hite communicates with the PI of any issues that may arise during the week. She will also remind the participants of the 15-minute discussion session with Ms. Rubio. Ms. Hite will communicate with Ms. Rubio any issues regarding the study via encrypted email or through Zoom.

*Ms. Rubio.* Ms. Rubio will continue to implement the individual 15-minute sessions to

each participant through Zoom. The outcomes of the discussions will be recorded using field notes (see Appendix 5). She will also randomly select six participants for the qualitative phase of the study. Ms. Rubio will invite the six selected participants to complete a 60-minute interview during her session on week 3.

**Study week 4.** The participants will continue with their occupational therapy program with their respective therapists following their individual plan of care. These sessions are not part of the study. The following section once again clarifies the role of the Ms. Hite and Ms. Rubio.

*Ms. Hite.* Ms. Hite will gather posttest data. She will complete the COH Data Collection Form (see Appendix 2), administer the MOHOST (see Appendix 3) and LyQoLI (see Appendix 4) to participants during the first week. Ms. Hite will meet with Ms. Rubio at the end of the week to discuss the outcome of the study via Zoom.

*Ms. Rubio.* Ms. Rubio will receive an electronic copy of the COH Data Collection Form, MOHOST, and LyQoLI through encrypted email. She will then meet with the participants individually for 15 minutes through Zoom. This is also the time when Ms. Rubio individually interviews the six selected participants to complete a 60-minute interview, which will be discussed in the section on qualitative study design.

**Week 8:** A follow-up will be completed during this week. Ms. Hite will help arranged the follow-up session between Ms. Rubio and each participant. Ms. Rubio will meet with each participant for another 15-minute discussion, which will follow the same format used in the study. The participants will also be asked how many times they were able to perform the SMP that week.. Ms. Hite will complete the COH Data Collection Form, MOHOST, LyQoLI of the participants who are scheduled to be seen by their occupational therapists during week eight. The results of the study will be shared with Ms. Hite after final data analysis for each cohort during the debriefing Through Zoom.  
Statistical Analysis Plan

The independent variable will be time between prettest and post test. Dependent variables will be the data from the outcomes measures. Paired t-test will be used to compare pretest and posttest scores to determine if there is a significant difference in the scores of the single group of participants who completed the study.

The outcome measures will be re-administered to the participants and will be compared with the posttest scores. Repeated measures ANOVA is used since the study will compare the prettest and posttest girth of the affected arm as well as compare the difference between the affected and non-affected arm at prettest and post test. Paired t-test, will compare the number of times the participant performs the self-management program at prettest and post test. Paired t-test will also be used to compare the scores of the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory. Pearson correlation will be used to determine the correlation between the score from the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory.

Non- parametric tests, will be used should the study does not meet the assumptions of parametric test. For non-parametric tests in this case, Friedman's ANOVA will be used to compare girth at prettest and posttest and Wilcoxon signed-ranks test will be used to compare the prettest and post test scores of the MOHOST, frequency of performing the SMP, and LyQoLI. The Spearman's ranks tests will be used to determine the correlation between the score from the Model of Human Occupation Screening Tool and scores from the Lymphedema Quality of Life Inventory. The qualitative phase follows a descriptive phenomenological design. Thematic analysis will be used to analyze data.

Data analysis will be as follows:

**Will the Remotivation Process, an occupational therapy intervention, lead to an increased daily performance of the lymphedema management techniques?** Frequency count will determine the number of times the participant performed the SMP during the first and fourth week, which is a 7-day period. The average number of days during the first and fourth weeks will be recorded. The average number of days in a week is a continuous variable. Paired t test will be used to determine if the difference in frequency of weekly performance is significant. Wilcoxon signed-ranks test will be used should the study does not meet the assumptions of parametric test.

**How does the Remotivation Process affect the manifestation of the client's upper extremity lymphedema?** Circumferential measurement will be obtained from each participant, which is a continuous variable. Arm girth of each of the participants will be calculated to determine the difference in girth of the affected limb before and after the 4-week period as well as the difference in girth between the affected and non-affected extremity after the study. The average difference in the two girth comparisons will be calculated for each participant. A difference of 2 centimeters between the affected and non-affected extremity is significant and indicative of lymphedema (Taghian, 2014; McGrath, 2013). Paired t test will be used to determine if there is a difference in the average change in girth over time. Wilcoxon signed-ranks test will be used should the study does not meet the assumptions of parametric test.

**How does the Remotivation Process affect the client's occupational participation and quality of life?** The MOHOST and LyQoLI will be used to measure occupational participation and QOL respectively. The MOHOST has six sections with 4 items in each section, with a total of 24 items. It involves a Likert Scale, which will be converted to a numeric score: 4 = Facilitates occupational participation, 3 = Allows occupational participation, 2 = Inhibits occupational participation, and 1 = Restricts occupational participation. The average score of each of the 6 sections, as well as the total score, will be calculated to determine the change score. Chronbach's alpha will be used to determine if the averaged items are conceptually related. Chronbach's alpha will be calculated at pretest.

The LyQoLI has 61 items divided into three sections, each representing a concern due to lymphedema. The physical concern section has 17 items, the social concern section has 10 items, and the practical concern section has 18 items. It also involves a Likert Scale, which will be converted to a numeric score: 4 = None, 3 = A little bit, 2 = Somewhat, and 1 = A little. The average score of each of the 3 sections, as well as the total score, will be calculated to determine the change score. Chronbach's alpha will be used to determine if the averaged items are conceptually related.

Paired t test will be used to determine if the difference in pretest and posttest scores is significant. Wilcoxon signed-ranks test will be used should the study does not meet the assumptions of parametric tests. The Pearson correlation will be used to determine if there is an association between LyQoLI and MOHOST scores. Spearman rank test will be used if the assumptions for the parametric test are not met.

**Participant drop-out.** The difference in girth and frequency of SMP performance between the single group of participants who completed the study and each participant who dropped out of the study will also be compared. ANOVA will be used since the study will compare the scores of 2 groups: the mean score of the participants who completed the study, and the score of each participant who dropped out. The Kruskal-Wallis test will be used should the study does not meet the assumptions of parametric test

Research Questions	Outcome Measure	Analysis
How does remotivation process change daily performance of the lymphedema management techniques?	Average # of days participant completes Self-Management Program in a 7-day period	Paired t-test
How does the Remotivation Process affect the client's manifestation of BCRL?	Physical domain of the Lymphedema Quality of Life Inventory (LyQoLI)  Girth measurement	Paired t-test  Repeated Measures ANOVA
How does the Remotivation Process affect the client's occupational participation and quality of life?	Model Of Human Occupation Screening Tool LyQoLI	Paired t-test Pearson's correlation
Comparison between participants who completed the study and those dropped out	Girth measurement frequency count	ANOVA
Comparison of outcome measures at the end of the 4-week study and during follow-up after 1 month	All outcome measures possible	1-way ANOVA

### Combining data from the cohorts

The pretest and posttest scores of the participants from each cohort will be analyzed at the end of the 12-month study period. Participants will only be included in one cohort. The pretest score of each participant at the first week of the intervention will be matched with her own posttest score at the end of the intervention, which is on the fourth week. Each cohort will have a different set of participants. Each cohort will receive the same intervention, following the same schedule. Therefore, t-test will be used to analyze the quantitative data at the end of the 12-month study period.

### Planned implementation of the qualitative study.

This phase aims explore the lived experience of the participants after occupational therapy. The perspectives of the participants will be compared with the quantitative data. In phenomenological research, the researcher's role is to analyze the experiences of the participant, perceive the meaning of the experience, and arrive at its essence. It seeks to understand the participant's perspective of a phenomenon and the effect of that perspective on the participant's life through her own personal accounts. The study will follow the tradition of phenomenology. Qualitative research expands a clinician's perspective of the therapy services he or she provides (Tomlin & Borgetto, 2011). The study will follow the tradition of phenomenology (Giorgi, 2009). Phenomenology investigates the meaning, structure, and essence of the lived experience to gain new insight into a particular phenomenon. It aims to capture the thoughts and feelings of the person who has experienced or currently experiencing the phenomenon of interest. Phenomenology is a qualitative research method based on the work of Edmund Husserl. He believed that the human

experience provides valuable information that will understand human motivation. He also created scientific methods to provide rigor in the psychologist's effort to study the participant's subjective experience and behavior (Flood, 2010; Giorgi, 2009). Two main phenomenological approaches were reviewed for the proposed study. Descriptive phenomenology is based on Husserl's approach to scientific inquiry. Hermeneutic phenomenology is based on the work of Heidegger, a student of Husserl who adapted and modified Husserl's approach (Corby et al., 2015; Flood, 2010). Both descriptive and hermeneutic phenomenology use qualitative, in-depth interview as the traditional data collection strategy. However, descriptive phenomenology and hermeneutic phenomenology differ in the approach to data analysis.

**Descriptive Phenomenology.** This study follows the Descriptive Phenomenological Method, outlined by Amedeo Giorgi (2009) who was also a student of Husserl. Descriptive phenomenology is based on Husserl's assumption that the experience perceived by the person's consciousness is able to generate valuable data and needs to be studied objectively. Humans, according to Husserl, generally do not take time to critically reflect on their experiences. There is a need for a scientific approach to gather and analyze the lived experience of a group of people specific to the phenomenon of interest. Husserl believes that the PI must suspend, or abstract themselves from all prior personal knowledge and biases related to the phenomenon of interest during data collection and analysis (Corby et al., 2015; Flood, 2010). This is referred to as bracketing. Bracketing is necessary to maintain a scientific approach and it reflects Husserl's attempt to provide rigor and establish phenomenology as a scientific inquiry. Husserl also believed that there are common features in the experiences of those individuals who live through the phenomenon of interest. Therefore the purpose of descriptive phenomenology as a scientific inquiry is to identify these commonalities, or what he called eidetic structures (Corby et al., 2015; Giorgi, 2009). Husserl's approach is aimed at describing how a phenomenon presents its self at that given moment. It seeks to use language to articulate or describe the phenomenon in the present rather than interpret or analyze based on past knowledge and experience.

**Week 3: Sampling.** There are no rules regarding sample size for qualitative inquiry (Patton, 2015). It is suggested that the sample size is small so that experiences can be examined in-depth (Mapp, 2008). Data saturation is reached when no new information is obtained and participant responses are similar or redundant (Patton, 2015). Previous PIs have reported that saturation was reached between 30 to 120 minutes (Mapp, 2008).

Random sampling will be used in this study to minimize bias should the PI purposefully selects the participants. Participants will only be included if they agree to participate in a 60-minute interview with Ms. Rubio. Ms. Hite will be informed which 6 participants will be participating in a 60-minute interview to help schedule the session via Zoom.

The unique identifier of each participant will be placed on a numbered list. An online randomization software, Research Randomizer (<https://www.randomizer.org>) will be used to draw six numbers. The names that correspond to the first six numbers will be invited for the face-to-face interview. The next six names will be the alternate participants should any of the first six participants are unable to participate in the interview.

#### **Week 4: Data collection procedures.**

**Week 4: Data collection procedures.** Ms Rubio will document her observations, insights, preliminary interpretation, her own feelings, and reactions through journaling in order to bracket her own perception and maintain the tradition of descriptive phenomenology.

Ms. Rubio will directly ask the participant if she was willing to participate in an interview at the end of the 15-minute discussion during the third week. Participants will be interviewed via Zoom at the end of their final therapy session during the fourth week. The interview is estimated to last for 60 minutes. Although the session will be completed through



video conferencing, it will only be recorded through a voice recording application. Interview questions were developed based on the focus of phenomenology. Ms. Rubio will use in-depth, semi-structured interview to gain a deeper understanding of the client's lived experiences of performing the SMP for BCRL and perception of her life with BCRL following therapy. The interview guide will focus on the client's source of motivation to manage the condition, her daily habits, and the skills that were involved in the therapy program (see Appendix 6). The interview will follow 3 main questions. However, the qualitative approach of the study provides flexibility and will allow the Ms. Rubio to explore topics that emerge during the interview aside from the planned set of questions. The participant will be informed that the Ms. Rubio will transcribe the interview and attempt to communicate with her via phone call after 1 week to verify the information gathered during the interview for member checking. The participant will also be informed that Ms. Rubio will follow up after another week to verify the interpretation of the transcription.

Field notes and the transcription of the interview will be collected at the end of the study to be used in the triangulation of qualitative data. **Week 5: Data transcription.** Each participant will be given a copy of her own transcript a week after the study to give them time to review the document. Ms. Rubio will send a copy of the transcript to the onsite collaborator to be handed to the participants. She will also meet with each participant who was interviewed to verify the accuracy of the transcription.

**Week 6: Data Analysis.** Ms. Rubio will attempt to verify the thematic analysis with the participants of the study through member checking by meeting each participant online through Zoom .. Field notes will be used to document main points discussed during the individual call but will not be audio recorded.

**Data analysis for descriptive phenomenology.** Ms. Rubio will transcribe the audio recordings prior to analysis. Interpretation of narrative in descriptive phenomenology begins with the PI reading the interview transcription to have a general understanding of the qualitative data. However, bracketing also occurs at this stage. Ms. Rubio identifies commonalities, which are assigned to natural meaning units or NMUs (Corby et al., 2015; Flood 2010; Giorgi, 2009; Devenish, 2002). These meaning units are considered separate entities, which are then organized into themes based on the research questions. The central themes are transformed into descriptive statements in relation to the research questions (Flood, 2010; Devenish, 2002). Husserl's approach to qualitative inquiry as a rigorous scientific method led to the emergence of phenomenological research methods. One of these methods is by Giorgi, who outlined four steps in the analyzing narratives in descriptive phenomenological research. These steps are (1) reading the transcript to obtain an overview, (2) identify natural NMU, (3) transformation of the data into central themes through terms used in psychology, and (4) development of a description based on the transformed NMUs (Corby et al., 2015; Flood, 2010; Giorgi, 2009).

**Step 1.** The interview will be transcribed for analysis during week 5. The transcript will be read once to have an initial impression of the content. Ms. Rubio will read the transcript again to gain an intuitive overview of the phenomenon under investigation. Ms. Rubio will call each participant to verify the initial analysis through member checking

**Step 2.** The NMUs are identified. Common NMUs will be reduced to central themes. Ms. Rubio will eliminate redundant central themes to form a thematic index. Themes that are identical or synonymous will be grouped together. Ms. Rubio plans to use NVivo qualitative data analysis Software Version 10. A second reviewer, who is also trained in the Model of Human Occupation, will review all of the transcriptions containing the de-identified data and identify his or her own set of NMUs

**Step 3.** Central themes will be transformed into psychological language and concepts from the MOHO, with emphasis on the phenomenon of BCRL. Ms. Rubio will create a rigorous description of the interpretation of these themes in relation to MOHO and BCRL. Other types of thematic analysis may be needed once data are collected. Ms. Rubio will confirm the central themes with the second reviewer. Ms. Rubio will attempt to verify the central themes with the participants of the study through member checking via individual phone call.

**Step 4.** The transformed central themes will be synthesized into a consistent statement in order to answer the questions that guided the qualitative inquiry.

**Trustworthiness techniques.** Trustworthiness strategies include triangulation, member checking, bracketing, and peer examination (Patton, 2015; Krefting, 1991). Ms. Rubio will address trustworthiness through the interview techniques, field notes, and use of the dense description of research methods (Krefting, 1991). Ms. Rubio will also follow up with the participants to clarify the main themes after coding, which is two weeks after the 60-minute interview. A field journal will be completed once a week, which will contain Ms. Rubio's weekly plan for the study, ideas on the methods for data collection and analysis, and personal reflections on the progression of the project. The journal will be the means for bracketing.

### **Combining data from the cohorts**

Each interview transcript will be analyzed separately for common themes. The themes from each individual interview will be combined and analyzed at the end of the 12-month study period.

## **Integration of data from quantitative and qualitative studies**

In a concurrent triangulation design, data gathered to answer the research question of quantitative study will be combined with the corresponding themes that answered the questions for the qualitative study. Data from the quantitative and qualitative studies will be combined at the end of the 12-month study period.

### **How does remotivation process change daily performance of the lymphedema management techniques**

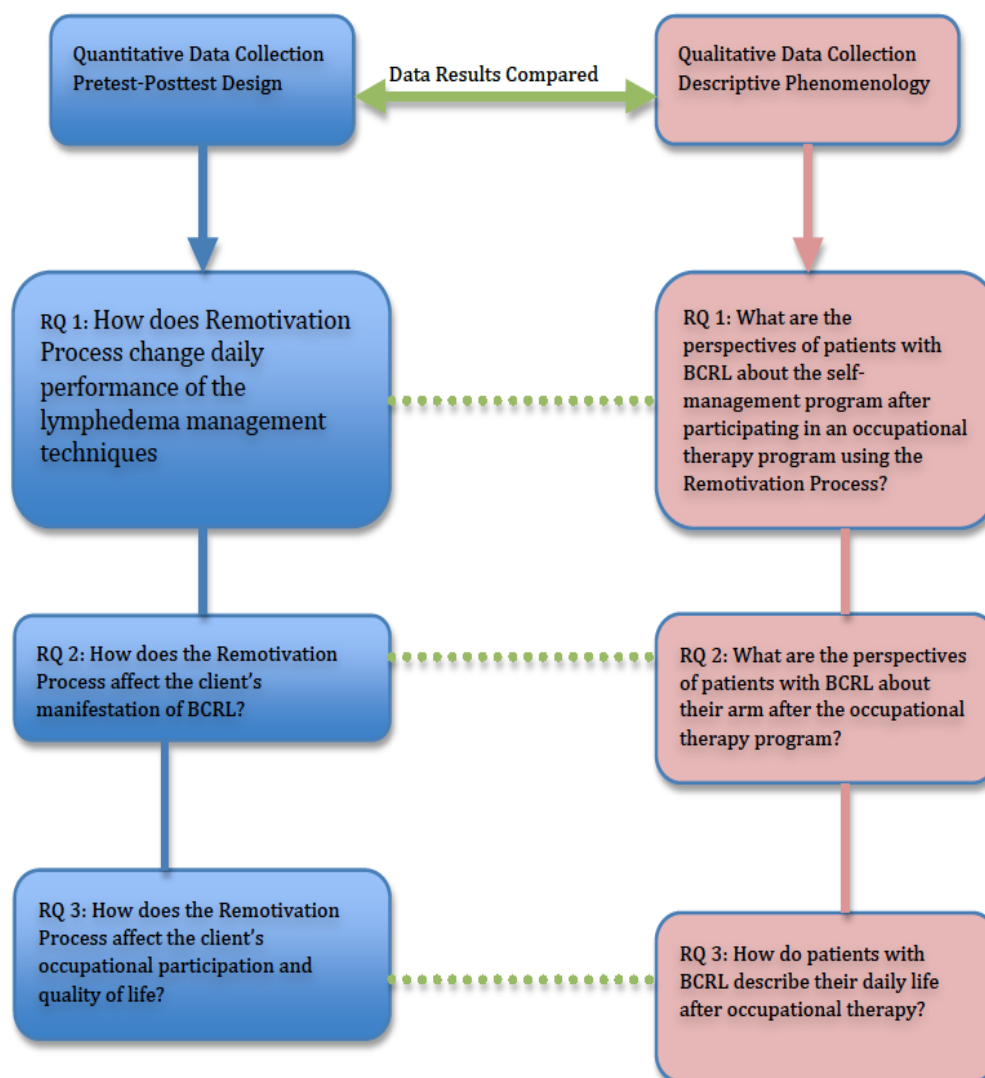
Ms. Rubio will compare the average number of days during the first and fourth week that the participants performed the SMP paired t-test. She will then compare the quantitative data with the perceived ability to perform the SMP of the participants.

### **How does the Remotivation Process affect the manifestation of the client's upper extremity lymphedema?**

The average difference in the two girth comparisons will be calculated for each participant. The Physical Domain of the LyQoLI will also be used to determine if there is a difference in the physical manifestation of BCRL between pretest and posttest. Paired t-test will be used to determine if there is a difference in the average change in girth and Physical Domain between pre and post test scores. This will then be compared with the quantitative data with the overall perception of the affected arm based on the thematic analysis.

### **How does the Remotivation Process affect the client's occupational participation and quality of life?**

The MOHOST and LyQoLI will be used to measure occupational participation and QOL respectively. Paired t-test will be used to determine if there is a difference in between pre and post test scores. This will then be compared with the quantitative data with the overall perception ability to perform daily activities based on the thematic analysis.



## 14.2 Sample Size Accrual Rate

In the original study, the G\*Power 3.1 software was used for a priori power analysis to determine the sample size. The study will involve one group of 42 participants, using effect size 0.5 and considering a 15% attrition rate.

The study aims to reach the target sample size in the first cohort. Ms. Rubio will conduct a preliminary analysis after each cohort to determine if the findings are significant.. Participants in the previous cohort will not be included in the subsequent cohorts. Subsequent cohorts will be recruited, with each cohort participating in the same 8-week schedule. The last cohort will be recruited on the 10<sup>th</sup> month of the study. This will allow the last cohort to complete the 8-week program at the end of the 12<sup>th</sup> month, which is the close of the study.

A non-parametric analysis will be used to confirm the results if the sample size is less than 42 or if basic assumptions (e.g. normality, equal variance, and no outliers, etc.) for parametric data analysis are not met after the last cohort completes the intervention.

## 15.0

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### 15.1 Institutional Review Board

In accordance with City of Hope policies, an Institutional Review Board (IRB) that complies with the federal regulations at 45 CFR 46 and 21 CFR 50, 56 and State of California Health and Safety code, Title 17, must review and approve this protocol and the informed consent form prior to initiation of the study. All institutional, NCI, Federal, and State of California regulations must be fulfilled.

### 15.2 Recruitment of Subjects

The study will involve adult females, ages 21 and older, with BCRL who were referred to the therapy department of COH for occupational therapy will be included in the study. Ms. Rubio will send Ms. Hite copies of the brochures (see Appendix 7) and consent form (see Appendix 8). Ms. Hite will invite potential participants with a brochure as an invitation to participate in the study (see Appendix 7). Ms. Rubio will then meet with the potential participant remotely through Zoom, a secure videoconferencing program, that is HIPAA certified, and used by COH to communicate with their clients. Participants will also be informed that they should be able to participate in a discussion for 15 minutes each week with Ms. Rubio and will possibly be asked to stay for a 60-minute interview through Zoom on the 4<sup>th</sup> week of the study. Informed consent will be obtained from participants prior to the commencement of the study (see Appendix 5).

The verbal script for the recruitment of the participant will be as follows:

“ You are invited to participate in a research study for Ms. Rubio’s dissertation at Texas Woman’s University. The purpose of this research is to gather your thoughts about your experience on lymphedema and the occupational therapy services you received. You have been asked to participate in this study because you were referred for occupational therapy services. As a participant in this study, you will be asked to participate in a 15-minute discussion with Ms. Rubio at the end of each week after your therapy session. This will be an opportunity for you to share your thoughts on your recovery during the week. You may also be asked to participate in an individual interview at the end of the 4<sup>th</sup> week. If selected, you will be asked to participate in a one-on-one interview with Ms. Rubio to further discuss your experience with lymphedema and the therapy you have received. Participation in this study is voluntary and you can withdraw at any time. You will still receive occupational therapy services for lymphedema without difficulty should you decide not to participate. We have prepared a brochure with more information on the study. If you are willing to participate, you will be provided a consent form that provides more detail about the study”

**COH recommended that Ms. Rubio perform a follow-up after one month. Ms. Rubio will then meet with the participants after one month through Zoom. Ms. Rubio will use the same set of guide questions used during the 15-minute weekly discussions. Due to this change, the participants will also be informed that the PI will contact them again after one month for another 15-minute discussion. Ms. Hite will again complete a Data Form for participants who are still receiving occupational therapy services at the time of the follow-up. The data collected during the follow-up will be compared with the participants' post test data. A**

**sentence will be added in the verbal script for the recruitment of the participant to reflect this change:**

**“ Ms. Rubio will follow up with you after one month to see how you are doing. The follow-up will be similar to the weekly discussion session and will last for about 15 minutes.”**

### **15.3 Advertisements**

Advertisements to include print, media (radio, television, billboards), telephone scripts, lay summary to be posted on City of Hope’s public Clinical Trials On-Line<sup>SM</sup> website, etc., will be reviewed and approved by the IRB prior to their use to recruit potential study subjects.

### **15.4 Study location and Performance Sites**

This study will be performed at COH.

### **15.5 Confidentiality**

This research will be conducted in compliance with federal and state of California requirements relating to protected health information (PHI). **COH will not grant access but agreed to have the onsite collaborator fill out a Data Form that will contain the patient’s medical history, age, diagnosis, surgical report, and occupational therapy documentation, which includes girth measurements taken at 4 cm from the wrist (Appendix B).** These forms will not contain the participant’s names and will instead use a unique identifier. The forms will follow the format used by COH and will be sent to Ms. Rubio using encrypted email. An audio recording will be only be used during the 60-minute interview. The interview will be conducted in Ms. Rubio’s private office with no other people present. The participant will be instructed not to use her name to protect her identity. Ms. Rubio will use “ma’am” or a pseudonym instead to address the participant. Only Ms. Rubio will have access to the recording. Ms. Rubio will be the only person to transcribe the interview. Audio recordings will be stored in a dedicated and encrypted USB Flash Drive labeled with the participant's unique ID number. Data will be sorted using unique ID numbers and will be stored in a dedicated external hard drive. The audio recording will be stored in a dedicated USB Flash drive. These external storage devices will be encrypted and kept in a locked cabinet or drawer at Ms. Rubio work office and only accessible to Ms. Rubio. The principal investigator and co-investigators will have access to this information, but all information will be treated confidentially. No identifiers will be used in any subsequent publication of these results.

### **15.6 Financial Obligations and Compensation**

The research participant will not be paid for taking part in this study. However, participants will still benefit from the study. Participants will receive access to added intervention provided by Ms. Rubio, which is an additional 15 minutes to discuss their concerns and activities related to therapy. They will also be provided with an opportunity to talk about and reflect on their recovery. The study will also provide an initial idea regarding the benefits of the Remotivation Process in improving the function and quality of life of women with breast cancer-related lymphedema when used in an occupational therapy program. It will provide the Department of Occupational Therapy of COH with a potential evidence-based option for their lymphedema program. The department will gain knowledge and additional skills that the department can use in their work as occupational therapists.

### 15.7 Informed Consent Processes

The Principal Investigator or IRB approved named designate will explain the nature, duration, purpose of the study, potential risks, alternatives and potential benefits, and all other information contained in the informed consent document. In addition, they will review the experimental subject's bill of rights and the HIPAA research authorization form. Research subjects will be informed that they may withdraw from the study at any time and for any reason without prejudice, including as applicable, their current or future care or employment at City of Hope or any relationship they have with City of Hope. Research subjects will be afforded sufficient time to consider whether or not to participate in the research.

The PI originally planned to recruit 20-42 breast cancer patients who will be assigned to treatment and control groups, each group with 10-21 participants. In the original plan, deception would be involved since the participants will be blind to the group assignment and will not be informed of the difference in the format of the 15-minute discussion between the treatment and control group. Deception was necessary because the intent of the study is to compare the effect of the Remotivation Process when added to the normal, customary occupational therapy program for lymphedema. The discussion will follow the guidelines of the Remotivation Process for the treatment group while the control group will follow a general format with open-ended questions. The differences in format are necessary to compare the outcome measures of participants receiving the Remotivation Process and those who do not.

However after discussing the study with the Breast Cancer team, it was agreed that the study should proceed with a single group due to the small sample size. Therefore, the study will only involve one group of 42 participants. There will be no deception involved since all of the participants will receive the same treatment, will be informed that the Remotivation Process will be used, and **will be informed about the intent of the study prior to participating**. Should sufficient doubt be raised regarding the adequacy of comprehension, further clarifications will be made and the questionnaire repeated until a satisfactory result is obtained. Prospective research subjects who cannot adequately comprehend the fundamental aspects of the research study with a reasonable amount of discussion, education and proctoring will be ineligible for enrollment. For those subjects who do comprehend the fundamental aspects of the study, consent will be obtained and documented, followed by eligibility testing. The research team will review the results of eligibility testing and determine if the subject is a candidate for study enrollment.

## 16.0 References

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- Corby, D., Taggart, L., & Cousins, W. (2015). People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities, 47*, 451-465.
- Davies, C., Ryans, K., Levenhagen, K., & Pardomo, M. (2014). Quality of life and functional outcome measures for secondary lymphedema in breast cancer survivors. *Rehabilitation Oncology, 32*(1), 7-12.
- Dawson, B. & Trapp, R.G. (2004). *Basic & clinical biostatistics* (4th ed.). USA: The McGraw-Hill Companies, Inc.
- de las Heras, C.G., Llerena, V. & Kielhofner, G. (2003). *A user's manual for remotivation process: Progressive intervention for individuals with severe volitional challenges*. University of Illinois at Chicago: Chicago: The Model of Human Occupation Clearinghouse, Department of Occupational Therapy, College of Applied Health Sciences.
- Faul, F., Erdfelder, E., Lang, A., & Buchner, A. (2007). G\* power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*(2), 175-191. doi:10.3758/BF03193146.
- Giorgi, A. (2009). *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. Duquesne University Press. PA: USA
- Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4th ed.). Baltimore:MD: Lippincott, Williams & Wilkins.
- Klernas, P., Johnsson, A., Horstmann, V., Kristjanson, L. J., & Johansson, K. (2015). Lymphedema quality of life inventory (LyQLI)-development and investigation of

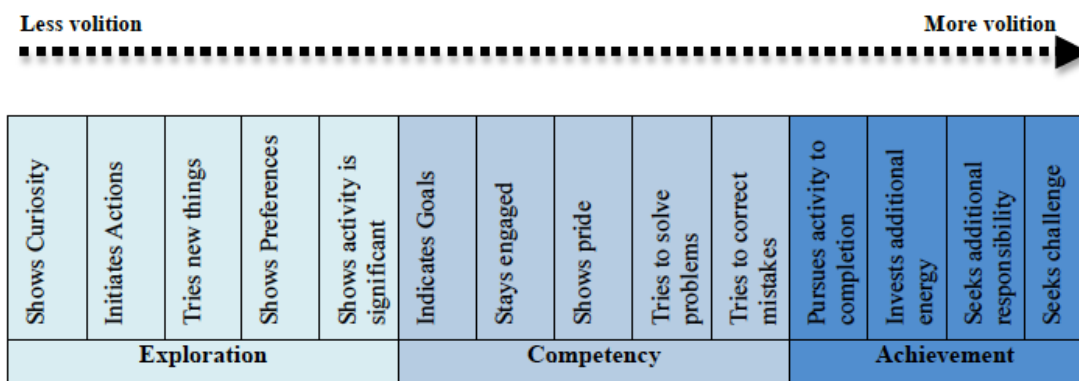
- validity and reliability. *Quality of Life Research*, 24, 427-439.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3), 214-222.
- Lasinski, B. B., Thrift, K. M., Squire, D., Austin, M. K., Smith, K. M., Wanchai, A., . . . Armer, J. M. (2012). A systematic review of the evidence for complete decongestive therapy in the treatment of lymphedema from 2004 to 2011. *Pm&r*, 4(8), 580-601. doi:http://ezproxy.twu.edu:2079/10.1016/j.pmrj.2012.05.003.
- Lee, S. W., Forsyth, K., Morley, M., Garnham, M., Heasman, D., & Taylor, R. (2013). Mental health payment-by-results clusters and model of human occupation screening tool. *OTJR: Occupation, Participation & Health*, 33(1), 40-49. doi:10.3928/15394492-20120426-01.
- Loh, S.Y. & Musa, A.N. (2015). Methods to improve rehabilitation of patients following breast cancer surgery: A review of systematic reviews. *Breast Cancer: Targets and Therapy*, 7, 81-98. doi:https://dx.doi.org/10.2147/BCTT.S47012
- Mapp, T. (2008). Understanding phenomenology: The lived experience. *British Journal of Midwifery*, 16(5), 308-311.
- McGrath, T. (2013). Irish insights into the lived experience of breast cancer-related lymphoedema: Implications for occupation focused practice. *WFOT Bulletin*, 68, 44-50. doi: ISSN 14473828
- Parkinson, S., Forsyth, K., Kielhofner, G. (2006). *The model of human occupation screening tool (MOHOST; version 2.0)*. University of Illinois at Chicago:
- Parmenter, V., Fieldhouse, J., & Barham, R. (2013). An occupational therapy intervention service to hostels for homeless people: An overview. *British Journal of Occupational Therapy*, 76(5), 242-245. doi:10.4276/030802213X13679275042807



- Patton, M. Q. (2015). *Qualitative research & evaluation methods* (4th ed.). CA: SAGE Publications.
- Pépin, G., Guérette, F., Lefebvre, B., & Jacques, P. (2008). Canadian therapists' experiences while implementing the model of human occupation remotivation process. *Occupational Therapy in Health Care*, 22(2), 115-124.
- Pullinger, W. F. (1960). Remotivation. *The American Journal of Nursing*, 60(5), 682-685.  
doi:10.2307/3418168
- Rubio, L. K. (2016). *Phenomenological study of breast cancer-related lymphedema*. Unpublished manuscript.
- Taylor, R. (2017). *Model of human occupation: Theory and application* (5th ed.). USA: Lippincott Williams and Wilkins
- Taghian, N. R., Miller, C. L., Jammallo, L. S., O'Toole, J., & Skolny, M. N. (2014). Lymphedema following breast cancer treatment and impact on quality of life: A review. *Critical Reviews in oncology/hematology*, 92(3), 227-234.  
doi:http://ezproxy.twu.edu:2079/10.1016/j.critrevonc.2014.06.004.
- Tahan, G., Johnson, R., Mager, L., & Soran, A. (2010). The role of occupational upper extremity use in breast cancer related upper extremity lymphedema. *Journal of Cancer Survivorship*, 4(1), 15-9. doi:http://ezproxy.twu.edu:2079/10.1007/s11764-009-0103-4

## APPENDIX B.1

### The Remotivation Process and Planned Discussion Guide



*Figure 2. The three stages of volitional development and corresponding VQ items. Adapted from “A User’s Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p.23.*

Guided questions for the treatment group as the person moves through the stages outlined in the Remotivation Process

#### Exploration

##### **Strategies that the researcher will use in the study**

The researchers will

- Build trust by providing a detailed explanation of lymphedema and CDT.
- Show the patient different methods to provide compression.
- Ask general questions in order to encourage the client to reflect on her condition and current behavior.
- Ask the patient to perform some components of CDT during the session
- Validates the patient’s effort despite not being able to follow through with the plans she had verbalized during the past session.
- Facilitate a discussion on the possible reason for her inability to perform at least one component of the SMP or follow through with her plans.
- Remain flexible, maintain an accepting environment, with no expectation and allow the patient space and time.
- Assist the patient to become aware of the benefits of CDT and adherence to SMP.

##### **Possible questions**

- What do you think of the information provided to you by the therapist?
- How do you feel about the home program?
- What do you think can help you perform your home program?
- What do you think will make it more difficult?
- Describe to me your daily routine. Do you think the home program can fit in? Why or why not?

## Competence

### Strategies that the researcher will use in the study

The researcher

- Maintains a strong presence during the patient-therapist collaboration.
- Increases expectations for the patient to perform all components of SMP.
- Facilitate
  - Skill learning include competency in performing components of the SMP
  - Understanding of the side effects of cancer treatment
  - Role reflection
- Encouragement:
  - During setbacks by using her volitional narrative to show the patient her past success, the difference in her behavior and what her goals are in the future.
  - As the client starts thinking about her life outside of therapy
- Discussions will focus on the client's
  - Initial plans to incorporate the SMP in the routine.
  - Perception of meeting new challenges.
  - Evaluation of her typical day and identify goals and possible methods to implement and incorporate it into her daily routine.
  - Concerns regarding performance and assure the patient that there will be moments of doubt and failure.
  - Feelings regarding her attempts to perform the SMP at home

### Possible questions

- Describe to me your daily routine. How well does the home program fit in now?
- Are you able to do all of the parts of the home program? Why or why not?
- What can be changed in your routines?
- What will help you do these?
- Are you satisfied with your current routine at home?
- Are you satisfied with the things that you are able to do at this point?
- What else do you want to achieve (or roles that you want to take on) now that you know more about lymphedema?

## Achievement

### Strategies that the researcher will use in the study

The researcher:

- Shifts focus on preparing the client for discharge
- Steps back by decreasing the frequency of the sessions
- Monitoring of symptoms
- Facilitates self-monitoring and self-evaluation.
- Gives feedback
- Provide resources and strategies for self-management and self-evaluation.

### Possible questions

- How satisfied are you with your daily activity?
- Do you feel that you are ready to manage lymphedema on your own? Why or why not?
- What do you think will help you manage the lymphedema on your own?

Suggested questions for formulating feedback as outlined in the Remotivation Process Manual

Sense of pleasure	<ul style="list-style-type: none"> <li>• Did you enjoy the activity?</li> <li>• What were the attractive elements of the things you found most enjoyable?</li> <li>• What moment in the activity stays most clear in your mind?</li> <li>• What did you most enjoy during your participation in this activity?</li> </ul>
Values	<ul style="list-style-type: none"> <li>• Did you look forward to participating in this activity?</li> <li>• Did the outcomes of the activity affect your own personal experience within participation?</li> <li>• How important is this activity in relation to your personal goals in life?</li> <li>• What are the positive and negative aspects about this activity that most affect you?</li> <li>• What has changed for you and what has not?</li> </ul>
Personal causation	<ul style="list-style-type: none"> <li>• How did you do?</li> <li>• What resulted from your participation?</li> <li>• What were these results due to?</li> <li>• Was this a familiar situation for you?</li> <li>• When things did not work out, why did they not work out?</li> <li>• What did you do then?</li> <li>• (In given situations) What was a result of your performance?</li> <li>• What elements depended more on the environment and others?</li> <li>• What circumstances motivated you to act?</li> <li>• Describe the attitude of others involved.</li> <li>• Describe what you did to solve problems</li> </ul>
Personal Analysis	<ul style="list-style-type: none"> <li>• Did you meet your objectives?</li> <li>• Did you reach your overall goal?</li> <li>• Did you perform your role in this situation or try to?</li> <li>• How did you do in accomplishing what you intended to?</li> <li>• Were you successful or not?</li> </ul>
Environment Analysis	<ul style="list-style-type: none"> <li>• Describe the circumstances around your performances.</li> <li>• What was happening at that time?</li> <li>• What was the attitude of others involved about your performance?</li> <li>• Did you have all the materials you needed?</li> <li>• How did the people present at that time affect the environment?</li> </ul>

From “A User’s Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p79-80.

APPENDIX B.2  
COH Data Collection Form



## IRB # \_\_\_\_\_ Data Form

Protocol ID:

Research Participant #:

Participant Initials:

Form:

Evaluation Code:

Date of Collection:

Month	Day	Year
<input type="text"/> <input type="text"/>	/ <input type="text"/> <input type="text"/>	/ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

Age:

Diagnosis:

\_\_\_\_\_

Date of Surgery:

<input type="text"/> <input type="text"/>	/	<input type="text"/> <input type="text"/>	/	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Date Completed				

# of lymph nodes removed

Radiation? (Circle one) Yes / No

Currently undergoing chemotherapy? (Circle one) Yes / No

If yes, # of radiation sessions?

Past Medical History:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Occupation: \_\_\_\_\_ Pain:  / 10

Living arrangement: \_\_\_\_\_

Marital status: ☐ Married, in a civil union, domestic partnership, or living as married  
☐ Divorced  
☐ Widowed  
☐ Never married  
☐ Other  
☐ I'd rather not say

**Provider/CRA** FULL NAME (Please Print)

Month	Day	Year
<input type="text"/> <input type="text"/>	/ <input type="text"/> <input type="text"/>	/ <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Date Completed		

<input type="text"/> <input type="text"/>	:	<input type="text"/> <input type="text"/>	AM/PM
Time Completed			



## IRB # \_\_\_\_\_ Data Form

Protocol ID:

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Research Participant #:

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Participant Initials:

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Form:

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Evaluation Code:

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Date of Collection:

Month	Day	Year								
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### Lymphedema:

#### Skin Integrity:

- ☐ Intact
- ☐ Fibrotic
- ☐ Hyperpigmentation
- ☐ Weeping edema

#### Edema:

- ☐ Pitting
- ☐ Non-pitting

Landmark (in cm)	RUE	LUE
MP		
Wrist		
4		
8		
12		
16		
20		
24		
28		
32		
36		
40		
44		
48		
52		
56		
60		

Notes:


Provider/CRA FULL NAME (Please Print)

Month	Day	Year								
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Date Completed

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Time Completed



APPENDIX B.3  
Model of Human Occupation Screening Tool

# Model of Human Occupation Screening Tool (MOHOST) Rating Form (UK English)

Participant ID# _____	Assessor: _____
	Designation: _____
	Date of assessment: ____/____/____

Rating Scale	F	Facilitates occupational participation
	A	Allows occupational participation
	I	Inhibits occupational participation
	R	Restricts occupational participation

## Analysis of Strengths & Limitations


## Summary of Ratings

Motivation for Occupation				Pattern of Occupation				Communication & Interaction Skills				Process Skills				Motor skills				Environment:			
Appraisal of Ability	Expectation of Success	Interest	Choices	Routine	Adaptability	Roles	Responsibility	Non-verbal Skills	Conversation	Vocal Expression	Relationships	Knowledge	Timing	Organisation	Problem-solving	Posture & Mobility	Co-ordination	Strength & Effort	Energy	Physical Space	Physical Resources	Social Groups	Occupational Demands
F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F
A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A
I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I
R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R

Adapted from "A User's Manual For Model of Human Occupation Screening Tool" by S. Parkinson, K. Forsyth, & G. Kielhofner, 2004, p.96.

APPENDIX B.4  
Lymphedema Quality of Life Inventory

Participant ID # \_\_\_\_\_

Date: \_\_\_\_\_

### **Lymphedema Quality of Life Questionnaire**

This questionnaire is concerned with the way lymphedema may affect your quality of life and activities of daily living. You may have experienced very mild lymphedema, moderate or severe symptoms. You may have lived with your symptoms for a short period of time or for a long time.

**Please answer these questions only as they concern your lymphedema**

Three sets of questions will be asked:

- How much do these concerns affect your quality of life?
- How many changes have you had to make in your everyday life because of these concerns?
- How difficult have these changes been for you?

**Please think about your Lymphedema and your Quality of Life in the past month.**

**For each question circle the answer that best matches your experiences. Try to answer all questions.**

**If a question does not seem to apply to you, please circle the choice that says "No" or "Not".**

Participant ID # \_\_\_\_\_

Date: \_\_\_\_\_

	Physical Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
1	Pain due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
2	Aching in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
3	Discomfort in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
4	A feeling of heaviness in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
5	Pins and needles in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
6	Burning sensation due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
7	Numbness due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
8	A feeling of tightness in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
9	Swelling of my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
10	Skin problems due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
11	Feeling of heat from my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
12	Needing to reposition myself to sleep	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
13	Difficulty sleeping due to my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
14	Movement difficulties due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
15	Feeling conscious of my limb all the time	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
16	Feeling a loss of power in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
17	Cellulites	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely

Participant ID # \_\_\_\_\_

Date: \_\_\_\_\_

	Social Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
34	Needing to make changes to sporting activities (e.g. swimming, tennis).	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
35	Needing to be more careful when doing hobbies (e.g. gardening, sewing)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
36	Concerns about attending special social occasions (e.g. weddings, celebrations)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
37	Concerns about attending outdoor social activities (e.g., picnics in the sun)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
38	Having to ask for help from family and friends (e.g. carrying groceries)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
39	Having to ask for help in public situations	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
40	Feeling self-conscious about my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
41	Concerned with changes in my appearance	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
42	Having to answer questions about my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
43	Not being able to do the things I used to enjoy	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely

Participant ID # \_\_\_\_\_

Date: \_\_\_\_\_

	Practical Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
44	Personal activities of daily living (e.g. dressing, combing hair, brushing teeth)	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
45	Normal daily activities (e.g. doing housework)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
46	Change of diet	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
47	Employment activities (e.g. unable to do the work, or the amount of time required)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
48	Learning to do things differently	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
49	Having less energy to do activities (e.g. personal, normal daily, or employment)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
50	Feeling fatigued after completing activities (e.g. personal, normal daily, or employment)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
51	Is the number of activities you do in one day reduced	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
52	The need to prioritise the activities you can do	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
53	Financial costs of managing my lymphedema (e.g. garments, treatments)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
54	Concern about finding good compression garment	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
55	Driving a car	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely

Participant ID # \_\_\_\_\_

Date: \_\_\_\_\_

	Practical Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
56	Finding clothes that are comfortable, the right size and type of material	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extreme
57	Needing to cover up in the sun	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extreme
58	The constant self care I need to do to stop my lymphedema from getting worse	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extreme
59	The time required to manage lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extreme
60	Obtaining information about how to manage my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extreme
61	Being prepared for emergencies (e.g. carrying first aid equipment, always having a script for antibiotics)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extreme

- 1 a. Taking all parts of your life into consideration, how would you describe your quality of life in the past month?  
Please circle the number below that best matches your overall quality of life.

0    1    2    3    4    5    6    7    8    9    10

Poor

Best Possible

- 1 b. Please think about how your lymphedema has affected you in the past 4 weeks and circle the number below that best matches your experience with lymphedema.

0    1    2    3    4    5    6    7    8    9    10

Poor

Best Possible

2. Has this been a typical month for you?                      Yes ( )      No ( )

- a. If you answered "No" to the question above, has this month been (tick one)

Much Worse ( )    Worse ( )    Better ( )    Much Better ( ) than usual.

- b. Why has this month been different?

3. Are there other things that have not been asked that you would like to add?

**Thank you for your time in completing this questionnaire.**

*Adapted from "Lymphedema Quality of Life Inventory (LyQLI) by P. Klernas, A. Johnsson, A., V. Horstmann, L.J. Kristjansson, & K. Johansson, 2015.*



APPENDIX B.5  
Field Note Used by the PI

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_\_

**Week Number:** \_\_\_\_\_

**Position on the volitional continuum:** \_\_\_\_\_

**Observation of the Participant:**

**Personal Reflections of the Participant:**

**Plan for the Following Week:**

## APPENDIX B.6

### Interview Guide for Qualitative Data Collection

**Introduction by the researcher:** Good morning/ good afternoon. Thank you for agreeing to spend some time with me after your therapy with (name of therapist). I also thank you for participating in this study for the past 4 weeks. As mentioned in the brochure and during the first week, I am conducting research on lymphedema after breast cancer and how occupational therapy can assist breast cancer survivors. I would like to know more about your experience with lymphedema and occupational therapy. There are no right or wrong answers and everything you tell me will remain private. Are you ready to begin?

*If participant disagrees, then the interview is ended. If the participant agrees, the researcher proceeds.*

**Researcher:** This interview will be recorded in order for me to capture everything that is said. I respect your privacy, so I will not use your name during the interview. I will be the only one who will know which audio recording belongs to which participant. These audio recordings will be deleted after it is analyzed and when the study is completed. I respect your feelings about this topic, so if you feel that you want to stop or leave during the interview, please let me know. The interview will be stopped. Do I have your permission to proceed?

*If participant disagrees, then the interview is ended. If the participant agrees, the researcher proceeds.*

*If the participant decides to end the interview before all the interview questions are asked. The researcher will ask if the participant's answers can still be used in the study. The participant's answers will be analyzed if she agrees. The recording will be deleted if the participant states that she does not wish her responses to be included in the study.*

Researcher: So let us begin. Can you tell me a little bit about yourself – what are your interests, what do you do every day?

*(Participant responds)*

Researcher: *(Echoes main points of the participant's response)*. So now let us talk about lymphedema.

*The researcher proceeds to ask the main research questions.*

Interview Question 1. What are your thoughts about the home program you were given for lymphedema?

Probe 1: What do you understand about lymphedema?

Probe 2: If there were challenges in doing the home program, how were these problems handled?

Probe 3: What has helped you do the home program?

Interview question 2. How do you feel about your body after spending some time with occupational therapy?

Probe 1: What have you noticed in your arm these past 4 weeks?

Probe 2: How do you feel about lymphedema when you first noticed changes in your arm (and chest)?

Probe 3: How do you feel about lymphedema after receiving occupational therapy?

Interview Question 3. How do you feel about your everyday life given what you understand about lymphedema?

Probe 1: What are some of the things that you engaged in before lymphedema?

Probe 2: What are some of the things that you engage in at this point after occupational therapy?

Probe 3: What are some of the activities that you were doing before lymphedema?

*If the client needs more probing questions: How about activities related to:*

- Personal care routine
- Home responsibilities
- Work
- Education (if applicable)
- Leisure
- Relationship with others (family, friends, co-workers)?

Probe 4: How would you describe your routine after occupational therapy?

*If the client needs more probing questions: How about routines that are related to:*

- Personal care
- Home responsibilities
- Work
- Education (if applicable)
- Leisure
- Relationship with others (family, friends, co-workers)?

Closing question: Is there anything else you would like to add at this time?

## APPENDIX B.7

### Recruitment Brochure

### What else should I know?

- The researcher may attempt to contact you either through video call, email, phone call, or by mail to obtain further information.
- Participation in the study is voluntary and may withdraw at any time. You will continue to receive the therapy services from City of Hope as planned by you and your occupational therapist.

### Where can I get more information?

You may contact the researcher of this study through the Information below:

Kaye Rubio, MHS, OTRL, CLT  
Researcher

[lrubio2@twu.edu](mailto:lrubio2@twu.edu)

727-408-1239



in partnership with



invites you to participate in the study

## **The Use of the Remotivation Process in an Occupational Therapy program for Breast Cancer-Related Lymphedema: A Feasibility Study**



This is an opportunity to participate in a research study about lymphedema. This study is being conducted by Kaye Rubio, MHS, OTRL, CLT at City of Hope in partnership with Texas Woman's University.

**How will this study help me?**

- As a participant in the study, you will have the opportunity to share your thoughts about lymphedema.
- You will receive information on lymphedema that is tailored to your needs.
- The study will teach you how to manage your lymphedema at home.
- You will be assisting the organization in further improving the therapy services they provide to people with lymphedema.

**How long will the study take?**

- You will participate in an individual session with Ms. Rubio once a week for 4 weeks.
- Each individual session is approximately 15 minutes.

- You may be asked to participate in a 60-minute interview at the end of the 4<sup>th</sup> week.

**What are the potential risks?**

- You may experience discomfort during the sessions. If you become tired or upset, you may take breaks as needed or stop the session at any time.
- There is the potential loss of confidentiality. Your information will be protected to the extent that is allowed by the law. The sessions will be conducted in the privacy of the therapy clinic.

**How am I protected should I decide to participate?**

The federal government has a law that requires studies such as this to have an Institutional Review Board (IRB). An IRB is a group of people assigned to review and monitor research. They help protect the rights, safety, and welfare of those participating in the study.

## APPENDIX B.8

### Informed Consent for Study Participants

TEXAS WOMAN'S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title: The Use of the Remotivation Process in an Occupational Therapy Program for Breast  
Cancer-Related Lymphedema: A Feasibility Study.

Investigator: Lester Kaye Rubio, MHS, OTRL, CLT .....[lrubio2@twu.edu](mailto:lrubio2@twu.edu) (727) 408-1235

Research Advisor: Patricia Bowyer, EdD, MS, OTR, FAOTA, SFHEA... [pbowyer@twu.edu](mailto:pbowyer@twu.edu) (713) 794-2125

Explanation and Purpose of Research

You are being asked to participate in a research study for Ms. Rubio's dissertation at Texas Woman's University. The purpose of this research is to gather your thoughts about your experience on lymphedema and the occupational therapy services you received. You have been asked to participate in this study because you were referred for occupational therapy services.

Description of Procedures

As a participant in this study, you will be seen an occupational therapist who specializes in therapy for lymphedema. You will be asked to participate in a 15-minute discussion with Ms. Rubio after your last therapy session of each week for 4 weeks. The onsite collaborator will gather information, such as the size of your arm, what you think about your quality of life, and your thoughts on how you go about your routines and daily activities, during your first session and during the 4<sup>th</sup> week. This will take approximately 30 minutes each time, for a total of 60 minutes. This information will be used to record the course of your therapy and will be used to understand the effect of occupational therapy on your condition. Ms. Rubio will follow-up with you after 1 month for another 15-minute discussion about your daily experience of lymphedema. You may be asked to participate in an individual interview at the end of the study. If selected, you will be asked to participate in a one-on-one interview with Ms. Rubio to further discuss your experience with lymphedema and the therapy you have received. The interview will be approximately 60 minutes in length. The interview will be held in a private room. The interview will be audio recorded using a phone application. You and Ms. Rubio will decide on a code name for you to use during the interview to protect your identity. Afterward, Ms. Rubio will type

Approved by the  
Texas Woman's University  
Institutional Review Board  
Approved: June 07, 2018  
Modifications Approved:  
September 17, 2018

(Initials) \_\_\_\_\_

Page 1 of 3

the interview so that it can be accurately analyzed. You may decline if you feel unable to participate in a face-to-face interview after your final session with the therapist. You will still receive therapy services from the occupational therapist. Ms. Rubio will also contact you through a phone call a week after the interview to verify your responses. The phone call may last up to 1 hour.

You must be at least 21 years of age or older and referred to occupational therapy for lymphedema of the arm and/or shoulder in order to participate in the study. Should you agree to participate, you will be contributing up to 4 hours and 15 minutes of your time to the study.

#### Potential Risks

Ms. Rubio will ask you questions about your thought on the therapy services you have received. You will be asked questions about your condition. A possible risk in this study is discomfort with these questions asked. If you become tired or upset, you may take a break as needed. You may also stop answering questions at any time and end the interview.

Although the techniques for lymphedema therapy are gentle, it is still possible to experience pain or discomfort during the session. You are encouraged to inform your therapist immediately. Treatment will be adjusted according to your tolerance. You may also ask to stop the treatment and inform the therapist when you are ready to resume.

Another risk in this study is the loss of confidentiality. There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings and Internet transactions. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a private location. A code name, not your real name, or "ma'am", will be used during the interview. No one but Ms. Rubio will know your real name. The storage device (SD card) and written interview will be stored in a locked cabinet in Ms. Rubio's office. Only Ms. Rubio, her adviser, and peer evaluator will hear the audio recording or read the interview transcription, which will be labeled with a unique ID number and not your name. Your information will not be included in the transcription. The SD card and transcription will be shredded within 5 years after the study is finished. The results of the study may be reported in scientific magazines and journals, but your name or any other identifying information will not be included.

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Texas Woman's University  
Institutional Review Board  
Approved: June 07, 2018  
Modifications Approved:  
September 17, 2018

(Initials) \_\_\_\_\_

Page 2 of 3

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they 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 involvement in this study is voluntary and you may withdraw from the study at any time. You will still receive normal occupational therapy services for lymphedema without difficulty should you decide not to participate in the study. By sharing your thoughts on the therapy service you have received, you will allow the researcher and therapist to provide better care to you and other patients. This study is aimed to help the facility provide specialized care to the community we serve. If you would like to know the results of this study we will mail them to you.\*

#### 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 e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

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Signature of Participant

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Date

\*If you would like to know the results of this study tell us where you want them to be sent:

Email: \_\_\_\_\_

or

Address:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Approved by the  
Texas Woman's University  
Institutional Review Board  
Approved: June 07, 2018  
Modifications Approved:  
September 17, 2018

Page 3 of 3

## APPENDIX C

### Recruitment Brochure



in partnership with



TEXAS WOMAN'S  
UNIVERSITY

invites you to participate in

**COH 18549: The Use of the Remotivation Process in an Occupational  
Therapy program for Breast Cancer-Related Lymphedema:  
A Feasibility Study**

This is an opportunity to participate in a research study about lymphedema. This study is being conducted by Kaye Rubio, MHS, OTRL, CLT at City of Hope in partnership with Texas Woman's University.

**How will this study help me?**

- As a participant in the study, you will have the opportunity to share your thoughts about lymphedema.
- You will receive information on lymphedema that is tailored to your needs.
- The study will teach you how to manage your lymphedema at home.
- You will be assisting the organization in further improving the therapy services they provide to people with lymphedema.

**How long will the study take?**

- You will participate in an individual session with Ms. Rubio once a week for 4 weeks.
- Each individual session is approximately 15 minutes.
- You may be asked to participate in a 60-minute interview at the end of the 4<sup>th</sup> week.

**What are the potential risks?**

- You may experience discomfort during the sessions. If you become tired or upset, you may take breaks as needed or stop the session at any time.

- There is the potential loss of confidentiality. Your information will be protected to the extent that is allowed by the law. The sessions will be conducted in the privacy of the therapy clinic.

### **How am I protected should I decide to participate?**

The federal government has a law that requires studies such as this to have an Institutional Review Board (IRB). An IRB is a group of people assigned to review and monitor research. They help protect the rights, safety, and welfare of those participating in the study.

### **What else should I know?**

- The researcher may attempt to contact you either through video call, email, phone call, or by mail to obtain further information.
- Participation in the study is voluntary and may withdraw at any time. You will continue to receive the therapy services from City of Hope as planned by you and your occupational therapist.

### **Where can I get more information?**

You may contact the researcher of this study through the Information below:

**Kaye Rubio, MHS, OTRL, CLT**

**Researcher**

**[lrubio2@twu.edu](mailto:lrubio2@twu.edu)**

**727-408-1239**



APPENDIX D  
Informed Consent

Principal Investigator: Sherry Hite  
Department/Division: Medical Oncology & Therapeutics Research  
Telephone number: (626) 256-HOPE (4673) Ext. 89200

Page 1 of 13



City of Hope<sup>®</sup>

## INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

**IRB# 18549: The Use of the Remotivation Process in an Occupational Therapy Program for Breast Cancer-Related Lymphedema: A Feasibility Study**

### KEY INFORMATION

You are invited to participate in a research study. The purpose of this research study is to gather your thoughts about your experience on lymphedema. It will involve the *Remotivation Process*, which is a discussion session between you and a member of the study team. The study aims to explore if the discussion has any effect on your condition and how you adjust to the changes in your life that you have experienced or are currently experiencing due to lymphedema. The information we learn by doing this research study may help future occupational therapy services given to patients with your type of cancer. The primary investigators for this study include Ms. Kaye Rubio from Texas Woman's University (TWU). However, the study only invites participants from City of Hope.

Participants in this study will be seen by an occupational therapist who specializes in therapy for lymphedema. Participants will engage in discussions and interviews about information such as what you think about your quality of life, and your thoughts on how you go about your routines and daily activities and arm measurements. Participation is expected to last up to a total of 4 hours and 15 minutes, which will include 5 discussion sessions, 1 interview, and 1 interview follow-up phone call.

The major risks associated with the study include that you may have some discomfort with the types of questions asked during the study interviews.

You do not have to join this research study. If you are interested in learning more about this study, please continue to read below.

- I. **PURPOSE OF THIS RESEARCH STUDY:** You have been asked to participate in this research study because you were referred for occupational therapy services. The purpose of this study is to gather your thoughts about your experience on lymphedema and the occupational therapy services you received. Your participation in this study is expected to last up to 4 hours and 15 minutes of your time.

About 42 people will take part in this study.

### INFORMED CONSENT AND AUTHORIZATION

COH INFORMED CONSENT APPROVED BY THE IRB  
IRB NUMBER: 18549  
APPROVED FROM: 04/19/2019

- II. **BACKGROUND:** Lymphedema treatment programs are well developed and effective, but adherence to these programs are an issue. The daily home self-care program takes 15-60 minutes or more. Less than half of all patients undergoing this type of program are able to keep up with the instructions and steps. This study will focus on improving adherence to these programs. Recently, there are more and more patients suffering from lymphedema, even though the medical treatments have become less invasive. This study will focus on your motivations and barriers and how to overcome these as it is believed that this focus is currently lacking in our health care system. Health care providers issue recommendations, but these may not fit into patient lifestyles.

III. **WHAT WILL BE DONE:**

**Data Collection:**

We will collect information about your demographics and medical history prior to your research discussion sessions.

**Research Discussion Sessions, Arm Measurement, and Questionnaires:**

As a participant in this study, you will be seen by an occupational therapist who specializes in therapy for lymphedema after your regular standard of care therapy sessions. You will be asked to participate in four 15-minute research discussions each week for 4 weeks for a total of 60 minutes. These discussions will be performed by a collaborating occupational therapist from Texas Women's University in a private room via Zoom. At your first and fourth discussion, the study team will measure the size of your arm, and administer two 10-minute questionnaires. The 2 additional questionnaires are the *Model of Human Occupation Screening Tool* and the *Lymphedema Quality of Life Inventory*. These 2 questionnaires will ask you what you think about your quality of life, and your thoughts on how you go about your routines and daily activities. These measurements will take an additional 30 minutes each time, for a total of 60 additional minutes.

This information will be used to record the course of your therapy and will be used to understand the effect of occupational therapy for your condition. After your fourth discussion, you will be followed-up with after 1 month for a fifth 15-minute discussion about your daily experience of lymphedema after your regular therapy session. The follow-up discussion will be through Zoom. No follow-up measurements will be performed at this time.

**Optional Research Interview:**

You may be asked to participate in an optional individual interview after your fifth discussion session. If selected and you agree, you will participate in a one-on-one interview with a study team member to further discuss your experience with lymphedema and the therapy you have received. The interview will be approximately 60 minutes in length. The interview will be held in a private room via Zoom. The interview will be audio recorded using a voice recorder, which saves the recording on a SD card. You and a study team member will decide on a code name for you to use during the interview to protect your identity. Afterward, the study team member will type the interview so that it can be accurately analyzed. You may decline if you feel unable to participate in a face-to-face interview. You will still receive therapy services from the occupational therapist. The study team will also contact you through a phone call a week after the interview to verify your

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**INFORMED CONSENT AND AUTHORIZATION**

COH INFORMED CONSENT APPROVED BY THE IRB  
IRB NUMBER: 18549  
APPROVED FROM: 04/19/2019

responses. The phone call may last up to 60 minutes. The interview will be audio recorded but not video recorded. Only the study team will have access to the recording and will be kept in a locked cabinet. These recordings will be destroyed after the study is completed, which is after five years.

You must be at least 21 years of age or older and referred to occupational therapy for lymphedema of the arm and/or shoulder in order to participate. Should you agree to participate, you will be contributing up to 4 hours and 15 minutes of your time to the study.

- IV. **POSSIBLE BENEFITS:** The study provides you with additional opportunity to discuss your concerns and also explore aspects of your life that motivate you to adjust to your condition. Potential benefit to others may result from the knowledge gained from your participation in this research study.
- V. **POSSIBLE RISKS:** You will be asked questions about your thought on the therapy services you have received during the research procedures. You will also be asked questions about your condition. A possible risk in this study is discomfort with these questions asked. If you become tired or upset, you may take a break as needed. You may also stop answering questions at any time and end the interview.

Lymphedema therapy, which may include massage, wrapping the arm with bandages or arm sleeves, and arm exercise, is standard of care for lymphedema. These are not part of the research procedures. Although the techniques for lymphedema therapy are gentle, there is a risk of possible pain or discomfort during the therapy session. You are encouraged to inform your therapist immediately. Changes made to lymphedema therapy or stopping treatment will refer to the standard of care and not the research procedures, sessions, or any research measurements.

**Questionnaires:** You may become tired from the amount of time needed to fill out the questionnaires. The questionnaires will focus on life issues that could cause you to become emotionally upset. If this occurs, you will be referred to your physician to determine how best to handle the concerns and issues. Support and counseling will be available from social workers and psychologists as needed.

Another risk in this study is the loss of confidentiality. There is a potential risk of loss of confidentiality in all email, downloading, electronic messages, and Internet transactions. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a private location. A code name, not your real name, or "ma'am", will be used during the interview. No one but the study team will know your real name. The storage device (SD card) and written interview will be stored in a locked cabinet in the study team's office. Only the study team will hear the audio recording or read the interview transcription, which will be labeled with a unique ID number and not your name. The identifiable information will not be included in the transcription. The SD card and transcription will be shredded within 5 years after the study is finished. The results of the study may be reported in scientific magazines and journals, but your name or any other identifying information will not be included. The SD card and transcription will not contain any of your identified data. However, these will be kept for 5 years to review the information gathered if needed within this time period.

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#### INFORMED CONSENT AND AUTHORIZATION

COH INFORMED CONSENT APPROVED BY THE IRB  
IRB NUMBER: 18549  
APPROVED FROM: 04/19/2019



Additionally, the researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you.

- VI. **ALTERNATIVES TO PARTICIPATION:** Your alternative is to choose not to participate in this study. Choosing not to participate will not interfere with any future treatment at City of Hope.
- VII. **CONFIDENTIALITY OF INFORMATION:** Any information learned from this study in which you might be identified will be confidential and disclosed only with your permission. Every effort will be made to keep any information collected about you confidential. However, it is impossible to guarantee that information about you will not be mistakenly released. If, despite our best efforts, identifying information about you is released, it could negatively impact you or your family members. This risk is small.

By signing this form, however, you allow the researchers to make your information available to City of Hope Institutional Review Board (IRB) Office, the Cancer Protocol Review and Monitoring Committee (CPRMC), the Office for Human Research Protections (OHRP), the National Cancer Institute (NCI), the collaborating institution (Texas Woman's University), and other regulatory agencies as required by law. If information learned from this study is published, you will not be identified by name.

**Future Use of Research Information**

The information that have been collected for this study will not be used for future research studies or shared with other researchers beyond the research activities described in this consent form.

- VIII. **OFFER TO ANSWER QUESTIONS:** The principal investigator, Sherry Hite or a colleague, \_\_\_\_\_, has offered to and has answered any and all questions regarding your participation in this research study. If you have any further questions, you can contact Sherry Hite at (626) 256-HOPE (4673) ext. 89200.
- IX. **SPONSOR OF THIS RESEARCH:** City of Hope is the sponsor of this research study. Texas Woman's University is a collaborating site for this research study.
- X. **COST TO THE RESEARCH PARTICIPANT FOR PARTICIPATION:** Neither you nor your insurance carrier will be charged for your participation in this study.
- XI. **EXPLANATION OF TREATMENT AND COMPENSATION FOR INJURY:** If you think you have been injured as a result of taking part in this research study, tell the person in charge of this research study as soon as possible. The research doctor's name and phone number are listed in this consent form. City of Hope will offer you the care needed to treat injuries directly resulting from taking part in this research. This care will be billed to you or your insurance company. You will be responsible for deductible and co-payments, or any costs not paid by your insurer. There

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are no plans to pay you or give you other compensation for the injury. You do not give up your legal rights by signing this form.

Texas Woman's University does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

- XII. **VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL:** You have been informed that your participation in this research study is voluntary. You are free to withdraw your consent for participation in this study without any loss of benefits, penalty, or interference with any future treatment at City of Hope.
- XIII. **IRB REVIEW AND IMPARTIAL THIRD PARTY:** This study has been reviewed and approved by the Institutional Review Board (IRB). A representative of that Board, from the Office of Human Research Subjects Protection, is available to discuss the review process or your rights as a research subject. The telephone number of the Office of Human Research Subjects Protection is (626) 256-HOPE (4673) ext. 62700.
- XIV. **FINDINGS RELATING TO WILLINGNESS TO CONTINUE PARTICIPATION:** The person consenting you to this study has explained to you that you will be informed of any significant new findings related to this study which might affect your willingness to continue to participate.

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**EXPERIMENTAL SUBJECT'S BILL OF RIGHTS  
FOR PSYCHOSOCIAL STUDIES**

Page 6 of 13

The rights below are the rights of every person who is asked to be in a research study. As a research subject in a psychosocial or quality of life study, you have the following rights:

1. To be told what the research study is trying to find out,
2. To be told what will happen to you and whether any of the study procedures to be used are different from what would be used in standard practice,
3. To be told about the risks, side effects, or discomforts of the things that will happen to you as part of the research study,
4. To be told if you can expect any benefit from participating in the research study, and, if so, what the benefit might be,
5. To be told of the other choices you have and how they may be better or worse than being in the research study,
6. To be allowed to ask any questions concerning the research study, both before agreeing to be in the study and during the course of the study,
7. To be told what support or treatment is available if any complications arise,
8. To refuse to participate in the research study or to change your mind about participation after the study is started. To be informed that this decision will not affect your right to receive the care you would receive if you were not in the study,
9. To receive a copy of the signed and dated research study consent form,
10. To be free of pressure when considering whether you wish to agree to be in the research study.

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APPROVED FROM: 04/19/2019

**SIGNATURE FOR CONSENT:** By signing this consent form, you are making a decision to participate in this research study. Your signature on this informed consent form indicates that you:

1. Have read and understood the information in this form.
2. Have had the information in this form explained to you.
3. Have had a chance to ask questions and these questions were answered to your satisfaction.
4. Have been informed that you will receive a copy of this signed consent form, which includes the "Experimental Subject's Bill of Rights."

I hereby agree to be a research participant in this research study:

\_\_\_\_\_  
 Research Participant's Signature      Date      Time  
 (date and time must be in research participant's handwriting)

\_\_\_\_\_  
 Print Research Participant's Name

#### INDIVIDUAL OBTAINING CONSENT SIGNATURE

\_\_\_\_\_  
 Signature of Individual Obtaining Consent      Date      Time

\_\_\_\_\_  
 Print Name of Individual Obtaining Consent

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 APPROVED FROM: 04/19/2019



**FOR USE WITH IRB APPROVED TRANSLATED SHORT/LONG CONSENT FORMS FOR  
NON ENGLISH SPEAKING PARTICIPANTS ONLY**

NOTE: To determine who should sign below, review the guidance document, *Consenting Non English Speaking Research Participants (Pediatric or Adult) – Who Signs What?*

Interpreter: By signing here, I attest that I have acted as interpreter and facilitated this consent process.

\_\_\_\_\_  
Interpreter's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

\_\_\_\_\_  
Print Interpreter's Name

Witness: By signing here, I attest that I witnessed the consent process and that the entire consent form was discussed.

\_\_\_\_\_  
Witness' Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

\_\_\_\_\_  
Print Witness' Name

**INFORMED CONSENT AND AUTHORIZATION**

COH INFORMED CONSENT APPROVED BY THE IRB  
IRB NUMBER: 18S49  
APPROVED FROM: 04/19/2019

**IRB# 18549: The Use of the Remotivation Process in an Occupational Therapy Program for Breast Cancer-Related Lymphedema: A Feasibility Study**

**AUTHORIZATION TO USE AND DISCLOSURE OF YOUR PROTECTED HEALTH INFORMATION (PHI) FOR PURPOSES OF THIS STUDY:**

- I. **Purpose of this Authorization:** The information about your health is something that is protected by law and cannot, except for certain purposes, be disclosed (shared) without your permission. As part of this research, you are agreeing to allow City of Hope, its affiliated research doctors, healthcare providers, and physician network to use and share with others your protected health information ("PHI"), as needed for the research. If you agree to participate in the study named above (called the "Study"), you must sign this authorization in addition to the *Study Consent Form*.
  
- II. **The Information About You that is Covered By this Authorization:** PHI refers to information that we maintain about you that identifies you and includes the information contained in your medical record. Your medical record consists of information related to your health and the treatment we provide to you, such as your medical history, the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures. If you sign this authorization, you are allowing City of Hope and the individuals indicated below to use and share any PHI we maintain about you that is required for your participation in the Study.
  
- III. **Purposes for Uses and Sharing of your PHI; Who Will Use, Share and Receive your PHI:** Your PHI will be used and shared with others for the purpose of doing this research as described in the *Study Consent Form*. Your PHI will also be used to keep the research sponsor informed about this Study, for reporting to those individuals and authorities responsible for overseeing our research activities to make sure that the activities are properly conducted, and to report to regulatory agencies as required by the Study.

The people authorized to use and share your PHI for purposes of the Study include the Principal Investigator and the research staff supporting the Study; your City of Hope physicians and the health care team; the Health Information Management Services Department (i.e., Medical Records Department); and affiliated research doctors and other medical centers participating in the research, if applicable. This also includes any agents or contractors used by these individuals or groups for

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 IRB NUMBER: 18549  
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purposes of conducting or managing this Study. At the City of Hope, the Institutional Review Board ("IRB"), and other City of Hope research regulatory committees will have access to your PHI as necessary to monitor research.

You are also allowing your PHI to be shared with the Office for Human Research Protections ("OHRP") and with any person or agency as required by law. In addition, certain other regulatory agencies, including, the National Cancer Institute ("NCI"), will have access to your PHI.

Also certain other groups and institutions, including, researchers at Texas Woman's University, a collaborating institution, will also have access to your PHI as necessary for research purposes and to conduct the Study.

This authorization will allow us to use and share your PHI for the Study. No other additional uses and disclosures other than for the purposes of the Study is included in this authorization. City of Hope's Notice of Privacy Practices will continue to protect your non-Study information. If necessary, another separate permission will be obtained from you for any non-Study uses or sharing of your PHI.

- IV. Expiration of this Authorization: This authorization to use and share your PHI will expire twenty-five (25) years from the date that you sign this authorization.
- V. Further Sharing of Your PHI: Your privacy is important and this is the reason for having rules which control who can use or see your PHI. City of Hope maintains control over your PHI at present, but once we share this information with a third party (for example, an individual or agency outside of the City of Hope), then it is no longer possible to maintain the same level of protection. The persons outside our control may not be governed by federal or state privacy laws and it is possible that they could share your PHI with others for whom you have not given permission.

The information from this Study may be published in scientific journals or presented at scientific meetings but your identity will be kept confidential.

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- VI. Your Rights Under this Authorization:** You may cancel this permission to use and share your PHI at any time by contacting City of Hope's Privacy Officer at (626) 256-HOPE (4673) ext. 64025. You should ask for the form, *Revocation (Cancellation) of Authorization for Use of Protected Health Information for Research*. Fill this form out and return it as the form instructs. Your cancellation begins when the Health Information Management Department of City of Hope receives this form. If you cancel this authorization to use and share your PHI, you will no longer be able to participate in the Study. This is because the research under this Study cannot be conducted without your PHI.

Once you cancel your permission to use and share your PHI, the researchers and others involved in conducting the Study will no longer be able to use or share your PHI for this research. PHI already used and shared up to this point as part of this Study will continue to be used for purposes of this research. This means that any uses of your PHI and any PHI shared about you by City of Hope prior to receiving your cancellation (revocation) form cannot be taken back. While no further PHI about you will be shared for the Study, your PHI already shared will continue to be used in the overall Study.

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**VII. Signing this Authorization is Your Choice:** Your ability to obtain care at the City of Hope will not be affected by your decision to sign this authorization form. You will be able to continue to receive health care at City of Hope if you choose not to sign this authorization form or if you sign this form and later cancel your permission to use and share your PHI.

If you agree to the use and sharing of your PHI, please sign below. You will be given a copy of this authorization form.

Research Participant's Signature

Date \_\_\_\_\_

Time

(date and time must be in research participant's handwriting)

---

**Print Research Participant's Name**

CLINICIANS  
USE

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APPROVED FROM: 04/19/2019

**INDIVIDUAL OBTAINING CONSENT SIGNATURE**

Page 13 of 13

\_\_\_\_\_  
Signature of Individual Obtaining Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

\_\_\_\_\_  
Print Name of Individual Obtaining Consent

**FOR USE WITH IRB APPROVED TRANSLATED SHORT/LONG CONSENT FORMS FOR NON ENGLISH SPEAKING PARTICIPANTS ONLY**

NOTE: To determine who should sign below, review the guidance document, *Consenting Non English Speaking Research Participants (Pediatric or Adult) – Who Signs What?*

**Interpreter:** By signing here, I attest that I have acted as interpreter and facilitated this consent process.

\_\_\_\_\_  
Interpreter's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

\_\_\_\_\_  
Print Interpreter's Name

**Witness:** By signing here, I attest that I witnessed the consent process and that the entire consent form was discussed.

\_\_\_\_\_  
Witness' Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

\_\_\_\_\_  
Print Witness' Name

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APPENDIX E  
Recruitment Script

The verbal script for the recruitment of the participant will be as follows:

“ You are invited to participate in a research study for Ms. Rubio’s dissertation at Texas Woman’s University. The purpose of this research is to gather your thoughts about your experience on lymphedema and the occupational therapy services you received. You have been asked to participate in this study because you were referred for occupational therapy services. As a participant in this study, you will be asked to participate in a 15-minute discussion with Ms. Rubio at the end of each week after your therapy session. This will be an opportunity for you to share your thoughts on your recovery during the week. You may also be asked to participate in an individual interview at the end of the 4<sup>th</sup> week. If selected, you will be asked to participate in a one-on-one interview with Ms. Rubio to further discuss your experience with lymphedema and the therapy you have received. Participation in this study is voluntary and you can withdraw at any time. You will still receive occupational therapy services for lymphedema without difficulty should you decide not to participate. We have prepared a brochure with more information on the study. If you are willing to participate, you will be provided a consent form that provides more detail about the study”



## APPENDIX F

### Remotivation Process Interview Questions and the Three Stages of the Remotivation Process, Stages, Goals and Application to the study on Breast Cancer-Related Lymphedema

Guided questions as the person moves through the stages outlined in the Remotivation Process

#### Exploration

##### **Strategies that the researcher will use in the study**

The researchers will

- Build trust by providing a detailed explanation of lymphedema and CDT.
- Show the patient different methods to provide compression.
- Ask general questions in order to encourage the client to reflect on her condition and current behavior.
- Ask the patient to perform some components of CDT during the session
- Validates the patient's effort despite not being able to follow through with the plans she had verbalized during the past session.
- Facilitate a discussion on the possible reason for her inability to perform at least one component of the SMP or follow through with her plans.
- Remain flexible, maintain an accepting environment, with no expectation and allow the patient space and time.
- Assist the patient to become aware of the benefits of CDT and adherence to SMP.

##### **Possible questions**

- What do you think of the information provided to you by the therapist?
- How do you feel about the home program?
- What do you think can help you perform your home program?
- What do you think will make it more difficult?
- Describe to me your daily routine. Do you think the home program can fit in? Why or why not?

#### Competence

##### **Strategies that the researcher will use in the study**

The researcher

- Maintains a strong presence during the patient-therapist collaboration.
- Increases expectations for the patient to perform all components of SMP.
- Facilitate
  - Skill learning include competency in performing components of the SMP
  - Understanding of the side effects of cancer treatment
  - Role reflection
- Encouragement:
  - During setbacks by using her volitional narrative to show the patient her past success, the difference in her behavior and what her goals are in the future.
  - As the client starts thinking about her life outside of therapy
- Discussions will focus on the client's

##### **Possible questions**

- Describe to me your daily routine. How well does the home program fit in now?
- Are you able to do all of the parts of the home program? Why or why not?
- What can be changed in your routines?
- What will help you do these?
- Are you satisfied with your current routine at home?
- Are you satisfied with the things that you are able to do at this point?
- What else do you want to achieve (or roles that you want to take on) now that you know more about lymphedema?

- Initial plans to incorporate the SMP in the routine.
- Perception of meeting new challenges.
- Evaluation of her typical day and identify goals and possible methods to implement and incorporate it into her daily routine.
- Concerns regarding performance and assure the patient that there will be moments of doubt and failure.
- Feelings regarding her attempts to perform the SMP at home

#### Achievement

##### **Strategies that the researcher will use in the study**

The researcher:

- Shifts focus on preparing the client for discharge
- Steps back by decreasing the frequency of the sessions
- Monitoring of symptoms
- Facilitates self-monitoring and self-evaluation.
- Gives feedback
- Provide resources and strategies for self-management and self-evaluation.

##### **Possible questions**

- How satisfied are you with your daily activity?
- Do you feel that you are ready to manage lymphedema on your own? Why or why not?
- What do you think will help you manage the lymphedema on your own?

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#### Suggested questions for formulating feedback as outlined in the Remotivation Process Manual

Sense of pleasure	<ul style="list-style-type: none"> <li>• Did you enjoy the activity?</li> <li>• What were the attractive elements of the things you found most enjoyable?</li> <li>• What moment in the activity stays most clear in your mind?</li> </ul>
Values	<ul style="list-style-type: none"> <li>• What did you most enjoy during your participation in this activity?</li> <li>• Did you look forward to participating in this activity?</li> <li>• Did the outcomes of the activity affect your own personal experience within participation?</li> <li>• How important is this activity in relation to your personal goals in life?</li> <li>• What are the positive and negative aspects about this activity that most affect you?</li> </ul>
Personal causation	<ul style="list-style-type: none"> <li>• What has changed for you and what has not?</li> <li>• How did you do?</li> <li>• What resulted from your participation?</li> <li>• What were these results due to?</li> <li>• Was this a familiar situation for you?</li> <li>• When things did not work out, why did they not work out?</li> <li>• What did you do then?</li> <li>• (In given situations) What was a result of your performance?</li> </ul>

- What elements depended more on the environment and others?
  - What circumstances motivated you to act?
  - Describe the attitude of others involved.
  - Describe what you did to solve problems
  - Did you meet your objectives?
  - Did you reach your overall goal?
  - Did you perform your role in this situation or try to?
  - How did you do in accomplishing what you intended to?
  - Were you successful or not?
- Personal Analysis
- Describe the circumstances around your performances.
  - What was happening at that time?
  - What was the attitude of others involved about your performance?
  - Did you have all the materials you needed?
  - How did the people present at that time affect the environment?
- Environment Analysis

From “A User's Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p79-80.

## STAGE: Exploration

### Volitional Questionnaire Items:

Shows Curiosity	Initiates Actions	Tries new things	Shows Preferences	Shows activity is significant	Indicates Goals	Stays engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenge
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Adapted from “A User's Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p.23.

Stage	Strategies outlined in the Remotivation Process Manual	Strategies that will be used by the researcher for the study	Goals outlined in the Remotivation Process Manual	Hypothesized behavioral manifestation of this level during the study
Validation	<ul style="list-style-type: none"> <li>• Significant greeting</li> <li>• Introduce meaningful elements into personal space</li> <li>• Participate in activities of interest to client in close proximity to client</li> </ul>	<p>The researcher will</p> <ul style="list-style-type: none"> <li>• Build trust by providing a detailed explanation of lymphedema and CDT.</li> <li>• Show the patient different methods to provide compression.</li> <li>• Ask general questions in order to encourage the client to reflect on her condition and</li> </ul>	<ul style="list-style-type: none"> <li>• A sense of personal significance</li> <li>• A basic sense of capacity</li> <li>• A sense of security with the environment.</li> </ul>	<p>The goal is for the patient to actively participate in the CDT</p> <p>The client will</p> <ul style="list-style-type: none"> <li>• Allow one or more components of the SMP into her activities at home, or personal space.</li> <li>• At least show interest in the compression garments.</li> <li>• Show interest in the</li> </ul>

- Generate interaction

- current behavior.
- Ask the patient to perform some components of CDT during the session
- Validates the patient's effort despite not being able to follow through with the plans she had verbalized during the past session.
- Facilitate a discussion on the possible reason for her inability to perform at least one component of the SMP or follow through with her plans.
- Remain flexible, maintain an accepting environment, with no expectation and allow the patient space and time.
- Assist the patient become aware of the benefits of CDT and adherence to SMP.

compression garments.

- Identify components of the SMP that she might try at home or initiates ordering compression garments
- State a plan to perform at least one component of the SMP at home.
- Attendance to sessions maybe inconsistent.

Disposition for exploration of the environment	<ul style="list-style-type: none"> <li>• Move familiar routines into novel spaces</li> <li>• Facilitate observation of others engaged in activities of interest</li> <li>• Invite participation through doing things in the presence of a client</li> </ul>	<p>The researcher</p> <ul style="list-style-type: none"> <li>• Assist the client initiate the discussion with the patient's family or caregiver.</li> <li>• Continue with the previous strategies</li> </ul>	<ul style="list-style-type: none"> <li>• Exploration of interests in novel contexts</li> <li>• Self-initiated occupational behavior</li> <li>• Confidence in trying new things</li> </ul>	<ul style="list-style-type: none"> <li>• The client: <ul style="list-style-type: none"> <li>• Attempts to perform one or more components of the SMP at home.</li> <li>• Identify aspects of her home environment that facilitate or hinder her performance of SMP.</li> <li>• Identify daily routines and activities that may or may not be compatible with the SMP</li> <li>• Invite a family member or caregiver to attend the session in an attempt to ask for assistance in performing the SMP at home</li> <li>• Initiate a conversation with the family regarding new roles in the presence of the researcher.</li> </ul> </li> </ul>
Choice Making/ Decision Making	<p>Similar to Stage 2</p> <ul style="list-style-type: none"> <li>• Increase novelty (new settings, people, etc.)</li> <li>• Increase</li> </ul>	<p>The researcher continues with the previous strategies</p>	<ul style="list-style-type: none"> <li>• Continue to develop exploratory feelings</li> <li>• Initiate a process of self validation by exploring one's</li> </ul>	<p>The client will</p> <ul style="list-style-type: none"> <li>• Identify modifications in her routine and roles that she is comfortable with.</li> <li>• Continues to keep her</li> </ul>

	invitations for participation		values and interests through activity <ul style="list-style-type: none"> <li>• Reinforce a sense of personal significance and capacity through opportunities to choose activities.</li> </ul>	appointments and involve significant others in her appointments. <ul style="list-style-type: none"> <li>• Chooses to attend the therapy sessions</li> <li>• Sets aside time for one or more components of the SMP.</li> </ul>
Pleasure and efficacy in action	<ul style="list-style-type: none"> <li>• Facilitate participation in collaborative projects</li> <li>• Incorporate feedback</li> <li>• Facilitate a sense of life story</li> </ul>	<p>The researcher</p> <ul style="list-style-type: none"> <li>• Continues to remind the client of her progress and success in order to maintain the patient's interest in SMP,</li> <li>• Affirm the value of behavior change,</li> <li>• Contribute to the client's personal causation that she is able to do something about the condition</li> </ul>	<ul style="list-style-type: none"> <li>• Reinforce exploratory feelings, the sense of personal significance and sense of capacity through preliminary participation in roles</li> <li>• Continue the process of self validation</li> <li>• Reinforce self-efficacy in decision-making</li> <li>• Develop an awareness of one's skills</li> </ul>	<p>The client</p> <ul style="list-style-type: none"> <li>• Continues to regularly attend the sessions</li> <li>• Verbalize satisfaction in the program, the outcomes observed, and her new knowledge of BCRL, CDT and SMP.</li> <li>• Share some of her success at home, challenges she encountered as she attempts to change her routines, and ask for suggestions from the researcher.</li> <li>• Begin to share her thoughts and concerns regarding long-term management of BCRL</li> </ul>



following discharge  
from therapy.

- Builds new routines with the assistance of the OT during the exploration stage
- Has not yet assumed full responsibility of SMP and still relies on the researcher.

## STAGE: Competency

### Volitional Questionnaire Items:

Shows Curiosity	Initiates Actions	Tries new things	Shows Preferences	Shows activity is significant	Indicates Goals	Stays engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibility	Seeks challenge
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Adapted from “A User's Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p.23.

Stage	Strategies outlined in the Remotivation Process Manual	Strategies that will be used by the researcher for the study	Goals outlined in the Remotivation Process Manual	Hypothesized behavioral manifestation of this level during the study
Meeting new performance expectations / Internalization of sense of efficacy	<ul style="list-style-type: none"> <li>• Provision of physical or emotional “accompaniment” in new and challenging situations</li> <li>• Facilitation of skill learning when appropriate</li> <li>• Introduction of the counseling process and use of feedback</li> </ul>	<p>The researcher</p> <ul style="list-style-type: none"> <li>• Increases expectations for the patient to perform all components of SMP.</li> <li>• Provides <ul style="list-style-type: none"> <li>○ Accompaniment in new and challenging situation to develop self-efficacy.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Increase emerging sense of efficacy</li> <li>• Begin looking at experiences as they relate to meeting goals</li> <li>• Develop a sense of responsibility with personal and collective projects</li> </ul>	<p>The patient</p> <ul style="list-style-type: none"> <li>• Becomes comfortable with the new normal, or new habits, and develops a sense of self-efficacy</li> <li>• Engages in spontaneous decision-making, realizes the value</li> </ul>

Increasing challenges and responsibilities within roles / Living and telling own story

- Allowance for “moments of reflections” or disorder in change process
- Continuation of the counseling process furthering insight through more in depth analysis and questions

- Information on other resources available in the patient’s environment
- Facilitate
  - Skill learning include competency in performing components of the SMP
  - Understanding of the side effects of cancer treatment
  - Role reflection
- Encouragement:
  - During setbacks by using her volitional narrative to show the patient her past success, the difference in her behavior and what her possibilities for the future.
  - As the client starts thinking about her life outside of therapy

- Reassess:

- Prepare for spontaneous participation in valued roles
- Increase processing of experiences and begin relating them to personal or occupational goals
- Increase the process of planning
- Increase sense of responsibility and autonomy on meeting the demands of personal projects and/or personal circumstances

- of the SMP, initiates SMP-related activities and indicates her goals without the assistance of the researcher
- Develops skills necessary to perform SMP and achieve personal goals
- Demonstrate behaviors that indicate spontaneity and continued engagement in the SMP, although inconsistent.
- Identify goals that will lead to incorporation of SMP in the routine.

- Performance of the components of the SMP and identify skills that may need to be addressed.
  - Frequency table to record the days that she was unable to perform the SMP and initiates a discussion on the possible reasons why she was unable to do so.
  - Girth measurements to demonstrate positive outcomes of the treatment.
  - Effectiveness of different strategies to perform the SMP at home
- Discussions will focus on the client's
    - Initial plans to incorporate the SMP in the routine.
    - Perception of meeting new challenges.
    - Evaluation of her typical day and

identify goals and possible methods to implement and incorporate it in her daily routine.

- Concerns regarding performance and assure the patient that there will be moments of doubt and failure.
- Feelings regarding her attempts to perform the SMP at home

## STAGE: Achievement

### Volitional Questionnaire Items:

Shows Curiosity	Initiates Actions	Tries new things	Shows Preferences	Shows activity is significant	Indicates Goals	Stays engaged	Shows pride	Tries to solve problems	Tries to correct mistakes	Pursues activity to completion	Invests additional energy	Seeks additional responsibilit	Seeks challenge
--------------------	----------------------	---------------------	----------------------	-------------------------------------	--------------------	------------------	-------------	-------------------------------	---------------------------------	--------------------------------------	---------------------------------	--------------------------------------	--------------------

Adapted from “A User's Manual For Remotivation Process: Progressive Intervention For Individuals With Severe Volitional Challenges,” by C.G. de las Heras, V. Llerena, & G. Kielhofner, 2003, p.23.

Stage	Strategies outlined in the Remotivation Process Manual	Strategies that will be used by the researcher for the study	Goals outlined in the Remotivation Process Manual	Hypothesized behavioral manifestation of this level during the study
Self-monitoring and identification of critical skills Self-advocacy/ Personal Advocacy	<ul style="list-style-type: none"> <li>Autonomous person-environment negotiation</li> <li>Autonomy in setting and striving for personal goals,</li> <li>Making occupational choices, and seeking new challenges in relevant occupational environments (a process that started in the Competency Module)</li> </ul>	<p>The researcher:</p> <ul style="list-style-type: none"> <li>Shifts focus on preparing the client for discharge</li> <li>Steps back by decreasing the frequency of the sessions</li> <li>Provides advice to facilitate interpretation and choosing courses</li> </ul>	<ul style="list-style-type: none"> <li>Maintains an objective perspective and an awareness of client's subjective experience</li> <li>Exploration of interests in novel contexts</li> <li>Self-initiated occupational behavior</li> <li>Confidence in trying new things</li> <li>Reshapes occupational identity</li> </ul>	<p>The client will:</p> <ul style="list-style-type: none"> <li>Continue with the new routine even after discharge from therapy</li> <li>Be able to use her knowledge and experience in occupational therapy to overcome challenges, doubt or setback.</li> </ul>

Continued learning of critical skills and the application of new strategies and tools for seeking and confronting new challenges

- of action in new challenges
- Monitors of symptoms
- Facilitates self-monitoring and self-evaluation.
- Gives feedback into personal causation and interpretation of environmental elements
- Provide resources and strategies for self-management and self-evaluation.
- Provides information and resources: give tool and strategies for self-monitoring
- Steps back: let the client practice autonomy, encourage self-help groups, etc.

- Be able to continue with SMP despite changes in personal life and family.

## APPENDIX G

### Participant Handout of the Remotivation Process



This home program provided by your therapist aims to help you control lymphedema. Learning to control lymphedema, like any medical condition, involves a change in routine and lifestyle. Your decision to change is affected by your thoughts and feelings. Some of these thoughts and feelings include:

- Your belief in your effectiveness to do something you intend to do
- Your personal assessment of your abilities to do what you intend to do.
- What you find important in life.
- Your interests.

The process of changing your routine and lifestyle involves three stages. These thoughts and feelings help you move through these stages.

1. Exploration – you are learning to adjust to lymphedema at this stage. This is also when you start to learn to do the home program on your own. You may feel emotions such as frustrations or uncertainty, but this is a normal part of change. This is an opportunity for you to find out what you are able to do for yourself and those important to you even with lymphedema. You begin to alter parts of your routine in an attempt to perform one or more parts of the home program.
2. Competence – you now gain an understanding of what you can do to control lymphedema. You are able to do the home program more often since it slowly becomes part of your routine. You may experience some setback, but you still try to do what you can everyday. You also feel more confident that you can control lymphedema.
3. Achievement – You are now able to create a routine that you follow everyday, which includes the home program for lymphedema. You can still perform the home program even when there is a change in your routine or schedule. You also feel confident that you can control your lymphedema even after you are discharged from therapy.

Reflecting on your progress may help you achieve maximum benefit from the therapy program. The following questions can help you reflect on your progress as you undergo this process of change.

- What did I intend to do this week to make my arm feel better?
- How effective was I in doing what I intend to do?
- How do I feel about myself this week?
- What was most important to me this week? How did it affect my decision to do what I intend to do this week?
- What did I find most interesting this week? How did it affect my decision to do what I intend to do this week?

Please feel free to discuss your thoughts with Kaye Rubio during your weekly phone calls. This part of your therapy aims to help you make the routine and lifestyle changes that will enable you to feel satisfied in what you can do despite lymphedema.

## APPENDIX H

Girth Measurement Chart in COH Data Collection Form

<u>Landmark (in cm)</u>	<u>RUE</u>	<u>LUE</u>
MP		
Wrist		
4		
8		
12		
16		
20		
24		
28		
32		
36		
40		
44		
48		
52		
56		
60		

## APPENDIX I

### The Model of Human Occupation Screening Tool

## Model of Human Occupation Screening Tool (MOHOST) Rating Form (UK English)

<b>Client:</b> _____ <b>Age:</b> _____ <b>Date of birth:</b> ____/____/____ <b>Gender:</b> Male <input type="checkbox"/> Female <input type="checkbox"/> <b>Identification code:</b> _____ <b>Ethnicity:</b> White <input type="checkbox"/> Black <input type="checkbox"/> Asian <input type="checkbox"/> Other: _____ <b>Health condition:</b> _____	<b>Assessor:</b> _____ <b>Designation:</b> _____ <b>Signature:</b> _____ <b>Date of first contact:</b> ____/____/____ <b>Date of assessment:</b> ____/____/____ <b>Treatment settings:</b> _____ _____
---	--

<b>Rating Scale</b>	<b>F</b> <b>A</b> <b>I</b> <b>R</b>	<b>Facilitates</b> occupational participation <b>Allows</b> occupational participation <b>Inhibits</b> occupational participation <b>Restricts</b> occupational participation
---------------------	--	--

### Analysis of Strengths & Limitations


### Summary of Ratings

Motivation for Occupation				Pattern of Occupation				Communication & Interaction Skills				Process Skills				Motor skills				Environment:			
Appraisal of Ability	Expectation of Success	Interest	Choices	Routine	Adaptability	Roles	Responsibility	Non-verbal Skills	Conversation	Vocal Expression	Relationships	Knowledge	Timing	Organisation	Problem-solving	Posture & Mobility	Co-ordination	Strength & Effort	Energy	Physical Space	Physical Resources	Social Groups	Occupational Demands
F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F	F
A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A
I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I
R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R	R

Adapted from “A User's Manual For Model of Human Occupation Screening Tool” by S. Parkinson, K. Forsyth, & G. Kielhofner, 2004, p.96.

## APPENDIX J

### Lymphedema Quality of Life Inventory

### **Lymphedema Quality of Life Questionnaire**

This questionnaire is concerned with the way lymphedema may affect your quality of life and activities of daily living. You may have experienced very mild lymphedema, moderate or severe symptoms. You may have lived with your symptoms for a short period of time or for a long time.

**Please answer these questions only as they concern your lymphedema**

Three sets of questions will be asked:

- How much do these concerns affect your quality of life?
- How many changes have you had to make in your everyday life because of these concerns?
- How difficult have these changes been for you?

**Please think about your Lymphedema and your Quality of Life in the past month.**

For each question circle the answer that best matches your experiences. Try to answer all questions.

If a question does not seem to apply to you, please circle the choice that says "No" or "Not".

	Physical Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
1	Pain due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
2	Aching in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
3	Discomfort in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
4	A feeling of heaviness in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
5	Pins and needles in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
6	Burning sensation due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
7	Numbness due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
8	A feeling of tightness in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
9	Swelling of my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
10	Skin problems due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
11	Feeling of heat from my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
12	Needing to reposition myself to sleep	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
13	Difficulty sleeping due to my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
14	Movement difficulties due to my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
15	Feeling conscious of my limb all the time	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
16	Feeling a loss of power in my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
17	Cellulites	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely

	Social Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
34	Needing to make changes to sporting activities (e.g. swimming, tennis).	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
35	Needing to be more careful when doing hobbies (e.g. gardening, sewing)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
36	Concerns about attending special social occasions (e.g. weddings, celebrations)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
37	Concerns about attending outdoor social activities (eg. picnics in the sun)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
38	Having to ask for help from family and friends (e.g. carrying groceries)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
39	Having to ask for help in public situations	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
40	Feeling self-conscious about my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
41	Concerned with changes in my appearance	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
42	Having to answer questions about my limb	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
43	Not being able to do the things I used to enjoy	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely



	Practical Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
44	Personal activities of daily living (e.g. dressing, combing hair, brushing teeth)	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
45	Normal daily activities (e.g. doing housework)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
46	Change of diet	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
47	Employment activities (e.g. unable to do the work, or the amount of time required)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
48	Learning to do things differently	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
49	Having less energy to do activities (e.g. personal, normal daily, or employment)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
50	Feeling fatigued after completing activities (e.g. personal, normal daily, or employment)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
51	Is the number of activities you do in one day reduced	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
52	The need to prioritise the activities you can do	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
53	Financial costs of managing my lymphedema (e.g. garments, treatments)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
54	Concern about finding good compression garment	No effect	A Little	A Bit	A Lot	No change	Few	Some	Many	Not difficult	Some	Very	Extremely
55	Driving a car	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely

	Practical Concerns due to lymphedema	How much do these concerns affect your quality of life?				How many changes have you had to make in your everyday life because of these concerns?				How difficult have these changes been for you?			
56	Finding clothes that are comfortable, the right size and type of material	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
57	Needing to cover up in the sun	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
58	The constant self care I need to do to stop my lymphedema from getting worse	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
59	The time required to manage lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
60	Obtaining information about how to manage my lymphedema	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely
61	Being prepared for emergencies (e.g. carrying first aid equipment, always having a script for antibiotics)	No effect	A Little	A Bit	A Lot	No changes	Few	Some	Many	Not difficult	Some	Very	Extremely

- 1 a. Taking all parts of your life into consideration, how would you describe your quality of life in the past month?  
Please circle the number below that best matches your overall quality of life.

0    1    2    3    4    5    6    7    8    9    10

Poor

Best Possible

- 1 b. Please think about how your lymphedema has affected you in the past 4 weeks and circle the number below that best matches your experience with lymphedema.

0    1    2    3    4    5    6    7    8    9    10

Poor

Best Possible

2. Has this been a typical month for you?                      Yes ( )      No ( )

- a. If you answered "No" to the question above, has this month been (tick one)

Much Worse ( )    Worse ( )    Better ( )    Much Better ( ) than usual.

- b. Why has this month been different?

3. Are there other things that have not been asked that you would like to add?

**Thank you for your time in completing this questionnaire.**

Adapted from "Lymphedema Quality of Life Inventory (LyQLI) by P. Klernas, A. Johnsson, A., V. Horstmann, L.J. Kristjanson, & K. Johansson, 2015.

APPENDIX K

Rsearcher's Journal Template

## **THE RESEARCHER'S JOURNAL**

**Week Number:\_\_\_\_**

**What were my expectations this week?**

**What have I observed in the patients this week?**

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

**What are some concerns or problems that I have encountered?**

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage the to bring to my attention any concerns.

## APPENDIX L

### Collaborating Institution's Data Collection Form



IRB # \_\_\_\_\_ Data Form

Protocol ID:

--	--	--	--	--	--

Research Participant #:

--	--	--	--	--	--	--	--

Participant Initials:

--	--	--

Form:

--	--

Evaluation Code:

--	--	--	--

Date of Collection:

Month

--	--

Day

--	--

Year

--	--	--	--

Age:

--	--

Diagnosis:

\_\_\_\_\_

Date of Surgery:

--	--

/

--	--

/

--	--	--	--

Date Completed

# of lymph nodes removed

--	--

Radiation? (Circle one) Yes / No

Currently undergoing chemotherapy? (Circle one) Yes / No

If yes, # of radiation sessions?

--	--

Past Medical History:


Occupation: \_\_\_\_\_

Pain:

--	--

/ 10

Living arrangement:

\_\_\_\_\_

Marital status: ☐ Married, in a civil union, domestic partnership, or living as married  
☐ Divorced  
☐ Widowed  
☐ Never married  
☐ Other  
☐ I'd rather not say

Provider/CRA FULL NAME (Please Print)

Month

--	--

Day

--	--

Year

--	--	--	--

Date Completed

--	--

--	--

AM/PM

Time Completed



IRB # \_\_\_\_\_ Data Form

Protocol ID:

--	--	--	--	--	--

Research Participant #:

--	--	--	--	--	--	--	--

Participant Initials:

--	--	--	--

Form:

--	--

Evaluation Code:

--	--	--	--	--

Date of Collection:

Month	Day	Year								
<table border="1"><tr><td></td><td></td></tr></table>			<table border="1"><tr><td></td><td></td></tr></table>			<table border="1"><tr><td></td><td></td><td></td><td></td></tr></table>				

Lymphedema:

Skin Integrity:

☐ Intact

☐ Fibrotic

☐ Hyperpigmentation

☐ Weeping edema

Edema:

☐ Pitting

☐ Non-pitting

Landmark (in cm)	RUE	LUE
MP		
Wrist		
4		
8		
12		
16		
20		
24		
28		
32		
36		
40		
44		
48		
52		
56		
60		

Notes:


Provider/CRA FULL NAME (Please Print)

Month	Day	Year								
<table border="1"><tr><td></td><td></td></tr></table>			<table border="1"><tr><td></td><td></td></tr></table>			<table border="1"><tr><td></td><td></td><td></td><td></td></tr></table>				

Date Completed

<table border="1"><tr><td></td><td></td></tr></table>			:	<table border="1"><tr><td></td><td></td></tr></table>			AM/PM

Time Completed

## APPENDIX M

### Field Notes of Participant 1



**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_\_1\_\_

**Week Number:**\_\_1\_\_

**Position on the volitional continuum:** \_\_\_\_\_Exploration\_\_\_\_\_

**Observation of the Participant:**

The participant is very busy with activities involving her family. The schedule of the weekly calls revolved around the schedule of her children. She was in the car with her son who is currently learning to drive during our call.

She seems familiar with lymphedema as she underwent CDT last year. The PI explained that her role in this study is to help her create a routine that includes whatever her therapist provides her as a home program.

The PI used the guide questions for the exploratory phase. She is exploring new ways to manage lymphedema, meaning she is trying new things. She says she sees the value of therapy, which shows that the activity is significant. She also shows preferences when she said she thinks she needs a shorter program to fit her schedule.

**Personal Reflections of the Participant:**

The participant was seen by Francis from June 2018 to January 2019. Her main problem was cording with mild lymphedema, which occurred 1 month after the surgery. She also underwent radiation from November 2018 through January 2019. She was “doing very well and did not have much swelling” and was discharged from therapy. The swelling began to worsen a few weeks later. The participant thinks this is the radiation “slowly showing signs”.

Francis gave her home exercises with 2 lbs weight, deep breathing exercise, and massage routine. She was also wearing a sleeve. She was able to do these because it did not take much time and can do it in between daily activities. However, she stated that “it was not working anymore” because the swelling is getting worse.

She was seen by Mahjabeen last Tuesday and will be going once a week. She found Mahjabeen’s program too long as the massage takes 30 minutes long. She says that her hands get tired after performing the massage and feels like she will develop “carpal tunnel” because of the repetition and amount of time. She found that the style of the 2 therapists was different. While she finds it helpful to see two different approaches, the new home program is too long. She finds it difficult to perform the massage herself even when her husband helps her. Her husband attended the session with Mahjabeen and took a video of the massage, but it is still hard because it takes time. The participant felt that she has so many other things to do as a mother and a wife. Her husband was sick this week so she had to take her kids to school and afterschool activities in addition to shopping and activities in the house.

She saw Francis this week as well. She agreed to have her arm bandaged, but she noticed that her fingers turned blue. Her fingers were not bandaged at that time. She had to take the bandage off and was afraid to put it back on because she fears that the bandages will cut the circulation off of her fingers. She was willing to try bandaging at night and wear the sleeve during the day but was concerned about her fingers turning blue

She says she sees the value of therapy. COH in Duarte is an hour away from her home, but she was willing to take time to drive there since the other locations of COH that was closer to her at Riverside do not offer therapy services. However, she is also wondering if she can go to another clinic for therapy, even if it is not with COH.

#### **Plan for the Following Week:**

The participant will again see Francis next week. She thinks that a shorter routine will be better for her. When asked what she thinks can be done to help her create a routine, her answer was “I don’t know”. She is comfortable with Francis. She thinks her arm feels much better, with a more comfortable sensation after the massage. She thinks she needs a shorter program for massage. She plans to ask Francis along with telling him about the blue discoloration of her fingers after the bandaging.

Friday, May 17, 4 pm PST, 25 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_1\_\_

**Week Number:** \_\_2\_\_

**Position on the volitional continuum:** \_\_Competency\_\_

**Observation of the Participant:**

- The participant is more able to verbalize her thoughts in Tagalog
- She says she says an improvement since we spoke
- She saw a different therapist this time and the therapist gave her a shorter home program
- She was working in her garden during the conversation
- The transcription below is a translation of Tagalog since the participant shifts between Tagalog and English. Some sentences were a mix of 2 languages.
- The PI used the questions from competency and achievement stage
- She says she keeps doing what I have been doing, showing that she stays engaged. However, she is still trying between the long and short programs. She also tried to solve the problem of stiffness in the arm by trying the elliptical. She seems to be between competency and achievement stage.

**Personal Reflections of the Participant:**

- “There is less swelling and my arm feels better, which is the proof of the importance”
- “The therapist gave me a shorter home program (massage and exercise)”
- She does the SMP as many times as she can because it is shorter. She does it morning and evening, but more in the evening because she has more things to do for her family and her home in the morning
- The elbow is not pitting anymore
- She is satisfied with the SMP because it is shorter and more realistic. It is less tiring
- Regarding her concern about the bandages being too tight:
  - She does not need the bandages anymore because she is improving
  - She is currently trying a new compression sleeve
  - The sleeve is thicker this time
- Regarding her next visit
  - She will be seeing the therapist who gave her a longer home program so she is a little anxious that she will be told to do the longer program again
  - She would like to have more consistency with her therapist
  - However, even is she is anxious, “I just keep doing what I have been doing”
- The PI then asked if she thinks she can do the SMP even after she is discharged. The participant hesitated and had a slight worry in her voice at first. But then she said:
  - I follow all orders, I will do it
  - The doctors said that I am a model patient
  - She regards therapy at COH as a “safety net”
  - She considers herself strong and blessed
    - When I was first diagnosed, I cried a bit then there was no crying

- Shake it off
  - Nasa Diyos lahat
  - I look good despite my treatment
  - I don't let things bring me down
  - If I get discharged and it comes back I can always contact the doctor
  - (She had therapy before) The doctor ordered to continue OT (after the swelling came back)
- Regarding her swelling
  - It is due to radiation side effect
  - She read that it can develop swelling
  - She had no swelling until last March
- When asked if she did her SMP
  - She performed the SMP for 1 whole week
  - I think what I did, for now, helped that's why my arm is smaller
  - Praise the Lord
  - She also did the elliptical (machine) even when her therapist did not tell her to
  - She was trying different exercises that were similar to the exercise program her therapist gave her
  - She likes the elliptical because it moves her arm, "I was thinking that will do my arm also"
- She stays active. She does gardening but she tries not to overdo it and do everything in moderation
- She then recalled her journey
  - She had breast surgery, underwent MRI, mammogram, and PET scan
  - July 3 was her first cycle
  - Her last cycle was June 4
  - She was given a different diagnosis this time around. She was HER 2 negative in 2017 but she is HER 2 positive this time so the type of treatment is different
  - He stays active ever since
  - She is still smiling even through the long treatment
  - She has a positive attitude
- She stated that she went to see her OB-Gyn and will make an appointment with plans to have her ovaries taken out. However, she would like to take a break in between her treatment for breast cancer and hysterectomy
- She waited a year after reconstruction. She does not mind the way she looks "There is more to life. I am more than my boob"
- She considers herself to have a strong support network of family and neighbors
- She provides advice to a family member ("pinsan ng husband ko may cancer din")
- Her husband supports her and they will be going to Vegas in June
- God is the Maker. He will heal me, here on earth or heaven. Either way, I will be healed. I am not afraid. God has sustained me, we are good. I have no pain.
- "Oh, kaya ko pala ito. I will be able to help other people"
- "Noong una (referring to her first diagnosis) I thought 'what is this a curse? But if this happens again I can do it. Makakaya ko pala kung uulit. Hindi na ako takot. I have a lot of friends. Swete parin ako. I was the best person to deal with it instead of my siblings (she thinks of genetic linking).

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. COH is a far drive from her house and she feels tired afterward.

Friday, May 24, 4 pm PST, *35 minutes*

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_1\_\_

**Week Number:** \_\_3\_\_

**Position on the volitional continuum:** \_\_Achievement\_\_

**Observation of the Participant:**

- She was still out of the house during the call
- She met with the other therapist
- She seems to be in the achievement stage as she was able to pursue the program to completion, saying that she has mastered the routine.

**Personal Reflections of the Participant:**

- The other therapist was more detailed, but it was still a good session
- I thought I have to do each step 10x, but it turns out I can do it 3-5 times.
- The SMP was shorter and more doable
- It was a blessing in disguise that I saw her (other therapist). She spent more time explaining
- The instructions were pretty much the same (as the shorter SMP), but with clearer instruction
- The SMP was more simple. The therapist made the sequence more clear and the reason was clear
- A piece of foam was added to her bra to address some swelling in the chest
- She felt that the female therapist can relate to her more
- She is happy to have 6 sessions with the female therapist
- She does the SMP every day, morning and night. She does it more at night because she has more time. She feels more rushed in the morning
- The arm is better than 3 weeks ago
- I feel it is improving
- Mas kabisado ko yung technique. Ok, rin yung routine.

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. COH is a far drive from her house and she feels tired afterward.
- The follow up will be on wk 7 because she and her husband will be on vacation

May 31, 4:30 pm PST, 10 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_1\_\_

**Week Number:** \_4\_

**Position on the volitional continuum:** \_\_\_\_\_**Achievement**\_\_

**Observation of the Participant:**

- She was still out of the house during the interview
- She seems to be at the achievement stage. She continues to pursue the activity to completion, even when they went on vacation. She also pursues the SMP even through the pain and fatigue. Although she has not sought challenges yet, she feels ready to take on new treatments for ovarian cancer.
- She feels that the arm is better, even when girth in the left arm did not significantly decrease. The difference between the affected and unaffected arm is minimal, with >2 cm increase in the elbow. MOHOST changed from a mix of A & F to all F.

**Personal Reflections of the Participant:**

- See transcription

**Plan for the Following Week:**

- The follow up will be on wk 7 because she and her husband will be on vacation

June 7, 4 pm PST, 30 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_1\_\_

**Week Number:** \_\_8\_\_

**Position on the volitional continuum:** \_\_\_\_Achievement\_\_

**Observation of the Participant:**

- The participant agreed to the transcription and the analysis
- Quantitative data provided by her therapist showed that girth and volume have decreased

**Personal Reflections of the Participant:**

- She is concerned with the swelling, particularly the discomfort and heaviness. However, she works through it even though it is difficult.
- She is anxious about the side effects of radiation, knowing that it can either show up now or down the road. It can get worse or better down the road.
- Frustration comes from not being able to do the things she enjoys and have to ask for help. However, she can still do most activities with limitations or modifications. She knows her limits.
- She still sets aside time to do the home program. It is routine.

**Plan for the Following Week:**

- The participant would like to receive a copy of the final analysis when the study concludes with City of Hope
- She requested a copy of the NLN position paper for air travel in preparation for their trip.

Date and time: Jun 21, 4 pm PST 20 minutes



## APPENDIX N

### Field Notes of Participant 2

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_2\_\_\_\_

**Week Number:** \_1&2\_

**Position on the volitional continuum:** \_\_\_\_Exploration/Competence\_\_\_\_

**Observation of the Participant:**

The PI was not able to speak with the participant during week 1, however, she was still able to share her thoughts about the past 2 weeks. The PI also provided her with a handout regarding motivation and lymphedema. According to the participant, she was in the middle of moving but was also very sick which is why she has not been able to return the calls. She was first seen at COH on May 7. She wanted to know more about lymphedema and seem to appreciate the information the therapist gave her. Even if the PI was not able to speak with her during week 1, these seem to show characteristics of exploration on the Volitional Questionnaire.

The participant was concerned with the time because she was busy with the day's activities. The conversation was kept at 13 minutes.

The participant readily shared her thoughts and experience with lymphedema and the home program. She was also willing to speak the PI next week but prefers Monday and Wednesday between 5 and 6 pm. She will be seeing her CLT every Tuesday for the next 5 weeks. Her appointments are in the afternoon and she has a 45-minute drive to COH. She has an appointment with her oncologist every Thursday.

**Personal Reflections of the Participant:**

The participant received therapy from another therapist after her mastectomy. She first saw the CLT on May 7. However, she feels that her arm is not that swollen. She now has a sleeve. The CLT also gave her a book that provided her with information on MLD. She thinks that the CLT also gave her very clear and detailed information. The CLT also gave her a diagram and illustration of the body and drew the direction of the flow of the lymph fluid towards the lymph nodes. She understood that the massage will push the lymph fluid.

She stated that she was able to wear the sleeve every day, during the day and takes it off at night. Her partner performs the MLD every day. She does the exercise every other day. She was able to wear the sleeve, but she needs some assistance to adjust the sleeve. She sometimes needs help to don the sleeve. She also shared that the sleeve initially felt weird but now she is starting to get used to it.

**Plan for the Following Week:**

The PI began with questions outlined in the Exploratory stage of the RP. However, the participant seemed more appropriate with the questions outlined in the Competence stage. The PI will ask the questions again outlined in the Competence stage. The participant is still in the middle of moving. The plan will be to explore the reasons for not being able to perform the SMP or how she was able to perform the SMP even in the middle of this life change.

May 20, total time 13 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_2\_\_

**Week Number:** \_\_3\_\_

**Position on the volitional continuum:** \_\_Competence\_\_

**Observation of the Participant:**

- She was sick again for 5 days but she was feeling fine and plans to attend her session the next day
- She sounded a bit tired, but this might be due to being sick. She still seemed eager to participate in the conversation. She sounded more tired towards the end of the conversation

**Personal Reflections of the Participant:**

- She used the exercise bands for exercise, but was only able to do her exercise twice because she was sick – “I was in bed for 5 days. But I think I am well enough to go tomorrow”
- She still used the sleeve and glove, her partner helped her with the massage – “wearing the sleeve has a difference”
- She is still adjusting after the move- “we are in a new place”
- However, she says “ I just need to get over it”
- She felt that she tends to retain fluid in the axilla and chest, which she attributes to having 22 axillary lymph nodes taken out. The exercises and massage helped.
- “You can tell the difference since I have not been doing it, I can tell the difference

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. COH is a far drive from her house and she feels tired afterward.
- Her next appointment is on May 22

May 27, 18 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_2\_\_

**Week Number:** \_\_4\_\_

**Position on the volitional continuum:** \_\_\_\_\_**Achievement**\_\_

**Observation of the Participant:**

- She was still out of the house during the interview
- She stated that she is satisfied with the SMP. She performs the SMP because she feels the effects if she does not do the massage or wear the sleeve. She feels the heaviness when she does not do the SMP. She also stated that the SMP fits her current routine because she does not work at the moment. When asked if she thinks she will be able to continue with SMP every day even after she returns to work. She stated that she thinks she will be able to do this because the SMP is easy and only takes 10 minutes.

**Personal Reflections of the Participant:**

- See transcription

**Plan for the Following Week:**

- Participant agreed to a follow up on week 8

June 3, 4 pm PST, 20 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_2\_\_

**Week Number:** \_\_8\_\_

**Position on the volitional continuum:** \_\_Achievement\_\_

**Observation of the Participant:**

- The participant's posttest data was received and compared with the preliminary coding of the interview.
- Pain and loss of motion is the main problem according to the interview
  - According to LyQoLI, the participant finds this frustrating and annoying. It has changed the way she does things and these changes have been very difficult for her.
  - The therapist assessed that the participant is limited by left shoulder pain
- The participant is motivated to perform the home program
  - According to the interview, the participant does it because it works. She thinks that she will continue with the home program even without the study because it works. She pursues the activity even through the discomfort.
  - The therapist stated that she has the willingness to do the home program
- The participant feels that she knew more about lymphedema after 4 weeks. The therapist reported that the participant shows an increased understanding of lymphedema.
- The conversation was 16 minutes on July 1, 2019. 5 pm

**Personal Reflections of the Participant:**

- The participant is still performing the home program after 4 weeks even after the weekly conversations
- She agreed to the findings
- She had to stop because of an error in her insurance, which is now resolved and she is going to reschedule
- “Pain is what is holding me back”
- Therapy is focused on lymphedema and pain management
- On what motivates her:
  - I have the willingness to do what I can to go back to normal
  - I want to know how I can move about it, how I can get back to my normal, whatever that will be
  - I have been through so much hardship in the past year. After all, I have been through, I am grateful
  - I am better
  - She finds willingness “I do it for my grandchildren”
    - I have to be strong for them

- I have a great relationship with my grandmother. I want them to have a great relationship with me as a grandmother. If I am gone, who will they have a relationship with? (legacy)
- She agreed that living for someone and being strong for someone motivates her
- She thinks she has a small support system; she only has her partner. Her 2 kids have their own lives
- Life before cancer was a 9-5 job

**Plan for the Following Week:**

- This concludes her participation in the study
- Results will be shared after the study write up.

Date and time: July 1, 5 pm PST 16 minutes

## APPENDIX O

### Field Notes of Participant 3



**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_3\_\_\_\_

**Week Number:** \_1\_

**Position on the volitional continuum:** \_\_\_\_Exploratory\_\_\_\_

**Observation of the Participant:**

The participant was at home with her husband. She has not received CDT in the past. She seems apprehensive but hopeful that the swelling will go away. The PI explained that her role in this study is to help her create a routine that includes whatever her therapist provides her as a home program. The PI used the guide questions for the exploratory phase.

The participant seems to be in the exploratory phase. She only wears the sleeve, which is one component of the SMP that she initiates. She goes to therapy even if she does not understand what it is for, showing that she shows curiosity.

**Personal Reflections of the Participant:**

The participant goes to COH every week for therapy. However, when asked, she then said that she does not know exactly how many times a week she goes to therapy because she has so many appointments. She had some therapy in the past, which includes carpal tunnel release. She also said that she stops going to therapy if she does not see any improvement.

When asked about her home program, the participant said that she only wears the sleeve although she does not understand what the sleeve is for. She has some exercises, but she feels that it is more for the flexibility of her arms and shoulders. She still feels some pulling sensation in the arm, but she feels that her flexibility is better. She says that the bandages did not help. She does the exercise every day as much as she can. However, she does not have time to sit around. She helps her husband with office work.

**Plan for the Following Week:**

The participant will meet with the therapist again next week. When asked what can be done to improve her performance of the home program, she says "I still do not what to do. What else can I do to help my arm get better?". The PI suggested asking the therapist during the session. She then replied that she will go with whatever, even if she has no idea what to do next. She also stated that she thinks she should be thankful over the process of recovering from cancer.

Monday, May 13. 22 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_3\_\_

**Week Number:** \_2\_\_

**Position on the volitional continuum:** \_\_\_\_exploration\_\_\_\_

**Observation of the Participant:**

- The participant lives with her husband. She is limited in mobility. She states that she is not well-versed in technology when the PI asked if she will be able to participate in a video call
- The participant had an anxious tone. She sounded upbeat but lets out a sigh a few times. This seems to show that she may be tired from the appointments but eager to share her story
- She saw her therapist again this week
- She still seems to be in the exploration phase. She initiates actions, performing 2 components of the SMP. She is satisfied with the activity but does not do it every day. It shows that the activity is significant.

**Personal Reflections of the Participant:**

- The swelling seems to be going down. The therapist took a piece of foam off last week, then he took 2 pieces this time
- Her home program consisted of wearing the sleeve and massage
- She was not able to state how many times she performed the program, but stated she did it “a few times, maybe half the time (half a time this week)”
- She said she is satisfied with the SMP because it is simple and not complicated
- Her legs are also a bit swollen

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. COH is a far drive from her house and she feels tired afterward.

May 23, 5 pm PST 9 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_3\_\_

**Week Number:** \_3\_

**Position on the volitional continuum:** \_\_\_\_exploration/competency\_\_\_\_

**Observation of the Participant:**

- The participant still had an anxious tone. She sounded upbeat but lets out a sigh a few times. This seems to show that she may be tired from the appointments but eager to share her story
- She sounded more tired
- She saw her therapist again this week
- She is still in the exploration phase, moving towards competence. She is still trying to adjust to the condition, hoping that it will go away. However, the activity is significant, expressing satisfaction with the therapists and the home program. She stays engaged, doing “half of it”.

**Personal Reflections of the Participant:**

- The swelling seems to be going down more. The therapist took all the foam off. She went back to wearing the sleeve and glove
- When asked if she is satisfied with the SMP, she thinks the SMP is “very fine” and the therapist is “very thorough”
- “I can use my hand quite a bit. I still can’t bend (my fingers) because of neuropathy but that is different. My hand is more useful now”
- Regarding her therapist: “ I asked her if it ever goes away but she did not tell”
- When asked if she can do the SMP: “the home program is ok and I will try to do it. I am not regular at it should be, but I cannot remember half of it”.
- She has no other concerns

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. COH is a far drive from her house and she feels tired afterward.

May 31, 5:30 pm PST 9 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_3\_\_\_\_

**Week Number:** \_4\_

**Position on the volitional continuum:** \_\_\_\_Competency\_\_\_\_

**Observation of the Participant:**

- She was a bit tired during the interview
- There was an insignificant change in girth, but her MOHOST scores improved from A to F in terms of responsibility, energy, problem-solving, and physical space.
- She seems at the competence stage because she is externally motivated. She feels that she needs to do it because she is instructed to do it. She does not quite understand why she needs to do it.

**Personal Reflections of the Participant:**

- See transcription

**Plan for the Following Week:**

- Participant agreed to a follow up on week 8

June 7, 5 pm PST, 20 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_3\_\_

**Week Number:** \_\_8\_\_

**Position on the volitional continuum:** \_\_Competence\_\_

**Observation of the Participant:**

- The participant's posttest data was received and compared with the preliminary coding of the interview.
- The swelling decreased overall but there was an increase in the upper arm as well as a 4% volumetric increase. However, the participant feels that her arm felt better.
- The participant is motivated to perform the home program
  - According to the interview, the participant does it because she is told to do so
  - However, she remains at the competence stage because she is externally motivated. She feels that she needs to do it because she is instructed to do it. She does not quite understand why she needs to do it.
  - The therapist stated that she is more motivated to do the home program
- She wants the swelling to go away. She said that the follow up was helpful because she was being reminded.
- She also feels that the limitation in motion is due to something else, which was neuropathy and not lymphedema
- The conversation was 12 minutes on July 1, 2019. 5:30 pm

**Personal Reflections of the Participant:**

- The participant is still performing the home program after 4 weeks even after the weekly conversations
- She agreed to the findings
- She feels that she is doing very well.
- She is currently using a Velcro wrap. The therapist feels that the sleeve is not appropriate at this time and she needs a heavier material
- She continues to ask the therapist if the swelling will ever go away, but the therapist still does not give her a definite answer
- She does the home program every day now. Her husband helps her with the Velcro wrap.
- She maintains a positive outlook. She described her experience as “an interesting year”, referring to her battle with cancer and lymphedema
- “It is what it is”. It is inconvenient to do the home program, but she does it. She is thankful for her husband who helps her. She is also thankful for the people at COH.

**Plan for the Following Week:**

- This concludes her participation in the study

- Results will be shared after the study write up.

July 1, 2019. 5:30 pm 12 minutes

## APPENDIX P

### Field Notes of Participant 4

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_4\_\_

**Week Number:**\_\_1\_\_

**Position on the volitional continuum:** \_\_Exploration\_\_

**Observation of the Participant:**

- The participant underwent CDT and LN transfer 7 years ago.
- 38 LN were removed and 16 were (+) for cancer
- There was a significant difference between the L (unaffected) and R (affected) arm
- Questions outlined in the exploratory stage were used.
- The participant verbalized frustration over the lack of information regarding lymphedema and the loss of function this time. She did not have loss in function 7 years ago.
- The conversation was 45 minutes (6/5/19 9 pm EST)
- She will continue to see the therapist every Tuesday at 11 am
- She has an appointment with the “lymphedema doctor at COH” on July 3
- She has a custom sleeve and glove (CG1-1R Jobst)
- Exploration stage – shows that SMP is significant, initiates actions and tries new things. She has a general goal to control the swelling but does not stay engaged yet. She cannot stay engaged because the home program does not seem to work. The pump “did not do anything”. The compression garments do not fit.

**Personal Reflections of the Participant:**

- Lymphedema was fine until Jan 28 when she underwent B mastectomy
- During the first incidence when she first diagnosed with BC, she had 38 LN removed, 16 were positive for cancer. She had 33 rounds of radiation afterward.
- Lymphedema did not start immediately
- She was frustrated because her surgeon, “who is world-renowned”, dismissed the swelling. She was not given any exercises or told anything about it.
- She went to see her oncologist who recognized the lymphedema. That was when she was first introduced to lymphedema. She got the “pump”, which is a basic pneumatic pump with 6-8 chambers”. She did everything she could
- She underwent lymph node transfer. “The arm shrunk after that and I regained function on my right arm”
- She was frustrated this time because the lymphedema came back after the double mastectomy. The lymphedema was more pronounced in the fingers that she developed trigger finger
- She was also frustrated because “back then (7 years ago) I had the means and people around me to assist me” referring to the bandaging and daily activities because the lymphedema affected her right, dominant arm.
- “This time I am alone, my family is in Michigan. I do not have friends. City of Hope is so far. And this home program, I realize now the importance”



- “It is hard because I have to drive an hour (to COH). I am limited to my left hand because my right is so swollen.
- When asked about the home program, “I can wrap and do exercise”
- When asked about her sessions: “This is my second session with him (Mahjabeen). He was the most helpful and thorough. He looked at how I am walking and helped build up my strength.”
- The swelling is pronounced in the fingers and elbow.
- Her frustration:
  - It is my fingers
  - Doctors dismissed my symptoms to trigger finger
  - (lymphedema) has never happened before
  - No one seems to know where the fluid is coming from and where does it go
  - You just want answers
  - Why is it so difficult (to find answers and solutions)?
  - As a cancer survivor, I have never heard of lymphedema
  - Never told that this could happen
  - I was a very active person – she does yoga and works out
  - Now I cannot do anything
- Questions for her therapist
  - Why is she flushed after the session
  - She feels completely drained
  - Her arm is so swollen that her ring and middle finger locks in the morning
  - She can’t put any pressure on her wrists
- Regarding the swelling at night, her therapist gave her the following instructions:
  - Try different positions to avoid blockage
  - Not to lay on one side so I can keep the flow working
- Regarding the sleeve and gloves
  - It pulses and throbs and she had to remove it
  - These were measured 7 years ago and may need remeasuring, which is a question for her therapist.

**Plan for the Following Week:**

- Call on Wednesday because she is too tired after her Tuesday sessions
- Use the exploration questions

June 3, 45 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_4\_\_

**Week Number:** \_\_4\_\_

**Position on the volitional continuum:** \_\_Exploration\_\_

**Observation of the Participant:**

- The participant has not returned any of the calls nor responded to the emails. The researcher has attempted to call on the usual schedule of Wednesday at 6 pm, a second attempt on Thursdays, and a third attempt on Fridays. The researcher also sent information regarding the study in an attempt to encourage her to continue with the weekly calls.
- However, posttest scores and measurements were received. The scores on the emotional subsection of the LyQoLI increased as well as the number of changes and the difficulty experienced from lymphedema also increased in the score, which means that QOL has improved in general.
- MOHOST also showed an improved overall score. Routine has improved, coordination has improved.
- Girth significantly decreased, but the affected arm is still significantly larger than the unaffected arm
- The participant wrote on her LyQoLI that her therapist is responsible for her improvement

**Personal Reflections of the Participant:**

- The participant has no interest in the study. Her therapist noted improved MOHOST scores and her measurements show improved in the presentation of lymphedema in terms of girth. However, the participant's appraisal of her physical concerns remained unchanged.
- Despite the improvement noticed by her therapist, she still feels that she has not enjoyed the things she enjoyed before. She still finds basic tasks such as writing difficult. She is still frustrated with lymphedema.

**Plan for the Following Week:**

- This concludes the participant's involvement in the study. No further follow up is expected unless she contacts the researcher.

July 4, 2019

## APPENDIX Q

### Field Notes of Participant 5

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_5\_\_

**Week Number:** \_\_1\_\_

**Position on the volitional continuum:** \_\_Exploration\_\_

The participant shows curiosity, she initiates actions related to the SMP, shows preferences in compression. Even though the SMP took time, she showed that the activity is significant.

**Observation of the Participant:**

- The participant was initially enthusiastic when the PI called her 2 weeks ago. The start of the intervention was postponed until after she had seen the therapist and received her SMP
- She stated that her SMP only consisted of compression wrapping at this point. Her daughter attended her sessions so that she can help her apply the bandages
- The PI tried several times to call. The participant explained that her schedule varies because of her work, but she would still like to participate in the study.
- The PI gave the participant her work phone number to make it easier to return the calls instead of using Zoom. The participant expressed her apologies and said that she was too tired to return the calls at the end of the day.
- She sees the therapist every Thursday.

**Personal Reflections of the Participant:**

- The participant stated that having her daughter with her helped her apply the compression bandaging everyday
- She thinks that the bandages are working, although it tends to be hot and troublesome. It also decreases the use of the arm
- However, she keeps at it because she knows she is improving and she thinks she is motivated to do her part in the program.

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. Phone calls were preferred over Zoom because she can return the call.

July 29, 11 pm PST 10 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_5\_\_

**Week Number:** \_\_2\_\_

**Position on the volitional continuum:** \_\_Competence\_\_

This week, the participant indicated her goal. She wants the arm to reduce in size so she can wear a sleeve instead of the bandages.

**Observation of the Participant:**

- The participant just finished her OT session during the call
- She will be seeing the OT and PT next Tuesday morning then transfusion later that day.
- The participant was out an about during the call
- She received lymphedema therapy in the past. She was familiar with the massage. The therapist from the other clinic did massage but did not use compression bandaging.
- The participant seems motivated by the results of the bandaging
- She was also pleased when the PI shared that grey foam is used in more advanced lymphedema. Not having to use the foam is a good sign, because the swelling is “not that bad”.

**Personal Reflections of the Participant:**

- The participant stated that she was having her daughter with her helped her apply the compression bandaging everyday
- “The arm is shrinking but it is not there yet. It is not yet ready for a sleeve. The therapist said that I was almost there. My arm is just 1.1 cm too big for the sleeve”
- When asked about MLD, the participant stated “I am familiar with it. I watched her (Mahjabeen) do the massage.”. She was also familiar with it from the other therapy clinic.
- When asked if she was willing to include the massage in her daily program, the participant stated that she also has physical therapy sessions. She feels that doing the bandaging, physical therapy, and occupational therapy will be too much. “I need to do something besides those”.
- However, when the PI learned that she was just 1.1 cm and when she said “I am close” to wearing a sleeve, the PI used that to encourage her to try and add the massage program to her daily routine to get her over that “hill”. The participant said, “Yes, I can do that”.
- However, she keeps at it because she knows she is improving and she thinks she is motivated to do her part in the program “ I am positive”. And “I do the best I can”

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. Phone calls were preferred over Zoom because she can return the call.

- The PI will call on Wednesday morning since she has busy Tuesday
- She said that if she does not answer, she will call the PI back that day

Aug 8, 10 AM PST 10 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_5\_\_

**Week Number:** \_\_3\_\_

**Position on the volitional continuum:** \_\_Competence\_\_

This week, the participant kept working on her goal. She wants the arm to reduce in size so she can wear a sleeve instead of the bandages.

**Observation of the Participant:**

- The participant was driving during the call
- She attended her OT session yesterday. Her arm still did not decrease in size enough to transition to a compression sleeve from bandaging
- She also attended the PT session yesterday where she did a different stretching program for her shoulder. She experienced severe spasms in her arms the entire week, which caused pain and discomfort.
- She was quite frustrated with the spasms, which hindered her from using the arm since the PT session

**Personal Reflections of the Participant:**

- The participant stated regarding her SMP “It is easy and pretty much straight forward”
- She was unable to do the MLD or exercises “the arm would spasm and hurt. It would bring me to my knees”
- She agreed that her inability to do the MLD and exercises were due to the pain and spasm and not the difficulty in the routine or finding time for it
- She was still able to have the arm wrapped with the help of her daughter

**Plan for the Following Week:**

- The participant agreed to do the 60-minute call via Zoom next week.

Aug 14, 12:30 PM PST 6 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_5\_\_

**Week Number:** \_4\_

**Position on the volitional continuum:** \_\_Competence\_\_\_\_\_

**Observation of the Participant:**

The participant stated that she was very busy and will not be able to participate in the follow-up call. She continued with the SMP as the previous week and had no other concerns.

**Personal Reflections of the Participant:**

**Plan for the Following Week:**

- The PI will again try to complete the 60-minute call via Zoom next week.

August 21, 11:00 AM PST 5 minutes



**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_5\_\_

**Week Number:** \_5\_

**Position on the volitional continuum:** \_\_Competence\_\_\_\_

I was unable to speak with the participant and she has not answered the call via Zoom, phone call, or email.

**Observation of the Participant:**

**Personal Reflections of the Participant:**

**Plan for the Following Week:**

- I will try to initiate the interview once again next week.

August 28- 30, 2019

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number: \_\_5\_\_**

**Week Number: \_8\_**

**Position on the volitional continuum: \_\_\_\_\_**

I was unable to speak with the participant and she has not answered the call via Zoom, phone call, or email. I sent her an email of the handout for Motivation and lymphedema.

**Observation of the Participant:**

**Personal Reflections of the Participant:**

**Plan for the Following Week:**

- This concludes the participant's role in the study.

Sept 16- 20, 2019

## APPENDIX R

### Field Notes of Participant 6

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_6\_\_

**Week Number:** \_\_1\_\_

**Position on the volitional continuum:** \_\_Exploration\_\_

The participant shows curiosity, she initiates actions related to the SMP, shows preferences in compression. Even though the SMP took time, she showed that the activity is significant.

**Observation of the Participant:**

- The participant went through R mastectomy with TRAM in 2005, L mastectomy with ALND, lateral flap and TE placement in 2016.
- She also had R shoulder fracture that led to reverse shoulder replacement. She experiences limited shoulder ROM because of this
- The participant seems motivated, which was also observed by her therapist.
- She tries her best to do the compression, exercise, and massage every day
- She is willing to do the SMP and sees the benefits of it, however, she wants to know if there is an easier way to do it.
- She fights to continue her participation in daily activities such as taking care of her grandson, participating in fine motor crafts and hobbies

**Personal Reflections of the Participant:**

- “I do the massage when I can but the pump takes care of it” referring to a pneumatic compression pump
- Her thoughts on the compression sleeve and bandaging
  - It is working so “I have to do it”
  - When she thinks about the SMP, she says it’s like having a devil and angel over her shoulder “do it”, “no, you don’t have to do it”.
  - She wears the sleeve but needs to wrap her arm because the sleeve does not fit her anymore. She wears a Solaris Tribute at night
  - The thickness of the layers is what’s debilitating
    - Decreased in movement
    - It is like a soft cast
    - It decreases function
    - She can only tolerate it in short doses
    - It tends to be hot
    - The layers “slows me up”
- She is limited more by her shoulder
  - “I am still recovering from a broken shoulder”
  - The pain in her shoulder increases when she has the compression bandaging
  - Pain is being managed through medication
- Her husband used to help her with the compression bandaging and self-MLD but it feels different

- She does her dry brushing and breathing exercises
- She does not have an exercise program for lymphedema
  - I have exercises for the shoulder
  - When asked about the exercises, “I need to be out”, meaning she needs time to do other things besides the home programs for lymphedema and her broken shoulder
  - (The PI explained that the exercises for the shoulder are similar to the exercises for lymphedema. So the exercise for the shoulder can serve 2 different purposes, which the participant seemed to be glad to hear. The PI also explained the purpose of the deep breathing exercises that were given to her by the therapist)
- When asked what she thinks can help her or encourage her to do the SMP more often:
  - She seemed interested in alternative compression that is not as thick
  - She needs reminders, like a person with a wooden paddle

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session. COH is very far from her house, at least an hour one way because of traffic.
- She agreed to ask the therapist regarding alternative compression garments in place of the bulky compression wraps.

July 22, 2:00 PM PST 6 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_6\_\_

**Week Number:** \_2\_

**Position on the volitional continuum:** \_\_Competence\_\_\_\_

This week, the participant indicated her goal. She wants the arm to reduce in size and lose weight.

**Observation of the Participant:**

- The participant participated in a 10-minute phone call this time. She was out of the house but was willing to talk. The PI attempted to call her at the set time of 10 am, but the participant did not answer. She answered on the PI's 3<sup>rd</sup> attempt in the afternoon, over the phone instead of Zoom.
- She was not as enthusiastic as the last week. At times it seems that she found the questions repetitive but appreciated the weekly call since it enables her to be more mindful of the SMP.

**Personal Reflections of the Participant:**

- She did the SMP 3x a week during week 1. Frequency increased to 4x this week
- She said that the pain is not as bad, which helped with the frequency
- The wrist, elbow, and hand are much better
- It is still frustrating because the arm is still swollen, but she sees that it is getting better
- She is more frustrated with the pain in the shoulder, which has not improved. She was more frustrated over not having answers from her orthopedic doctor, "which is supposed to be one of the best"
- When asked about her daily routine and the "fit" of the SMP
  - "I think I have adapted my routine to it. I wrap it (bandaging the arm), I wear the sleeves, I use the compression pump at night and the Tribute. I wear the sleeve in the morning. However, the compression tends to be tight so it hurts the shoulder. It is easier to put the sleeve on if I do it right after the pump."
  - She does the home program consistently because it works
  - "I did not know how important deep breathing is"
  - "I think I have got it down. I see the difference (in the size of the arm)"
  - "You do the best you can by yourself" since her husband cannot help her all the time
  - She appreciates having the weekly calls because it makes the SMO more consistent
  - Her goal: get the lymphedema under control, lose weight, so I can undergo the lymph node omentum flap

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session.
- She would like to find out more about donning aids. She already tried the Medi butler and Juzo Slippie Gator but both did not work.

July 29, 10:00 AM PST 20 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_6\_\_

**Week Number:** \_3\_

**Position on the volitional continuum:** \_\_Competence/Achievement\_\_

This week, the participant stays engaged even through the busy week. She tries to solve problems by continuing to look for better donning aid for the compression sleeve.

**Observation of the Participant:**

- The participant participated in a 5-minute phone call this time. She was on her way to a doctor's appointment but was willing to talk. The PI attempted to call her at the set time of 10 am. The call was completed over the phone instead of Zoom.
- The participant was in a hurry but appreciated the weekly call since it enables her to be more mindful of the SMP.
- She is still able to do the SMP even though she is helping to take care of her grandson and planned to visit her daughter today.

**Personal Reflections of the Participant:**

- Frequency remained at 4x this week
- She said that the pain is not as bad, which helped with the frequency
- The wrist, elbow, and hand are still getting better
- She still hoped to find a better donning aid

**Plan for the Following Week:**

- The participant agreed to participate once again in a call the day after her session.

August 5 1:00 PST 13 minutes



**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_6\_\_

**Week Number:** \_4\_

**Position on the volitional continuum:** \_\_Achievement\_\_

The 60-minute interview was completed this week.

**Observation of the Participant:**

She seemed eager to share her views and experiences about lymphedema.

**Personal Reflections of the Participant:**

- See transcription

**Plan for the Following Week:**

- The participant agreed to participate once again during the follow-up call in 4 weeks, which will be on September 16.

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_6\_\_

**Week Number:** \_\_8\_\_

**Position on the volitional continuum:** \_\_\_\_Achievement\_\_

**Observation of the Participant:**

- The participant agreed to the transcription and the analysis

**Personal Reflections of the Participant:**

- Her concerns are the feelings of heaviness, swelling, and appearance
- The arm is “gross” and feels like a broken arm
- She uses leggings to cover the arm. She jokes about it. These are her responses to feelings of self-conscious and concern over the appearance of the arm.
- She still has shoulder pain and experiences discomfort. She will soon follow up with the orthopedic doctor
- She thinks the hand is getting smaller.

**Plan for the Following Week:**

- The participant would like to receive a copy of the final analysis when the study concludes with City of Hope

Date and time: September 19, 1:00 PM PST 14 minutes

## APPENDIX S

### Field Notes of Participant 7

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_7\_\_

**Week Number:** \_\_1\_\_

**Position on the volitional continuum:** \_\_Achievement\_\_

The participant pursues the activity through completion. She said that she always applies the bandages, even when she is out of town. She does the exercises every morning. She tries to solve problems (competence) and invested additional energy by looking for alternative compression garments herself, which is how she got the Circaid Ready Wrap Velcro compression system in place of the compression bandages. She said this made compression easier to don and doff. She has been doing this home program for 15 years. She has yet to call the representative to recalibrate her pneumatic compression pump.

**Observation of the Participant:**

- The participant had indicated in the LyQoLI that her biggest concerns include movement difficulties due to lymphedema. She felt embarrassed and irritated by the inconveniences. The financial cost of lymphedema is also a concern
- She underwent L mastectomy and ALND in 2000. According to the participant, she did not develop lymphedema until her car accident in 2003. She said that she was told she had traumatized the arm during the accident
- She has no pain, but the arm becomes heavy. The pain occurs in her shoulder and back because of the heaviness in the arm. She is more limited by the ROM in the right shoulder
- She had difficulty bandaging and doing the MLD due to decreased ROM

**Personal Reflections of the Participant:**

- The arm does not get in the way. Her arm is getting better with therapy
- It does get in the way because she needs to use her arm and it is bandaged
- When asked about her thoughts on her routine:
  - I did all 3 when I first get up in the morning
  - It is rare that I do not wrap my arm. I wrap it even when I am out of town
  - If it is really hot, I have to take it off
  - The sleeve gets too tight if it is hot
  - The arm gets bigger if it gets too cold or hot
  - She has a pump to help her with the MLD but it needs calibration and she has yet to call the representative to have this done
  - When her arm swelled up until her therapy at COH in 2016, she had to take care of her mother. Even when she knew she should not be lifting, she still did that because she had to take care of her mom. "I had no choice, I have to take care of her"
  - Her mother has since passed away.

- Regarding her arm
  - She gets depressed over the size of her arm because it makes it difficult for her to buy clothes. She needs to buy clothes that are one size bigger than what she would normally wear because the sleeve of the clothing tends to be too small for the arm
  - She has had therapies in the past, but the arm does not go down
  - It is depressing to buy clothing
  - The arm does not go down in size even with therapies

**Plan for the Following Week:**

- The participant is already between competence and achievement. The questions for achievement can be used to determine if she continues to demonstrate more characteristics of the achievement stage.
- The participant agreed to participate once again in a call on Tuesdays since she has therapy MWF.

August 8, 10:00 AM PST 23 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_7\_\_

**Week Number:** \_\_2\_\_

**Position on the volitional continuum:** \_\_Achievement\_\_

This week, the participant stayed engaged even though she was not feeling well. She pursued the activity through completion even though she was light-headed. She tried to solve the problem of feeling ill when she stood up by completing the SMP while seated or sitting up in bed. She invested additional energy by participating in the discussion.

**Observation of the Participant:**

- The participant participated in a 23-minute phone call this time. She was in the middle of her SMP when the PI called
- She had a sore throat but was willing to participate in the conversation.

**Personal Reflections of the Participant:**

- She had canceled her appointment today because she felt light-headed
- She felt bad about canceling today. She knows that attending her therapy sessions help make the arm feel better.
- She had been to 7 different therapy clinics before she received therapy from COH. She found that most doctors do not believe in lymphedema
- COH is closer to her house, about 30 minutes away. She attends MWF
- About therapy:
  - The exercise and massage are helping me move more
  - Therapy helps decrease the size of the arm so she can use it more
  - The shoulder and her back start to hurt because it becomes heavy from the swelling
  - The shoulder and her back does not hurt that much when she goes to therapy
  - Therapy and her SMP help her use her arm more. Pain decreases to just discomfort. Therapy provides relief.
  - She can move it without pain, especially in the morning while she doing the home program
- [Therapy and SMP] It is helping me be more independent

**Plan for the Following Week:**

- The participant agreed to participate once again in a call on Tuesdays since she has therapy MWF.

August 13, 10:00 AM PST 15 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_7\_\_

**Week Number:** \_3\_

**Position on the volitional continuum:** \_\_Achievement\_\_

This week, the participant continued with her home program

**Observation of the Participant:**

- The participant participated in a 23-minute phone call this time. She was again in the middle of her SMP when the PI called
- She did not have a good night's sleep but she was still doing the SMP, but feel asleep. She still participated in the call and said that she will continue with the SMP after the call.

**Personal Reflections of the Participant:**

- She had a new therapist this week, but she was still very pleased with the program and felt that the therapy is helping her.
- It has been very hot lately, but she still wears the ReadyWrap. She was bandaged by the therapist yesterday. She said she keeps it on despite the heat because it helps her arm.
- She has no other concerns and feels that she will be ok after she discharged from therapy.

**Plan for the Following Week:**

- The participant agreed to the 60-minute interview the next week.

August 20, 10:00 AM PST 21 minutes

**FIELD NOTE**  
**Weekly Discussion with Participant**

**Participant number:** \_\_7\_\_

**Week Number:** \_4\_

**Position on the volitional continuum:** \_\_Achievement\_\_

The 60-minute interview was completed. However, the participant did not have a computer and had to complete the interview through phone calls.

**Observation of the Participant:**

- She had to cancel this week's appointments because she did not have a car.
- She had asked a friend to take her to COH yesterday. However, she did not want to ask another friend to take her to the 2 other appointments this week.

**Personal Reflections of the Participant:**

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**Plan for the Following Week:**

- The participant agreed to the follow-up phone call after 4 weeks, which is the week of September 16. She would be discharged from therapy by then

August 27, 10:00 AM PST 25 minutes



**FIELD NOTE**  
**Weekly Discussion with Participant**

**Patient number:** \_\_\_\_7\_\_\_\_

**Week Number:** \_8\_

**Position on the volitional continuum:** \_\_\_\_\_Achievement\_\_\_\_

**Observation of the Participant:**

- The participant agreed to the transcription and the analysis
- She was already discharged from therapy

**Personal Reflections of the Participant:**

- She feels able to manage BCRL because she has been doing it since 2005
- She sees a big change in the size of the arm
- It still affects her ability to do things
- She wears compression daily. She does her massage and exercises 5 to 7 days out of a week

**Plan for the Following Week:**

- The participant would like to receive a copy of the final analysis when the study concludes with City of Hope

Date and time: September 17, 10:00 PM PST 10 minutes

## APPENDIX T

### Interview Guide for Qualitative Data Collection

Introduction by the researcher: Good morning/ good afternoon. Thank you for agreeing to spend some time with me after your therapy with (name of therapist).

I also thank you for participating in this study for the past 4 weeks. As mentioned in the brochure and during the first week, I am conducting a research on lymphedema after breast cancer and what occupational therapy can do for breast cancer survivors like yourself. I would like to know more about your experience with lymphedema and occupational therapy. There are no right or wrong answers and everything you tell me will remain private. Are you ready to begin?

*If participant disagrees, then the interview is ended. If the participant agrees, the researcher proceeds.*

Researcher: This interview will be recorded in order for me to capture everything that is said. I respect your privacy, so I will not use your name during the interview. I will be the only one who will know which audio recording belongs to which participant. These audio recordings will be deleted after it is analyzed and when the study is completed. I respect your feelings about this topic, so if you feel that you want to stop or leave during the interview, please let me know. The interview will be stopped. Do I have your permission to proceed?

*If participant disagrees, then the interview is ended. If the participant agrees, the researcher proceeds.*

*If the participant decides to end the interview before all the interview questions are asked. The researcher will ask if the participant's answers can still be used in the study. The participant's answers will be analyzed if she agrees. The recording will be deleted if the participant states that she does not wish her responses to be included in the study.*

Researcher: So let us begin. Can you tell me a little bit about yourself – what are your interests, what you do everyday?

*(Participant responds)*

Researcher: *(Echoes main points of the participant's response)*. So now let us talk about lymphedema.

*The researcher proceeds to ask the main research questions.*

Interview Question 1. What are your thoughts about the home program for lymphedema?

Probe 1: What do you understand about lymphedema?

Probe 2: If there were challenges in doing the home program, how were these problems handled?

Probe 3: What has helped you do the home program?

Interview question 2. How do you feel about your body after spending some time with occupational therapy?

Probe 1: What have you noticed in your arm these past 4 weeks?

Probe 2: How do you feel about lymphedema when you first noticed changes in your arm (and chest)?

Probe 3: How do you feel about lymphedema after receiving occupational therapy?

Interview Question 3. How do you feel about your everyday life given what you understand about lymphedema?

Probe 1: What are some of the things that you engaged in before lymphedema?

Probe 2: What are some of the things that you engage in at this point after occupational therapy?

Probe 3: What are some of the activities that you were doing before lymphedema?

*If the client needs more probing questions: How about activities related to:*

- Personal care routine
- Home responsibilities
- Work
- Education (if applicable)
- Leisure
- Relationship with others (family, friends, co-workers)?

Probe 4: How would you describe your routine after occupational therapy?

*If the client needs more probing questions: How about routines that are related to:*

- Personal care
- Home responsibilities

- Work
- Education (if applicable)
- Leisure
- Relationship with others (family, friends, co-workers)?

Closing question: Is there anything else you would like to add at this time?

## APPENDIX U

### Researcher's Journal Entries

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_\_1\_ May 12 - 18**

### **What were my expectations this week?**

I was expecting that all 3 participants will be interviewed this week. I had no expectations regarding their responses.

### **What have I observed in the patients this week?**

I had to clarify my role with the participants. They were not sure what my role will be. It seems that they think I was there as a quality control person.

### **What have I observed in the therapists this week?**

They are eager to recruit participants.

### **How do I feel about this week?**

It is a bit frustrating to run after the participants. It is not the same as being onsite. I also had to be careful not to make recommendations so that I do not take over the role of the therapist. As a clinician, I feel a strong urge to solve the participants' dilemma, but I had to focus on helping them reflect and at the same time maintain my role as a PI and not the therapist.

I am also seeing a lot of parallels between the literature and the reflections of the participant. Both felt a bit lost and did not know what to do. Both stated that time is a big factor in their daily performance of SMP

### **What are some concerns or problems that I have encountered?**

I had to be persistent in calling the participants. Using telehealth is very different than speaking with the person face-to-face when they are at the clinic during their appointment. I have less control over their availability, unlike when the visits are onsite.

### **How can we make this therapy program better based on my observations this week?**

The length of time involved in performing the home program and understanding the purpose of the component of the home program are 2 important factors that may help the participants establish a habit that includes the home program.



## **THE RESEARCHER'S JOURNAL**

**Week Number: \_\_2\_ May 19 -25**

### **What were my expectations this week?**

I decided not to go over the pretest data so that I will form any expectations regarding the participant's place on the VQ.

### **What have I observed in the patients this week?**

The participants see more as a therapist as well. They seem more comfortable to share their experiences with me, not just with the therapy sessions, but also about their daily routines and perceptions about lymphedema. Conversations are even longer than 15 minutes because of the amount of information they shared.

Once again, I am seeing a lot of parallels between the literature and the reflections of the participant. Time was a factor in their adherence. They identified some questions to ask their therapists last week, which they were able to do this week during their session. They said they feel less lost, but they still had questions and concerns. I encouraged them to keep providing feedback and be open with their therapists. I also assured them that I will only share the information with the therapist that they agreed to share.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I am still very careful not to take over the role of the therapist. I also had to review the IRB protocol so that I can remain focused on my role. I am still a bit nervous about the weekly calls. It feels different from my interaction with my clients. I am trying to be encouraging, not patronizing. I struggle to not speak to solve the problem but to let them say what they want to say, which is different from what I do in the clinic, where the interactions are limited to an hour due to the schedule. I keep forgetting that the interaction is limited by the participant's time and willingness to talk.

### **What are some concerns or problems that I have encountered?**

Still, I had to be persistent in calling the participants. Using telehealth is very different than speaking with the person face-to-face when they are at the clinic during their appointment. I have less control over their availability, unlike when the visits are onsite. Participants also prefer to speak a day or two after the appointment because they are very fatigued after their long drive to COH. I hope that they remember the session, but at the same time, I also realized that the delay will enable them to process what transpired and what their thoughts are during the session before our conversation.

**How can we make this therapy program better based on my observations this week?**

Being open to the therapists and asking questions allow them to understand the program and facilitate adherence.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_\_3\_\_ May 26 – June 1**

### **What were my expectations this week?**

This week was supposed to be when we randomize the names of the participants and pick 6 names for the interview. Unfortunately, I only have 3 participants so all the names were drawn.

### **What have I observed in the patients this week?**

The participants seem to be progressing with the frequency and position on the VQ. The conversations were shorter and they did not have anything new to share. They also did not have any other questions or concerns that they can think of.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I am still very careful not to take over the role of the therapist. I also had to review the IRB protocol so that I can remain focused on my role. I am still a bit nervous about the weekly calls. It feels different from my interaction with my clients. I am trying to be encouraging, not patronizing. I struggle to not speak to solve the problem but to let them say what they want to say, which is different from what I do in the clinic, where the interactions are limited to an hour due to the schedule. I keep forgetting that the interaction is limited by the participant's time and willingness to talk.

### **What are some concerns or problems that I have encountered?**

I am concerned about the availability of the participants for the interview. At this point, I am so focused on the number of participants and accommodating their availability. I believe this has helped me bracket my expectations about the data that I have and will be collecting. It is also mentally tiring for me due to the time difference. The participants are on Pacific time, I am in Eastern time. Telehealth can be a valuable tool, but the difference in time zones can affect the participation of the participants, but more so with the mental and physical well being of the researcher or clinician.

### **How can we make this therapy program better based on my observations this week?**

The participants did not identify ways to improve the program. We might be able to identify more ways during the interview.

## THE RESEARCHER'S JOURNAL

**Week Number: \_4\_ June 2 -8**

### **What were my expectations this week?**

Qualitative data collection will happen this week in the form of an interview. I have not expectations. I just hoped that all the participants are available to talk this week, which they were. I also did not review the post-data so that it does not influence my questions. The onsite collaborator also began sending the posttest data of cohort 1, particularly those who are not scheduled next week.

### **What have I observed in the patients this week?**

The participants shared more this week during the interview. The questions allowed them to share more of their concerns. 2 seem to have achieved the last stage of RP, one seems to stay on the *competence* stage.

Cohort 2 only had one participant. She was very frustrated about lymphedema. She also felt that she did not have enough information about lymphedema. The conversation was long, around 45 minutes. She voiced her frustration. I provided her with some information to ease her frustration, which she said she appreciated. As before, I provided her with the same explanation of my role and kept referring her back to her therapist.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration. I shared with the onsite collaborator the frustrations of participant 4.

### **How do I feel about this week?**

Qualitative data collection is mentally, emotionally, and physically exhausting. I still need to process my thoughts about this week. However, I noticed that I am able to understand the nuances of lymphedema through my 7 years of experience as a CLT. However, I had to suspend what I know and ask the participant to elaborate. However, I was able to understand when the participant referred to chemotherapy, medications, neuropathy, heaviness, and types of pain.

### **What are some concerns or problems that I have encountered?**

I could not do a video call with the participants. Two were out on an errand on the time they were willing to talk. They had so many appointments and things to do, so I had to fit in when they are available. One participant is not well-versed with the computer and preferred a video call, which I had to respect.

**How can we make this therapy program better based on my observations this week?**

I will share the findings of the thematic analysis to identify ways to improve it.

## THE RESEARCHER'S JOURNAL

**Week Number:** 5 June 9 - 15

### **What were my expectations this week?**

Once again, I have not expectations. I still did not review the post-data so that it does not influence my transcription and preliminary coding. I completed the initial transcription of the interviews as soon as the interviews were completed so that I can take note of the initial impressions I had. I used Nvivo transcribe. I also sent the transcriptions to the participants for verification so that the interview is still fresh in their minds. I also began initial coding.

### **What have I observed in the patients this week?**

The participants shared more this week during the interview. The questions allowed them to share more of their concerns. Two seem to have achieved the last stage of RP, one seems to stay on the *competence* stage.

Participant 4 did not answer any of my calls and emails. I had emailed her a hand out of the Remotivation Process in an attempt to encourage her to participate in the study.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I am a bit frustrated with the recruitment. However, I am able to compartmentalize my clinical role and my researcher role. However, I feel that I may need to ask more questions about motivation than adherence alone. I do ask the questions during the weekly conversations, but the conversations tend to focus on their thoughts on the home program and function instead of what motivates them.

I had to stop several times during the initial transcription because I found my self immediately comparing what was said to the literature. I realized it would have been helpful to know the pretest and posttest scores so I can fully appreciate the participants' journey. I could have also used the scores as a prompt or probing question to verify the findings.

### **What are some concerns or problems that I have encountered?**

I could not do a video call with the participants. Two were out on an errand on the time they were willing to talk. They had so many appointments and things to do, so I had to fit in when they are available. One participant is not well-versed with the computer and preferred a video call, which I had to respect.

**How can we make this therapy program better based on my observations this week?**

I will share the findings of the thematic analysis to identify ways to improve it. I am still working on it. I also communicated with the onsite collaborator regarding participant 4.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_6\_ June 16 - 22**

**What were my expectations this week?**

I am trying not to expect anything as I continue to try and analyze the transcripts. Stepping back over the weekend allowed me to suspend all that I know about BCRL and motivation. This is the start of the summer semester and I am supposed to submit my preliminary analysis at the end. Knowing that I have a deadline helped me focus. I also continued to receive the posttest data for cohort 1. I found a second coder/peer reviewer. I submitted a modification to TWU IRB and received the approval. I sent the transcripts to the second coder as soon as I received the approval.

**What have I observed in the patients this week?**

Participant 4 refused to answer calls and emails. I received the posttest LyQoLI and read her sentiments though. She seemed still very frustrated. She states that motivation and problem solving is the responsibility of the therapist. It seems that she still sees herself as separate from the condition, even if she has acquired extensive knowledge about it. I did not receive any confirmation from the participants of cohort 1 regarding the transcripts.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I still want to solve the participants' problems and focus on the condition. But I am able to refocus myself on the study, which is centered on motivation. The focus is not on girth reduction, but motivation to be responsible for the condition, to own the condition and control it. As a clinician, my patients tend to give the responsibility to fix them. But as a researcher, the study is to enable them to be responsible for the condition.

I am more focused on the study now. I am not as anxious, but I still have doubts if I am really helping them. I was able to step away and analyze the quantitative data.

**What are some concerns or problems that I have encountered?**

I still need more participants. It is very challenging to schedule a video call because patients are usually on the go.

**How can we make this therapy program better based on my observations this week?**

I still need to analyze the quantitative data and compare with the interview.



## **THE RESEARCHER'S JOURNAL**

**Week Number: 9 July 7 - 13**

### **What were my expectations this week?**

I expected to be able to work on thematic analysis while on vacation.

### **What have I observed in the patients this week?**

I did not interact with the participants of cohort 1. Their role in the study is already over.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel this week?**

I am on vacation this week. I was able to disengage from my work as an OT.

### **What are some concerns or problems that I have encountered?**

I sent my preliminary SPSS output to CRDA for review. I think I might have been overwhelmed with the details of my study that I made quite a few mistakes in my SPSS output. I am very thankful that I have the guidance of Dr. Wang from CRDA who pointed me in the right direction. However, after 8 weeks of intense engagement in the study, my brain cannot seem to process any of the information. I had sent the transcripts to the second coder. I felt that I was not in the correct mindset to deal with any of the qualitative and quantitative data. I feel very exhausted and I know in my heart that I need a break. I need to step away from the study for a while.

I received feedback from Dr. Wang on 7/8/2019. I spent 1 day of my vacation the next day since I cannot really enjoy my vacation knowing that there was something that needs to be done. I received feedback on 7/12/19. I had to stop checking my email so I can disengage and rest.

### **How can we make this therapy program better based on my observations this week?**

Recruitment continued at COH. I received preliminary information on participant 5, but she does not start with therapy until the week of July 18. I informed the onsite collaborator of my absence but I check my email every day while on vacation. I also received information on participant 6.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_10\_ July 14 - 20**

### **What were my expectations this week?**

I finally accepted that I will not be able to do anything involved in the study and I need to take a break.

### **What have I observed in the patients this week?**

I did not interact with the participants of cohort 1. Their role in the study is already over. I received the consent form for participant 6 and the rest of the pretest documents for participants 5 and 6. I am still overseas so I did not begin the interaction or intervention yet. I plan to contact them when I return to the USA.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I still did not interact with any of the participants nor patients since I am on vacation

### **What are some concerns or problems that I have encountered?**

I felt more refreshed after stepping away for a week. I had some downtime during this second week of vacation so I reviewed the comments by CRDA through Dr. Wang. I gave Dr. Wang some clarifications and ran SPSS again. I sent the output to her for review. I informed Dr. Wang that I will be back in the USA at the end of this week and I will be more able to focus on the study.

My mind is calmer this week, but I felt tense once again after just 2 hours of looking at the quantitative data. The data did not show that there was a significant difference between pretest and posttest, but Dr. Wang had said that my sample size is too small. I will be including the data from the second cohort. This round of data analysis is just to make sure that I am analyzing the quantitative data correctly. I think I met this goal based on the feedback from Dr. Wang.

Even if the quantitative data did not show a significant change, the qualitative data seem to show that the participants feel that they are getting better. I cannot fully analyze this yet since I have not reviewed the work of the second coder. The second coder already sent me her codes, but I am still too mentally detached that I was in no position to compare the codes.

### **How can we make this therapy program better based on my observations this week?**

Recruitment continued at COH. I informed the onsite collaborator that I will be back this week.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_11\_ July 21 - 27**

**What were my expectations this week?**

I was hoping to have at least 3 new recruits.

**What have I observed in the patients this week?**

I spoke with participants 5 and 6. They were eager to participate but had mentioned that using Zoom might be a problem because they are out most of the day. Calling through a phone line was preferred over video calls.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

As a therapist, I experienced the post-vacation blues. I also realized that I am not thinking of my study or my interactions with the participants at any point during my work in the clinic. It is like I am a completely different person when I am in the clinic and another person when I am doing my study. I do not apply any of the concepts of the Remotivation Process or MOHO when I am at the clinic. I am in "autopilot mode" as I try to catch up with work that had piled up during my vacation.

I have limited interaction with my patients this week. I was only at work for 2 days since I had Lasik eye surgery. I was trying to get my work done. However, I was still able to send the 3<sup>rd</sup> draft of the quantitative analysis to Dr. Wang on 7/23/19. I received feedback on 7/25/19. I also continued working on the coding through Nvivo. I definitely feel that transitioning between qualitative and quantitative analysis helped me stay objective. The quantitative analysis, working with numbers, reminded me to take things for what it is and not find what I am looking for or what I know when I am working with codes and nodes on Nvivo. I also found myself just focused on finishing what I need to do and not keep worrying about the statistical significance of the quantitative data or if the nodes in Nvivo match the literature.

**What are some concerns or problems that I have encountered?**

I was able to review the codes of the second coder and we have the same codes so there was no need to meet. I am concerned that the next participants will be difficult to talk to through Zoom.

**How can we make this therapy program better based on my observations this week?**

I will keep the therapists and onsite collaborators informed as we begin the first week of intervention the next week.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_\_7\_ June 23 -29**

### **What were my expectations this week?**

I continue to suspend any expectations as I continue to analyze the transcripts. I also received the documents for participant 5, who will be in cohort 2.

### **What have I observed in the patients this week?**

- I find myself not thinking about the study during my work as a clinician
- I am able to identify my own patient's place on the VQ, but I did not tend to apply the RM or its questions

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

- I am able to compartmentalize my roles now. I am more focused when I am involved with the study and able to step away from my clinician role.
- Participant 4 continued to ignore the calls and emails
- I did not interact with the other participants and focused on quantitative data analysis
- The qualitative data has been coded and I am currently waiting for the second coder
- Preliminary quantitative data shows that the difference between pretest and posttest were not significant, which does not seem to reflect the qualitative data

### **What are some concerns or problems that I have encountered?**

- I did not review the pretest data in an attempt to minimize bias. But I realized by doing so, I was unable to tailor my responses and explanation to each participant. It also made data management difficult. The onsite collaborator needed to send me some of the pretest forms because some of the documents were missing. Going forward, I will review all the pretest data.

### **How can we make this therapy program better based on my observations this week?**

- I still would like to integrate the quantitative and qualitative data before updating the team

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_\_8\_ June 30 – July 6**

### **What were my expectations this week?**

- I was very nervous because I was not sure if I am going to be able to contact the participants for a follow-up. I need this follow up, and I was feeling a bit desperate. However, this feeling was only over the possibility of calling the participant. I had no expectations regarding what they will say.
- I ran SPSS this week, eager to know if improvements were made. I also received the analysis from the second coder.

### **What have I observed in the patients this week?**

- I am distracted by an upcoming vacation at work, so I have not been able to really focus on my work. However, being able to sit and complete the quantitative data helps me focus on the study
- I sent my preliminary analysis to CRDA at the end of the week, so I feel more focused on the study. With the upcoming holiday, I also wanted to follow up with the participants as soon as I can.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

- I am able to compartmentalize my roles now. I am more focused when I am involved with the study and able to step away from my clinician role. This week, I want to step away from my clinician role more due to the deadline I have imposed on myself.
- The remaining preliminary quantitative data shows that the difference between pretest and posttest was not significant. I will compare the codes of the second coder with the findings.
- The participants of cohort 1 agreed to the findings and added a few more thoughts on motivation.
- All 3 are motivated by their relationship with others. It may not be the number of people in the support system, but the quality.
- Motivation is fueled by their need to leave a legacy through their relationships.
- The second coder and I agreed on our individual codes so we agreed to combine these codes as I proceeded with qualitative data analysis.

### **What are some concerns or problems that I have encountered?**

- The first week of trying to establish a research relationship is always difficult.

### **How can we make this therapy program better based on my observations this week?**

- I still would like to integrate the quantitative and qualitative data before updating the team

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_12\_ July 28 – Aug 3**

### **What were my expectations this week?**

This is my first intervention week so I wanted to suspend any expectations. Although I had planned to speak to them through Zoom.

### **What have I observed in the patients this week?**

I spoke with participants 5 and 6. Both are familiar with lymphedema and CDT from a previous therapy program not with COH. Although this is their second “round” of CDT, they both seem to consider the SMP as a new program. They both know that SMP is important, but they are both “figuring it out”, which make it seem that they are in the exploration stage.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

As a therapist, I continued to experience the post-vacation blues. I am still in “autopilot mode” as I try to catch up with work that had piled up during my vacation. However, I feel more energized in the study, especially after my first interaction with the participants.

I am still on autopilot because new referrals piled up while I was away on vacation and Lasik. I was just going with the flow and I did not feel as energized as I am when I focus on the study.

### **What are some concerns or problems that I have encountered?**

I was able to do a preliminary thematic analysis, but I cannot fully finalize the qualitative analysis because I am lacking 3 interviews. As expected, I had to use my phone in a private room at work to interact with the participants. Both would like me to call in the morning, which will be in the middle of my workday at the clinic. I was lucky to find a private room where we conduct our patient intake to ensure the privacy of the participants.

I reviewed the transcripts of cohort 1 once again to complete the preliminary analysis of the qualitative data. I had to be careful not to let the analysis cloud my interaction with cohort 2.

### **How can we make this therapy program better based on my observations this week?**

I will keep the therapists and onsite collaborators informed as we begin the first week of intervention the next week.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_13\_ Aug 4 -10**

### **What were my expectations this week?**

This is my second week with cohort 2. I had hoped to speak with participants 5, 6, and 7 through Zoom. I continued to receive pretest data for cohort 2 as well. I sent the preliminary drafts to Dr. Bowyer in time for the end of the semester.

### **What have I observed in the patients this week?**

I had to try three times before I was able to speak with the participants. Both had to call me back, so we were unable to use Zoom. We instead spoke through my secure line in my private room at the clinic. They both indicated goals for the intervention, which make it seem that they are in the competence stage. The seventh participant is in the exploration stage.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I continue to detach my “clinical self” and my “researcher self”. I was also covering for another therapist, so I just focused on getting my work done. I did not apply any of the concepts of Remotivation and MOHO. My goal was just to meet the expected units and productivity requirements at work.

I am still on autopilot because new referrals piled up while I was away on vacation and Lasik. I was just going with the flow and I did not feel as energized as I am when I focus on the study.

I was able to work on the quantitative analysis after receiving feedback from Dr. Wang. I also revised the preliminary analysis and include future directions. I was unable to integrate the quantitative and qualitative data yet because I still do not have 6 participants. I need to wait until I am able to interview the participants of cohort 2. However, I started the initial draft of the qualitative analysis by changing the tense in the section that I submitted to the committee in January 2018 when I defended the proposal. Doing so refreshed my focus on the study.

### **What are some concerns or problems that I have encountered?**

Speaking through the Zoom platform is very problematic. I really wish I can meet with the participants in person. I do not feel that I establish a connection with the participants through phone calls.

**How can we make this therapy program better based on my observations this week?**

I will keep the therapists and onsite collaborators informed as we continue with the intervention next week.



## **THE RESEARCHER'S JOURNAL**

**Week Number: 14 Aug 11 -17**

### **What were my expectations this week?**

I had hoped to use Zoom and talk to all 3 participants for intervention week 3. I also expected to invite them for a 60-minute discussion next week.

### **What have I observed in the patients this week?**

They indicated goals for the intervention, which make it seem that they are in the competence stage.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

### **What are some concerns or problems that I have encountered?**

The participants had to call me back, so we were unable to use Zoom. We instead spoke through my secure line in my private room at the clinic. Speaking through the Zoom platform is very problematic. I really wish I can meet with the participants in person. I do not feel that I establish a connection with the participants through phone calls.

### **How can we make this therapy program better based on my observations this week?**

I will keep the therapists and onsite collaborators informed as we continue with the intervention next week. I will review the field notes, researcher journals, and pretest data to prepare for the 60-minute interview.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_15\_ Aug 18 - 24**

### **What were my expectations this week?**

I had hoped to use Zoom and talk to all 3 participants for intervention week 4. The 60-minute interview will be completed this week for participants 6.

### **What have I observed in the patients this week?**

She indicated goals for the intervention, which make it seem that she is in the competence or achievement stage. However, I still have to analyze the transcript. I sent the transcript to her for her review.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

It is quite frustrating because I had to call the participants several times. They would not respond to the video calls even though we had already scheduled them last week. Once again, I had to resort to phone calls using a private line in my office. I would have captured their non-verbal language had it been a video call. I am frustrated that participant 5 could not participate in the 60-minute interview.

### **What are some concerns or problems that I have encountered?**

The participants had to call me back, so we were unable to use Zoom. We instead spoke through my secure line in my private room at the clinic. Speaking through the Zoom platform is very problematic. I really wish I can meet with the participants in person. I do not feel that I establish a connection with the participants through phone calls. Participant 5 did not answer any of the calls despite trying 3 different days, twice a day. I will call her next week.

### **How can we make this therapy program better based on my observations this week?**

I will keep the therapists and onsite collaborators informed as we continue with the intervention next week. I will review the field notes, researcher journals, and pretest data to help with the analysis.

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_16\_ Aug 25 - 31**

**What were my expectations this week?**

I had hoped to use Zoom and talk to participant 7 for intervention week 5 since she started a week later. I plan to send the transcription to all participants for verification.

**What have I observed in the patients this week?**

Participant 7 also indicated goals for the intervention and also said that she feels able to manage her BCRL even without therapy, which makes it seem that she is in the competence or achievement stage. However, I still have to analyze the transcript. I sent the transcript to her for her review. I am again unable to complete the interview of participant 5

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I am deeply worried that I will not be able to get 6 interviews. I am not concerned with the content or findings of either the quantitative or qualitative data. I am so focused on getting the planned 6 participants for the qualitative analysis that I am just treating the transcriptions for what it is. My worry has completely blocked everything that I know about the study that I am merely dealing with words and the accuracy of the Nvivo transcription. I sent the transcription to the second coder and tried to move forward with coding the transcript of participants 6 and 7. I feel that I will just move forward with what I can do and handle the data before I forget what has transpired in the past weeks.

**What are some concerns or problems that I have encountered?**

The participants had to call me back, so we were unable to use Zoom. We instead spoke through my secure line in my private room at the clinic. Speaking through the Zoom platform is very problematic. I really wish I can meet with the participants in person. I do not feel that I establish a connection with the participants through phone calls.

I received the posttest data from the onsite collaborator. However, it does not seem like I can move forward with analysis even if I have the pretest and posttest data because I did not have 6 interviews at this point.

**How can we make this therapy program better based on my observations this week?**

I will communicate any pressing issue to the therapists and onsite collaborator

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_17\_ Sept 1 -7**

**What were my expectations this week?**

This is week 6 of the cohort. I am waiting for them to verify the transcript. The onsite collaborator continued to send me the posttest data of participants 5, 6, and 7. I hoped to receive a reply from participant 5.

**What have I observed in the patients this week?**

I am on vacation once again, which allowed me to step away from the study to regain a better mindset.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

Being on vacation allowed me to calm my worry and frustration with the study.

**What are some concerns or problems that I have encountered?**

I am still worried about the number of participants but not as much because I am on vacation.

**How can we make this therapy program better based on my observations this week?**

I will communicate any pressing issue to the therapists and onsite collaborator

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_18\_ Sept 8 - 14**

**What were my expectations this week?**

I hoped to collaborate with the second coder and complete the thematic analysis. This is week 7 of the cohort.

**What have I observed in the patients this week?**

I am on vacation once again, which allowed me to step away from the study to regain a better mindset.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

As before, I am still worried. I felt the strong urge to update my committee about the study, hoping that I will be allowed to proceed with the data analysis with the number of participants that I have.

**What are some concerns or problems that I have encountered?**

Recruitment is very slow and it is very difficult to follow up with the participants. I did not hear back from participant 5 at all this week.

**How can we make this therapy program better based on my observations this week?**

I will communicate any pressing issue to the therapists and onsite collaborator

## **THE RESEARCHER'S JOURNAL**

**Week Number: \_19\_ Sept 15 - 21**

### **What were my expectations this week?**

I hoped to call all 3 participants for 1 month follow up. I was able to speak with participants 6 and 7. I sent my qualitative analysis to Dr. Bowyer which contained the analysis of participants 1, 2, 3, 6, and 7.

### **What have I observed in the patients this week?**

The participants echoed what was said in the interview. They verified the transcript, agreed with the posttest scores in the quantitative study, and with the main themes that were discovered in the qualitative analysis.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I am relieved that at least participants 6 and 7 were available for follow-up. That way I have more data to analyze. I was quite disappointed that the committee did not allow me to proceed and will need to recruit the third cohort. This is the last cohort in the planned study, so I really hope I will have participants this fall semester.

### **What are some concerns or problems that I have encountered?**

The participants had to call me back, so we were unable to use Zoom. We instead spoke through my secure line in my private room at the clinic. Speaking through the Zoom platform is very problematic. I really wish I can meet with the participants in person. I do not feel that I establish a connection with the participants through phone calls.

### **How can we make this therapy program better based on my observations this week?**

I will communicate any pressing issue to the therapists and onsite collaborator

## **THE RESEARCHER'S JOURNAL**

**Week Number: 20 Sept 22 – 28, 2019**

**What were my expectations this week?**

I hoped to start with cohort 3 this week after receiving the consent forms and data forms for participants 8 and 9.

**What have I observed in the patients this week?**

The study did not have any participants this week. Unfortunately, both participants did not answer the calls either through Zoom or my private line.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I was quite disappointed because I did not get to start week 1 of cohort 3. However, I received the codes from the second coder. The second coder and I agreed on the codes, nodes, and themes for both cohorts 1 and 2. I wanted to work on quantitative and qualitative analysis again. I wanted to prepare the first draft of the dissertation as much as I can while I wait for cohort 3.

**What are some concerns or problems that I have encountered?**

The same problems as before regarding Zoom and telehealth.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number:** 21 Sept 29 – Oct 5

### **What were my expectations this week?**

I again tried to contact participants 8 and 9, but both did not return any of my calls. I completed the first draft of the qualitative analysis write-up and sent it to CRDA on 9/29/19.

### **What have I observed in the patients this week?**

The study did not have participants this week because both did not answer the calls through Zoom or private line.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

This was a very frustrating week because cohort 3 has not started again. I continued with the qualitative analysis after receiving feedback on 9/30/19. I am trying to distract myself but at the same time stay engaged in the study. Teaching was also a distraction for me. I think the frustration over the study and my academic role helped me compartmentalize my researcher self, my clinician self, and my instructor self.

### **What are some concerns or problems that I have encountered?**

Recruitment is a painfully slow process and telehealth seems to lack the personal touch that may have kept the participants engaged in the study.

The problem with my analysis was I used the terms “codes”, “nodes”, and “themes” interchangeably. I have to review Giorgi’s method so that I can reconcile his method with the headings used in Nvivo. CRDA’s feedback was that my write up lacks clarity from the description of the process up to the results and analysis. I also need to work on the triangulation of data and include the field nodes.

### **How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.



## **THE RESEARCHER'S JOURNAL**

**Week Number: 22 October 6 - 12, 2019**

**What were my expectations this week?**

I still hoped to try to start with cohort 3.

**What have I observed in the patients this week?**

The study did not have any participants this week because neither answered or returned my calls.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

Like last week, I once again tried to distract myself by moving forward with the qualitative analysis. I went ahead and analyzed the field notes for triangulation. I included this in the second draft of the qualitative analysis, which I sent to CRDA.

**What are some concerns or problems that I have encountered?**

Same as before, recruitment is a painfully slow process and telehealth seems to lack the personal touch that may have kept the participants engaged in the study.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 23 October 13 – 19, 2019**

### **What were my expectations this week?**

I had hoped to hear back from cohort 3. Unfortunately, I was informed by the onsite collaborator that participant 9 withdrew. Participant 8 finally returned my call only to tell me that she was also withdrawing from the study. I was unable to share anything about the study with her.

### **What have I observed in the patients this week?**

The study did not have any participants this week.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

This is a devastating week. The study aimed to recruit 3 cohorts and I only have 6 participants for the quantitative data analysis and 5 for qualitative analysis. At least the quantitative data from participant 4, 8, and 9 can be used in the comparison. I still need to stay engaged, but I was devastated that I need to step away from the study.

### **What are some concerns or problems that I have encountered?**

The study saw 3 participants withdraw – participant 4, 8, and 9. I was also informed by the onsite collaborator that they do not have any potential participants at this time.

### **How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 24 October 20 -26, 2019**

**What were my expectations this week?**

I am patiently waiting for any potential participants and emails from the onsite collaborator. I also hoped to receive feedback from CRDA.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I am glad that I will be on vacation again for a week so I can step away from the study. I received feedback from CRDA at the start of the week. I scanned the feedback and edited the relatively easy parts. I took note of the major revisions, which I will work on after I come back from vacation.

**What are some concerns or problems that I have encountered?**

The study is once again on hold, similar to how it was when waiting for the approval from the facility.

As for CRDA, the analysis makes more sense but I need to include more quotes. I only had quotes with a few words or 1-2 sentences. The quotes should be longer so that the context of the statement is clearly presented. I should also be careful not to make sweeping generalizations. For example, do not say "the participants", but substantiate it by saying "participant 5 stated ....". I should also fix the format so that the parent nodes, child nodes, and subnodes are clearly seen in the tables. I need to review the transcription again to find quotes to substantiate the nodes.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 25 October 27 – November 2, 2019**

**What were my expectations this week?**

I planned to step away from the study.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

It was refreshing to step away again. I had time to renew my hope.

**What are some concerns or problems that I have encountered?**

Again, no participants were recruited.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 26 November 3 – November 9, 2019**

**What were my expectations this week?**

I am patiently waiting for any potential participants and emails from the onsite collaborator.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I have no new participants, so I reviewed the SPSS output and Nvivo codes to refresh my mind.

**What are some concerns or problems that I have encountered?**

Again, recruitment is a painfully slow process and telehealth seems to lack the personal touch that may have kept the participants engaged in the study. The study is on hold for now.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 27 November 10 – 16, 2019**

**What were my expectations this week?**

I am patiently waiting for any potential participants and emails from the onsite collaborator.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I have no new participants, so I reviewed the SPSS output and Nvivo codes to refresh my mind.

**What are some concerns or problems that I have encountered?**

Again, recruitment is a painfully slow process and telehealth seems to lack the personal touch that may have kept the participants engaged in the study. The study is on hold for now.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 28 November 17 – 23, 2019**

### **What were my expectations this week?**

I emailed the onsite collaborator and asked if there were any potential participants. The fall semester is coming to a close and I would like to know if I was going to get anything accomplished in terms of cohort 3.

### **What have I observed in the patients this week?**

The study did not have any participants this week. There were no new or potential participants either. However, I received posttest data for participant 9. Participant 8 did not attend her sessions at the facility either.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I had to send my concerns to my mentor. I fear that this study will never be completed. We have been recruiting for the past 30 weeks, and I only ended up with a total of 9 participants, with 3 dropping out.

Since it was almost certain that I will not have any new participants, I went ahead and worked on the analysis again as if this study was completed. I did what I could to have 3 cohorts as planned.

### **What are some concerns or problems that I have encountered?**

The study did not progress as I had hoped in terms of the number of participants.

### **How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 29 November 24 – 30, 2019**

**What were my expectations this week?**

I am patiently waiting for any potential participants and emails from the onsite collaborator.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I ran SPSS again to include cohort 1 and 2, following the instructions of CRDA that I received during the preliminary analysis. I also completed the 3<sup>rd</sup> draft of the qualitative analysis so that I can receive feedback from CRDA before the semester ends.

**What are some concerns or problems that I have encountered?**

Again, recruitment is a painfully slow process and telehealth seems to lack the personal touch that may have kept the participants engaged in the study. The study is on hold for now.

As for CRDA, I had to make sure that I am not trying to fit the transcript and quotes into the nodes that I am trying to present. I had to read the quote 3 separate times and read the section after I inserted the quote to make sure that I am still presenting the participant's expressions for what it is and not according to how I want the quote to appear.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.



## **THE RESEARCHER'S JOURNAL**

**Week Number: 30 December 1 – 7, 2019**

**What were my expectations this week?**

I was informed that my committee would like to see the analysis I have so far. I sent the most current version of all the chapters of the dissertation write up.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

I was a bit relieved that the committee allowed me to move forward. I also received general comments from the committee, which I can address during the holiday break.

**What are some concerns or problems that I have encountered?**

I still have no word if I have potential participants, but I can now move forward. I will not finish the study this semester as I had hoped, but I can move forward.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 31 December 8 – 14, 2019**

### **What were my expectations this week?**

I received feedback from the committee. I need to be careful not to fit the qualitative analysis into preconceived MOHO concepts when I translate the statements in a language consistent with MOHO.

### **What have I observed in the patients this week?**

The study did not have any participants this week.

### **What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

### **How do I feel about this week?**

I reviewed the MOHO section of the analysis and I feel that I translated it for what it is. However, I would like to ask for assistance from the committee regarding this and other lingering questions that I have.

### **What are some concerns or problems that I have encountered?**

CRDA recommended that I include longer quotes, but the committee said my quotes are too long. I do not know how to proceed.

The first draft is very lengthy with a lot of tense and format issues. I will have to take my time.

### **How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 32 December 15 – 21, 2019**

**What were my expectations this week?**

I was too busy at my clinical work that I did not have time to work on the write-up.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

The holiday preparations and clinical hours made it difficult to focus on the write-up.

**What are some concerns or problems that I have encountered?**

I am not in the correct mindset to focus on the study right now due to physical and mental exhaustion.

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 33 December 22 – 28, 2019**

**What were my expectations this week?**

I had the time to focus on the write up this week.

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

**What are some concerns or problems that I have encountered?**

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## **THE RESEARCHER'S JOURNAL**

**Week Number: 34 December 29, 2019 – January 4, 2020**

**What were my expectations this week?**

**What have I observed in the patients this week?**

The study did not have any participants this week.

**What have I observed in the therapists this week?**

I did not receive any feedback from the onsite collaborator regarding the concerns of the therapists nor they have any feedback about the collaboration.

**How do I feel about this week?**

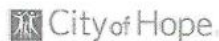
**What are some concerns or problems that I have encountered?**

**How can we make this therapy program better based on my observations this week?**

I will communicate with the onsite collaborator any pressing issues and updates. I will also encourage her to bring to my attention any concerns.

## APPENDIX V

### Example of a Completed Data Collection Form



## IRB #18549 Data Form

Protocol ID: 18549 Research Participant #: 01 Participant Initials: MF Form:      Evaluation Code:     

Date of Collection: Month 05, Day 01, Year 2019

Age: 55 Diagnosis: Left Breast Cancer

Date of Surgery: 03 / 26 / 2018 # of lymph nodes removed       
Date Completed

Radiation? (Circle one) Yes / No

Currently undergoing chemotherapy? (Circle one) Yes / No

If yes, # of radiation sessions?     

### Past Medical History:

Patient was diagnosed with left Breast Cancer in 2017, S/P Left MRM, with ALND on 5/21/18, Adjuvant Chemotherapy & Radiation. Patient had Complaint of LUE Lymphedema since last year, she was seen for lymphedema management and discharged with the home program, But pt- also has increased weight since the treatments last year & increased Edema of Left arm.

Occupation:      Pain: 0 / 10

Living arrangement: Patient lives with her husband & 2 children in a 2 story house

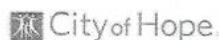
Marital status: ☒ Married, in a civil union, domestic partnership, or living as married  
☐ Divorced  
☐ Widowed  
☐ Never married  
☐ Other  
☐ I'd rather not say

Mahjabeen Hashmi

Provider/CRA FULL NAME (Please Print)

Month 05, Day 01, Year 2019  
Date Completed

01 : 00 AM / PM  
Time Completed



## IRB #18549 Data Form

Protocol ID:

1 8 5 4 9

Research Participant #:

0 1

Participant Initials:

M F

Form:

Evaluation Code:

Month

Day

Year

Date of Collection:

0 5 / 0 1 / 2 0 1 9

### Lymphedema:

### Skin Integrity:

☒ Intact

☒ Fibrotic

☐ Hyperpigmentation

☐ Weeping edema

### Edema:

☒ Pitting

☐ Non-pitting

Landmark (in cm)	RUE	LUE
MP	19	18.5
Wrist	15	15.5
4	16	16
8	17	18
12	21	21
16	23	24
20	24	25
24	24	25
28	25.5	27
32	27	29
36	28.5	31
40	31	31
44	32	31
48		
52		
56		
60		

Notes:



## APPENDIX W

TWU IRB Approval and National Institute of Health Certificate of Second Coder



**Institutional Review Board**

Office of Research

6700 Fannin, Houston, TX 77030

713-794-2480

[irb-houston@twu.edu](mailto:irb-houston@twu.edu)

<https://www.twu.edu/institutional-review-board-irb/>

DATE: June 21, 2019

TO: Ms. Lester Kaye Rubio  
Occupational Therapy - Houston

FROM: Institutional Review Board - Houston

*Re: Notification of Approval for Modification for The Use of the Remotivation Process in an Occupational Therapy Program for Breast Cancer-Related Lymphedema: A Feasibility Study (Protocol #: 20044)*


The following modification(s) have been approved by the IRB:

Vidya Pingale has been added to the research team and will be coding de-identified transcriptions of interviews.


cc. Dr. Patricia Bowyer, Occupational Therapy - Houston



## Certificate of Completion



The National Institutes of Health (NIH) Office of Extramural Research certifies that **vidya pingale** successfully completed the NIH Web-based training course "Protecting Human Research Participants."



**Date of Completion:** 06/22/2018

**Certification Number:** 2849257



## APPENDIX X

Chronbach's Alpha of MOHOST at Pretest

**Items with good inter-item correlation (0.30 to 0.70)**

<b>Item 1</b>	<b>Item 2</b>	<b>Inter-item Correlation</b>
Interest	Expectations of success	0.580
Routine	Interest	0.545
Adaptability	Expectations of success	0.350
Adaptability	Interest	0.399
Adaptability	Choices	0.399
Responsibility	Appraisal of ability	0.664
Nonverbal skills	Appraisal of ability	0.395
Nonverbal skills	Routine	0.688
Vocal expression	Expectations of success	0.395
Vocal expression	Adaptability	0.316
Knowledge	Expectations of success	0.632
Knowledge	Interest	0.574
Knowledge	Routine	0.500
Knowledge	Adaptability	0.316
Timing	Routine	0.354
Timing	Responsibility	0.325
Organization	Appraisal of ability	0.350
Organization	Expectations of success	0.350
Organization	Routine	0.395
Organization	Adaptability	0.550
Organization	Nonverbal skills	0.316
Organization	Vocal expressions	0.316
Organization	Knowledge	0.316
Organization	Timing	0.559
Problem solving	Appraisal of ability	0.316
Problem solving	Expectations of success	0.316
Problem solving	Responsibility	0.328
Problem solving	Nonverbal skills	0.687
Problem solving	Timing	0.619

Problem solving	Interest	0.545
Problem solving	Organization	0.395
Posture & Mobility	Choice	0.421
Posture & Mobility	Knowledge	0.459
Coordination	Choice	0.649
Strength & Effort	Choice	0.445
Strength & Effort	Coordination	0.490
Energy	Expectations of success	0.478
Physical space	Adaptability	0.350
Physical resources	Coordination	0.354
Physical resources	Physical space	0.316
Social groups	Choice	0.421
Social groups	Strength & Effort	0.414
Social groups	Energy	0.347
Social groups	Physical resources	0.574
Occupational demands	Vocal expression	0.500
Occupational demands	Posture & Mobility	0.574
Occupational demands	Strength & Effort	0.555
Occupational demands	Physical resources	0.500
Occupational demands	Social groups	0.574

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Note: Pre\_Roles, Pre\_Conversation, and Pre\_Relationships has zero variance and is removed from the scale.