REMOTE DELIVERY OF A STANDARDIZED EDUCATIONAL PROTOCOL FOR SELF-MANAGEMENT OF CHRONIC SWELLING OF THE LOWER LIMBS IN INDIVIDUALS WITH LIMITED MOBILITY

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The purpose of this study was to develop and evaluate the remote delivery of a standardized self-management protocol for chronic swelling of the lower limbs, termed *Telerehabilitation to Empower You to Manage and Prevent Swelling (TR-PUMPS).* This protocol was a component of a clinical trial designed to evaluate an in-home self-management program for chronic lower limb swelling in people with limited mobility that utilized TR to provide real time face-to face interactive educational and assessment sessions over a six week period. Developed as a series of videos, the protocol was designed to encompass 10 learning goals for self-management of chronic swelling/lymphedema. Content validity was determined by eight certified lymphedema therapists. The mean score for the videos was 4.5 ± 0.35 (Likert scale of 5 = strongly agree to 1 = strongly disagree). The readability level of 5th grade and superior suitability rating using the Suitability Assessment of Materials indicated materials were appropriate for various levels of health literacy in the study population.

TR-PUMPS was implemented utilizing the *Versatile and Integrated System for Telerehabilitation (VISYTER)* software platform, a secure system that provides the ability for real-time teleconferencing. Evaluation of the subjects' post intervention Competency in Self Care and Self-Management (CSCSM) of their chronic swelling resulted in a mean score of 94% $\pm$ 4%. Inter-rater reliability of the CSCSM was high. The Intraclass Correlation Coefficient (ICC) for

single measures was .958 with a 95% confidence interval of .913 - .980 (p = .000). ICC of average measures was .979 with a 95% confidence interval of .955 - .990 (p = .000). Self-identified performance goals measured by the Canadian Occupation Performance Measurement showed significant improvement post intervention (p = .008) and exceeded the minimal importance difference. There was no significant change in the subjects' self-efficacy in management of their chronic swelling scores (p = .065). The subjects' perceived usability of the remote delivery of TR-PUMPS was high with a mean score of 6.4 $\pm$ 0.65 (Likert scale of 1 = disagree to 7 = agree). These results support TR-PUMPS as a viable method for providing a home-based self-management program for chronic swelling.

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PREFACE

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1.0 INTRODUCTION

An estimated 18.6 million persons in the United States (US) have mobility limitations (Iezzonni, McCarthy, Davis & Siebens, 2000). Individuals who rely on wheelchairs for mobility are at higher risk for chronic swelling due to limited or absent calf-pump function (Cavorsi, 2000) and the negative effects of sitting for long periods of time such as limb dependency and impeded venous and lymphatic flow. If untreated, chronic swelling may lead to lymphedema. Lymphedema is a chronic debilitating disease that requires life-long management. Without proper management, lymphedema can progress, causing proliferation of fibrotic tissue, an increase in size of affected limb, increase risk of wounds (Dupay et. al 1999; Baddour, 2006), life threatening infections, functional impairment of the limb, (ISL, 2009), and a decrease in quality of life (Morgan, Franks & Moffatt, 2005; Franks, et. al, 2006). Traditional therapy (complete decongestive therapy) may be difficult for people with limited mobility to obtain. Treatment within the geographic area they live in may be hindered by the limited number of lymphedema therapists (LANA, n.d.). Lack of access to transportation have been shown as a detriment to obtaining medical care by people who use wheelchairs for mobility (Kaye, Kang & LaPlante, 2000) Alternatives in care need to be addressed to overcome barriers people with limited mobility may encounter that prevent them from utilizing traditional care. Telerehabilitation (TR) for patients with chronic swelling/lymphedema that provides a self-

management program within the comfort of the patient's home can potentially address many of these barriers.

Self-management programs have been shown to improve healthcare outcomes (Chodosh, et al., 2005; Lorg, Ritter, Laurent & Plant, 2006; Lorig, Sobel, Ritter, Laurent & Hobbs, 2001; DeWalt, et al., 2004). Few studies have attempted to identify how to best provide patients with chronic swelling/lymphedema and mobility limitation the knowledge and skills they need to perform optimal self-management. This research is essential to provide evidence that can be utilized to assist in guiding both health care and health policy decisions. This study involved the development and evaluation of the remote delivery of a standardized educational protocol for the self-management of chronic swelling/lymphedema of the lower extremities in people with limited mobility.

1.1 OBJECTIVE

The objective of this study was to develop and evaluate the remote delivery of a standardized self-management and preventive care educational protocol for chronic swelling of lower limbs, termed *Telerehabilitation to Empower You to Manage and Prevent Swelling (TR-PUMPS).* This educational protocol was developed as a component of a clinical trial designed to evaluate an in-home self-management program for chronic lower limb swelling in people with limited mobility that utilized TR to provide real time face-to face interactive educational and assessment sessions.

1.2 SPECIFIC AIMS

1.2.1 Primary Aims

To develop a standardized self-management protocol (TR-PUMPS) for persons with chronic swelling of the lower extremities and evaluate its content validity, completeness, clarity, readability and suitability for the targeted population.

1. To determine if TR-PUMPS changes subjects' perceived self-efficacy in self-management of their lower limb(s) chronic swelling as measured by the Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SE-6 item).
    - H_A: As a result of TR-PUMPS there will be a significant change in the subjects' pre and post intervention perceived self-efficacy in the prevention and management of their chronic swelling.
    - $H_{O:}$ As a result of TR-PUMPS there will be no significant change in the subjects' pre and post intervention perceived self-efficacy in the prevention and management of their chronic swelling.
2. To determine if TR-PUMPS changes the subjects' perception of their performance and satisfaction with their performance in achieving their self-identified occupational performance goals as measured by the Canadian Occupational Performance Measure (COPM).
    - H_A: As a result of TR-PUMPS there will be a significant change in the subjects' perception of their performance and satisfaction with their performance in

achieving self-identified occupational performance goals in the self-management of their chronic swelling.

- H_O: As a result of TR-PUMPS there will be no significant change in the subjects' perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling.

3. To evaluate the relationship between the subjects' competence in self-care and self-management of their chronic swelling (CSCSM), their perceived self-efficacy in management of their chronic swelling (SE-6 item) and their performance and satisfaction with their performance of self-identified occupational performance goals (COPM).

    - H_A: As a result of TR-PUMPS there will be a significant relationship in the subjects' performance and knowledge in the care and management of their chronic swelling, perceived self-efficacy in managing their chronic swelling and their perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling.
    - H_O: As a result of TR-PUMPS there will be no significant relationship in the subjects' performance and knowledge in the care and management of their chronic swelling, their perceived self-efficacy in managing their chronic swelling and their perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling.

4. To evaluate subjects' perceived usability of the remote delivery of TR-PUMPS through real-time interactive education and evaluation sessions as measured by the Telehealth Usability Questionnaire (TUQ).

1.2.2 Secondary Aims

A number of parameters were evaluated to determine if they had a significant impact on the outcome measurements of COPM, SE-6 item, CSCSM, and Telehealth Usability. These included the subject's initial knowledge of self-management of lower limb chronic swelling and selected demographic variables (age, education level, health literacy level, information technology familiarity, stage of lymphedema, and previous treatment for chronic swelling).

2.0 BACKGROUND

2.1 LYMPHEDEMA

2.1.1 Lymphatic system function

The main function of the lymphatic system is to protect the body against infections by the destruction of infectious organisms and return excess fluid and protein from the interstitial spaces back to the blood stream. The lymphatic system consists of lymphoid organs and tissue and the lymphatic vessels and ducts. The lymphoid organs and tissue include the thymus, spleen, lymph nodes and mucosa lymphoid tissue (Porth, 2002). The thymus is responsible for the maturation of T lymphocytes. Upon maturity, lymphocytes leave the thymus and travel through the blood stream to lymphoid tissue. The spleen's primary function is to filter antigens from the blood. Lymph nodes filter pathogens from the lymph as it passes through these nodes. The mucosa lymphoid tissues contain high levels of lymphocytes and macrophages. Located in the respiratory, digestive and urinary tracts, they provide the body's first line of defense against organisms entering the body in those areas (Porth, 2002).

The lymphatic vessels form a unidirectional system that parallels the venous vascular system (Kerchner, Fleischer & Yosipovich, 2008). The smallest of the lymphatic vessels, the lymphatic capillaries, are located in most of the body's tissue and organs. Lymph capillaries are

blind ended vessels that are made of overlapping endothelium cells. This overlapping of endothelium cells creates openings in the lymph capillaries that have one way valves. Anchoring filaments are attached to the lymph vessels and surrounding tissue. Variation in surrounding tissue pressure and the pulling of filaments, as a result of increased fluid in the interstitial spaces, cause the valves of the lymph capillaries to open allowing lymph fluid to enter the vessel (Zawieja, 2009; Kelly, 2002). The openings in the lymphatic vessels are large enough to allow the passage of large molecules. Proteins, cell debris and macrophages in the interstitial fluid, which are too large to pass through the capillary walls and enter the venous blood stream, are removed from the interstitial space by the lymph vessels (Korosec, 2004; Kelly, 2002).

Next, the lymph passes through the capillaries vessel and enters the precollectors. The precollectors are thicker and less permeable and have semilunar one-way valves which help facilitate the movement of lymph. The lymph flows into the deep vessels from the precollectors.

The deep vessels have one-way valves that divide the vessels into segments of smooth muscle called lymphangions. As a segment fills with lymph, contraction of the vessel's smooth muscle occurs as a result of the tension on the wall. The lymph is pushed forward into the next segment where the process is repeated. The vessels have sensory nerve fibers that respond to sympathetic and parasympathetic stimulation. Contractions of these segments occurs at a rate of six to ten times per minute at rest, but can increase up to twenty times per minute. The contractions of these vessels are the lymphatic system's intrinsic pump and essential to facilitate lymph flow (Korosec, 2004).

The deep vessels that carry lymph to the lymph nodes are grouped in areas throughout the body. The function of the lymph nodes is to filter and concentrate the lymph. Approximately

99% of antigens are removed from the lymph within the lymph nodes. The lymph node venous system absorbs approximately 50% of the liquid in the lymph (Korosec, 2004).

After passing through the lymph nodes, lymph enters the lymphatic trunk vessels. If the lymph is coming from the legs or left side of the body, it will then pass through into the thoracic duct. The thoracic duct starts at the L1-L2 vertebrae level and ascends up through the trunk of the body to where it empties into the left venous angle which is located at the junction between the left subclavian and left jugular vein (Korosec, 2004). Changes in thoracic and abdominal pressures facilitate the movement of the lymph through the thoracic duct. Abdominal breathing creates a negative intrathoracic pressure that results in a suction-like force to aid in the flow of the lymph through the duct (Kelly, 2002). The thoracic duct carries lymph from the left side of the body and the right side of the body below the diaphragm. Lymph from the upper right side of the body is carried through the right thoracic duct and empties into the right venous angle which is located at a junction between the right subclavian and right jugular vein (Korosec, 2004; Kelly, 2002).

2.1.2 Development of lymphedema

Chronic edema or lymphedema is an incurable and debilitating health condition that requires lifelong management. The removal of fluid from the interstitial space and maintenance of interstitial fluid balance are both achieved primarily through lymphatic transport and not by venous circulatory reabsorption (Mortimer & Levick, 2004). Along with the removal of fluid from the interstitial space, the lymphatic system also removes macromolecules that are too large for reabsorption back into the circulatory system such as protein and cell debris (Mortimer &

Levick, 2004; Mayrovitz, Brown-Cross, Mayrovitz, & Golia, 2009). Chronic edema or lymphedema occurs when an impairment of the lymphatic system results in a lymphatic load that is greater than the lymphatic transport capacity. This results in an accumulation of protein rich fluid in the interstitial space. As protein levels increase in the interstitial fluid, there is an increase in the interstitial colloid osmotic pressure (Warren, Brorson, Borud & Slavin, 2007; Petrek, Pressman & Smith, 2000). Interstitial hydrostatic pressure is increased due to a decrease in lymphatic transport. The elevation of these pressures results in increased accumulation of fluid in the interstitial space (Petrek, et al., 2000). The high concentration of protein stimulates an inflammatory response in the surrounding subcutaneous tissue. This chronic inflammation can lead to fibrotic changes in the subcutaneous tissue and hypertrophy of adipose tissue (Mayrovitz, et al., 2009). The protein rich lymph provides a fertile medium for bacteria growth, leading to frequent infections (Kelly, 2002). Chronic edema is a prominent risk factor for cellulitis of the legs. Studies show that 38% (Dupay, et al, 1999) to 46% (Cox, 2006) of patients with cellulitis of the leg have chronic edema of the extremity. If untreated, chronic edema or lymphedema can progress, causing continued proliferation of fibrotic tissue, an increase in size of affected limb, increase risk of wounds (Dupay et. al 1999; Baddour, 2001), life threatening infections, functional impairment of the limb, (ISL, 2009), and a decrease in quality of life (Morgan, Franks & Moffatt, 2005; Franks, et al, 2006).

The severity of lymphedema can be evaluated using a staging system developed by the International Society of Lymphology (ISO). The ISO 2009 Consensus Document on the diagnosis and treatment of peripheral lymphedema describes the stages as follows:

> Stage 0: A latent or subclinical condition where swelling is not present despite impaired lymph transport.

> Stage I: Pitting may occur. Edema will subside with leg elevation.
>
> Stage II: Elevation alone rarely reduces tissue swelling. Pitting is manifest. As stage progresses limb may not pit as excess fat and fibrosis supervenes.
>
> Stage III: Encompasses lymphostatic elephantiasis where pitting can be absent and trophic skin changes such as acanthosis, further deposition of fat and fibrosis, and warty overgrowths have developed (ISO, 2009, p. 53).

2.1.2.1 Etiology of lymphedema

Lymphedema is classified as either primary or secondary depending on the etiology. There are three types of primary edema: congenital lymphedema, which is present at birth; lymphedema precox, which occurs at puberty or before the age of 30; and lymphedema tarda which, begins after the age of 35 (Szuba & Rockson, 1998). All three of the primary lymphedemas are associated with chromosomal abnormalities (Szuba & Rockson, 1998).

Secondary lymphedema occurs when there is an injury to the lymphedema system. Common causes of secondary lymphedema include surgery for carcinoma that involves damage or dissection of sentinel lymph nodes, radiation therapy, trauma in areas of lymph nodes or vessels, chronic infections, chronic venous insufficiency, tumors that obstruct the lymphatic flow, and filariasis (ISL, 2009; Kerchner et al., 2008; Kelly, 2002).

2.1.2.2 Prevalence of lymphedema

Approximately one million people have lymphedema in the United States (Rooke, 2006). Moffatt, et al, (2003) surveyed health professionals to determine the prevalence of lymphedema in a community in West London, England. The study found an overall prevalence of

lymphedema of 1.33/1000 people, with an increase of 1/200 in those individuals 65 years or older. Secondary lymphedema is seen in approximately 20% to 30% of people with advanced chronic venous insufficiency (Raju, Furrh & Neglen, 2012). Leg lymphedema has been reported in 3.4% of patients with surgery for uterine cancer who had 10 or more lymph nodes removed (Abu-Rustum, et al., 2006). The occurrence of lymphedema has been shown to be as high as 9.2% in spina bifida patients (Garcia & Dicianno, 2011).

2.1.2.3 Complete decongestive therapy

Currently, complete decongestive therapy (CDT) is the best practice for managing lymphedema (National Lymphemeda Network [NLN], 2011; Rockson, 2001; Foldi, 1998; Mayrovitz, 2009). The goals of CDT are to reduce swelling and fibrotic changes in the extremity, improve the functional ability of the extremity, prevent infections, and provide self-management education (Mayrovitz, 2009; NLN, 2011). CDT is provided in two phases. Phase I is completed within the clinical setting by a certified lymphedema therapist. It consists of manual lymphatic drainage to facilitate central lymph flow and promote movement of the lymph out of the effected limb, multilayer short stretch compression bandaging of the extremity, decongestive exercises, diaphragmatic breathing and meticulous skin care (Mayrovitz, 2009; NLN, 2011; Foldi, Foldi & Clodius, 1989; Kerchner, Fleischer, & Yosipovitch, 2008; Szuba & Rockson, 1998; Petrek, et al., 2000, Learner, 1998). Phase II is the life-long self-management of the lymphedema that the patient performs within the home setting. This involves the patient continuing with skin hygiene, manual lymphatic massage (MLD), compression garments, and exercises (NLN, 2011; Kerchner, et. al, 2008; Ko, Learner, Klose & Costimi, 1998).

Several studies have evaluated the effectiveness of CDT and MLD. In 299 patients with lymphedema, CDT produced a mean lymphedema reduction of 59.1% (SD $\pm$ 8.2) for patients with upper extremity edema and 67.7% (SD $\pm$ 6.7) for patients with lower extremity edema (Ko, et al., 1998). Koul, et al., (2006), evaluated the effectiveness of MLD, CDT, or exercise only in 138 women who developed lymphedema following breast cancer treatment. The results of the study showed a significant reduction in the arm volumes in the women who received CDT and MLD ($p < 0.0001$). Treatment with CDT had the greatest reduction with a mean volume reduction of 233 ml (55.7 %). Women treated with MLD had a mean volume reduction of 164 ml (41.2 %) and those with exercise alone had a reduction of 98 ml (24%).

Despite these promising findings, Adam, et al. (2010) reported that only 50% - 80% of patients with arm lymphedema who received professional CDT were able to maintain benefits for greater than one year. A major reason for this outcome was nonadherance with prescribed self MLD (Adams, et al., 2010). Nonadherance with home maintenance therapy has been shown to minimize the benefits of the initial treatment (Ko, et al., 2008).

2.1.2.4 Pneumatic compression therapy

Several pneumatic systems have been developed to assist in promoting lymph drainage. The low sequential pressure of a pneumatic compression device simulates the technique of MLD and has been shown to be effective in decreasing extremity volume. Adams, et al. (2010), used near infrared fluorescence imaging to evaluate response to lymphedema treatment with an advanced pneumatic compression device on six women with breast cancer-related lymphedema. A significant pre to post treatment increase in lymphatic propulsion rates was reported in four of the six women ($p < 0.05$). Klein, et al., (1998) compared pre and post circumferential

measurements on 73 subjects with lower extremity lymphedema who underwent a 48 hour pneumatic compression therapy program. A significant decrease in mean leg circumference following completion of the program ($p < 0.00005$) was reported.

Prior studies suggest that pneumatic compression therapy is highly effective. A prospective crossover design study by Wilburn, Wilburn & Rockson (2006) of 10 breast cancer patients who had lymphedema, compared use of an advanced pneumatic compression device and self-manual lymphatic drainage. Subjects were randomly assigned to use the advanced pneumatic compression device or to perform self-manual lymphatic drainage for one hour per day for a two week period. They then switched treatments after a one week wash-out period. Utilization of the advanced pneumatic compression device resulted in a mean decrease of 207 ml in the effected arm verses a mean increase of 53 ml in the arm with self-manual lymphatic drainage ($p = 0.07$).

Pneumatic compression devices offer the potential of overcoming some of the barriers encountered when performing MLD. When performing MLD, patients have reported difficulty in both learning the skill and challenges in regard to performing it properly, thus rendering MLD ineffective. Improper performance of MLD can result in excessive pressure during a massage and a collapse of lymph vessels. Advanced pneumatic compression devices offer an alternative therapy that appears to be effective and well accepted by patients.

2.1.3 Chronic venous insufficiency

Chronic venous insufficiency (CVI) is a condition that results in venous hypertension in the legs (Eberhardt & Raffetto, 2005), and occurs in approximately 3-5% of the adult population (Abbade

& Lastoria, 2005). Primary causes of CVI include incompetency of venous valves or venous obstruction. There is also an association between CVI and a decrease in muscle pump function. A study by Yang, Vandongen & Stacey (1999) compared calf muscle strength of people with recently healed venous ulcers to people with no history of CVI. Results of the study showed that calf muscle strength endurance was significantly decreased in people with healed venous ulcers compared to the group without CVI.

Complications associated with CVI include edema, pain, changes in skin, and ulceration of the effected extremity (Eberhardt & Raffetto, 2005). Secondary lymphedema is seen in approximately 20% - 30% of people with advanced chronic venous insufficiency. This outcome is the result of damage to the lymphatic system from fluid overload or repeated episodes of cellulitis (Ragi, et al., 2012).

Classification of CVI can be done utilizing the CEAP assessment tool. This validated tool was developed to provide a unified assessment that can be utilized in the documentation, diagnosis and treatment of CVI (Eberhardt & Raffetto, 2005). The clinical component of CEAP rates the severity of CVI on a scale of "0" for no disease to "6" for CVI with an active ulcer. The etiology section of CEAP designates whether the CVI is a congenital, primary, or secondary disease process. The actual veins involved in the CVI are designated in CEAP's anatomic section and the pathophysiology section of CEAP focuses on the underlying mechanical problem that resulted in CVI (Eberhardt & Raffetto, 2005).

Venous ulcers, a common complication of CVI, comprise 50% - 70% of leg ulcers. Leg ulceration resulting from CVI effects more than 2.5 million adults in the United States annually (Gillespie, 2010). The average healing time of venous ulcers ranges between 6-12 months, with as many as 70% of the ulcers reoccurring within five years from when they initially healed

(Gillespie, 2010). Venous ulcers negatively impact individuals' quality of life, and cause increased medical costs and lost revenue from missing work. The cost of treatment for patients with venous ulcers in the United States alone is approximately $3 billion annually (Eberhardt & Raffetto, 2005). As for productivity, it has been calculated that in the United States 6 million days of work are lost due to complications associated with CVI (Abbade & Lastoria, 2005).

Treatment of CVI is dependent on the severity of the disease, the underlying mechanism that caused the CVI, and secondary complications. Conventional treatment of CVI involves reducing symptoms, preventing secondary complications, and preventing CVI from progressing (Eberhardt & Raffetto, 2005). Conventional treatment includes the use of compression garments, exercise, skin care, and elevation. A prospective study by Finlayson, Edwards and Courtney (2011) followed 80 subjects with healed venous ulcers for one year. Results of the study showed that leg elevation for one hour per day, and wearing of a Class 2 or 3 compression garment for six or more days per week, significantly associated the reoccurrence of venous ulcers (Finlayson, Edwards and Courtney, 2011). Milic et al., (2010) evaluated the effectiveness of three pressure levels of compression therapy on venous leg ulcers healing. The results of this randomized prospective study showed that healing rates were significantly greater with higher pressures of compression. However, nonadherance rates with regard to wearing the compression bandaging were significantly greater in the highest compression group, with the majority of people who were noncompliant having smaller calf circumferences. The reason for nonadherance was discomfort as a result of the bandaging. The conclusion reached by Milic, et al. (2010) was that compression pressure should be individualized based on the patient's calf circumference and leg characteristics. In those undergoing treatment with compression therapy, a decrease in calf muscle pump function has been associated with slow healing or non-healing venous ulcers.

Milic, Zivic, Bogdanovic, Karanovic & Golubovic (2009) performed a study to determine possible risk factors that are associated with prolonged healing times of venous ulcers that were treated with compression bandaging. They reported a positive correlation between walking less than 200 meters per day and prolonged healing. Other factors associated with slow healing were a high BMI, history of wound debridement, and ulcerations deeper than 2 cm (Milic, et al., 2009).

Prior research supports benefits of intermittent pneumatic compression (IPC) to promote healing of venous leg ulcers. The use of intermittent compression, along with compression garments, may be the best treatment for chronic venous ulcers (Comerota, 2011). As a result of studies on IPC for treatment of venous leg ulcers, the American College of Chest Physicians suggested that IPC be used to improve healing times of large venous leg ulcers and ulcers that are difficult to manage with other treatments (Comerota, 2011).

2.2 IMOBILITY AND CHRONIC SWELLING/LYMPHEDEMA

As of 2010, there were over 23.8 million community dwelling Americans who reported difficulty in walking. Of these people, 11.5 million used assistive devices of crutches, walkers or canes and over 3.6 million use a wheelchair for mobility (Brault, 2012). The top five conditions that have been associated with wheelchair or scooter use in ages 18-64 are multiple sclerosis, paraplegia, cerebrovascular disease, quadriplegia and osteoarthritis (Kaye, et al., 2000).

People with mobility limitations are at a higher risk for lower extremity chronic swelling. The return of fluids via the venous and lymphatic system is facilitated by muscle contractions of

the legs. During walking, the calf muscle contraction applies greater than 200mm Hg of pressure to intramuscular veins and lymphatic vessels in the legs. This pressure compresses the veins and lymphatic vessels and directs the flow upward to return to the central circulatory and lymphatic system (Cavorsi, 2000). This normal physiological mechanism is hindered and sometimes absent in people who utilize wheelchairs for mobility. This results in a decrease in venous and lymphatic flow from the legs resulting in chronic swelling. If left untreated, chronic swelling causes damage to the lymphatic system due to fluid overload of the lymphatic system and the repeated occurrence of cellulitis (Raju, Furrh & Neglen, 2012). Sitting for long periods of time applies pressure to capillaries and lymphatic vessels which can also impede flow. Improper seating for wheelchair dependent people can aggravate this impedance even further (Geyer, 2010). Poor body trunk alignment could negatively affect the normal respiratory pump for the lymphatic system if trunk support is not addressed in people who require it for wheelchair seating (Geyer, 2010).

Traditional therapy for chronic swelling/ lymphedema may be difficult to achieve for people with limited mobility for a variety of reasons. Accessibility to certified lymphedema therapists may be limited in their geographic area. The Lymphology Association of North America (LANA) currently has only 1014 certified lymphedema therapists registered on their website (LANA, n.d.). These therapists are located primarily in metropolitan areas. The percentage of people who use mobility devices is greater in rural areas compared to metropolitan areas (Kaye, et. al, 2000). Lack of transportation may also be a barrier to accessing traditional therapy. Eighty-two percent of wheelchair users reported that public transportation systems were too difficult to get to or to use (Kaye, et al., 2000). Costs associated with traditional therapy are an additional factor in the accessibility of care. Traditional therapy involves multiple

clinic visits over several weeks. Most third party payers of health care have a limit on the number of physical therapy visits per year that they reimburse. Many third party payers require a co-payment to be made by the patient for each outpatient visit. Approximately nine percent of people with disabilities report they have no health care insurance (Brault, 2012). Only 40.8% of people with a physical disability are employed compared to 79.1% of people without a disability (Brault, 2012). According to the U. S. Census Bureau, in 2010, the median monthly income for people with disabilities was $1961 compared to $2724 for people without disabilities (Brault, 2012). Low income in people who use wheelchairs for mobility has been associated with a decrease in access to medical care (Hoenig, Landerman, Shipp & George, 2003).

Additional issues relates to provision of the therapy. Traditional home maintenance of chronic swelling/lymphedema involves manual lymphatic massage and application of compression bandaging or garments. These tasks may require physical strength, range of motion and dexterity that, due to their underlying disease process, people with limited mobility may not possess. Manual lymphatic massage and effective compression bandaging requires special training to obtain optimal results. Bandaging that is applied with too low of pressure can result in poor outcomes; conversely, bandaging applied with pressure that is too high can result in arterial occlusion and ulceration to the extremity (Partsch, 2008). Compression garments are made of short stretch material. When the patient is not moving light pressure is applied by the compression garment to the extremity. This light pressure is known as the resting pressure. As muscles contact against the short stretch compression garment, the interstitial pressures increases creating what is called the peak pressure. The fluctuation between the resting and peak pressures produced by the compression garment, known as the working pressure, facilitates the muscular pumping mechanism to remove venous blood and lymph out of the extremity. The short stretch

garment also helps prevent the fluid from returning to the extremity (NLN, 2011). Muscle contraction of the leg occurs with movement of the ankle as a person walks. In people who use a wheelchair for mobility, ankle movement is limited or nonexistent. Therefore, they do not receive the pumping benefit provided from the compression garment. An alternative for this is the active pumping received from a pneumatic compression device (Partsch, 2008).

Alternatives to traditional care need to be addressed to overcome barriers people with limited mobility may encounter that prevent them from utilizing traditional care. TR for patients with chronic swelling/lymphedema that consists of face-to-face education within the comfort of the patient home, and the use of a pneumatic compression device in place of manual lymphatic massage to augment the effect or replace compression garments, could potentially address many of these barriers.

2.3 TELEREHABILITATION

TR is the utilization of telecommunications to provide remote rehabilitation services to people with disabilities (Schmeler, Schein, McCue & Betz, 2009). Services that can be provided include consultation, therapy, education and physical monitoring. The use of TR can help eliminate barriers that patients face in receiving therapy (e.g., inability to access specialized health care locally, transportation issues, travel expense and fatigue and pain associated with travel).

Winters (2002) describes four conceptual models of TR service delivery. The first is a face-to-face model that uses real-time videoconferencing. This model is often used for remote

consultations by specialists to other clinicians and patients. The second is the telehomecare model that involves a clinician using telecommunication to coordinate in-home therapy and patient support. The third model involves telemonitoring wherein technology is used to provide in-home physical monitoring of the patient and transfer of data to clinicians for review. The fourth and final model is teletherapy, wherein the patient uses interactive programs to promote exercising. The therapist can monitor the patient's progress; provide coaching to the patient and make adjustments to the program remotely (Winter, 2002).

In a White Paper for the RERC on Telerehabilitation's *Virtual State of the Science Conference* in 2008, Pramuka and van Roosmalen described technologies that are available for TR in a somewhat different format. Text based technology is an asynchronous technology and can be utilized by clinicians to relay pertinent information and provide prompting and reminders to patients (Pramuka and van Roosmalen, 2009). Audio-based technology provides the ability to project sound over distance. Audio based technology may be synchronous in the form of telephone conversations or asynchronous by downloading podcasts to an MP3 player. Vision technology may be synchronous as in real-time videoconferencing or asynchronous through the use of videos and digital pictures (Prumuka and van Roosemalen, 2009). Virtual reality refers to the use of computer programs to create an artificial environment to provide patient simulation experiences. Web based technology allows for interaction through chat rooms and discussion boards and access to audio and visual information. Finally, smart phones and wireless technology allow podcasts, sending of digital imaging and patient cueing (Prumuka and van Roosemalen, 2009). These options allow telerehabilitation to be provided through a variety of approaches. The type of technology utilized is dependent on the targeted population needs, the goal the clinician wishes to achieve, available equipment capabilities, available bandwidth

between the sites, and whether users have the required informational technology skills to use the equipment.

2.3.1 Telerehabilitation usability

The International Organization for Standardization defines usability as the "extent to which a product can be used by specific users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" (ISO, 9241-11, p. 6). Effectiveness of a product is proven by its ability to allow the user to obtain goals specific to the use of the product. Efficiency relates to the ability of the product to achieve the goal completely and accurately. Factors that can be used to evaluate efficiency of a product are the amount of time and effort extended by the user for the product to achieve the goal, the amount of materials needed for the production and utilization of the project, and any costs associated with the use of the product. Satisfaction is the attitude of the user about the product. It is a subjective evaluation of the user in regards to the acceptability of the product and is dependent on the user's experience with the product (ISO, 1998).

The implementation of an effective and efficient telerehabilitation service is dependent on several factors. First, both the correct model of telerehabilitation and the appropriate type of telecommunication technology need to be chosen based on the desired goals of the telerehabilitation service. Once the model and type of technology is determined, the availability of the appropriate equipment for both the therapist and the client needs to be assessed along with costs associated with acquiring it. Knowledge of the bandwidth between intended sites is necessary to see if it is sufficient to support the data rate needed for the telecommunication

technology that is to be implemented. Finally, prior to the first telerehabilitation session, training of both the therapist and the client on the telerehabilitation equipment should be done to assure ease of use of the equipment.

2.3.2 Clinical effectiveness of telerehabilitation

Numerous research studies have evaluated the effectiveness, efficiency and patient satisfaction with the use of telecommunication technology to provide health care service. Studies have shown that telerehabilitation is an effective alternative for traditional home based therapy. A pilot study by Finkelstein, Lapshin, Castro, Cha & Provance (2008) evaluated the effectiveness of a home-based telerehabilitation program for patients with multiple sclerosis. Twelve patients with MS received a 12 week exercise program. An automated tele-management system (HAT) was used to guide the patients through their exercise program with the utilization of text, audio and video prompts. A self-reported exercise log was completed each day by the patients and sent to the HAT server for review by a physical therapist. Clinical outcome measures included a timed 25-foot walk, a 6 minute walk, Berg Balance Scale, 12-Item MS Walking Scale, Modified Ashworth Scale, MSQOL-54, and the MOS Patient Adherence Measure. Results of the study showed a significant improvement in the timed 25 foot walk, Berg Balance Scale and the 6 minute walk. There was an improvement in the Modified Ashworth Scale in the quadriceps, but only significant improvement in the left quadriceps. The MOS Patient Adherence Measure increased, but not significantly. There was no significant improvement in the MSQOL-54 (Finkelstein, et al., 2008). Tousignant, Boissy, Corriveau, & Moffett (2006 & 2009) performed a pilot studies to evaluate the effectiveness of using a home telerehabilitation physiotherapy program by real-time

videoconferencing as an alternative to traditional home care visits. In the first study, four adults between the ages of 60-82 received 12 sessions of telerehabilitation via teleconferencing over a four week period (Tousignant, et al., 2006). The second pilot study involved four subjects who received 16 sessions of telerehabilitation via teleconferencing following surgery for a knee arthroplasty (Tousignant, Boissy, Corriveau, Moffett & Cabana, 2009). The results of both studies showed clinical outcome improvement in all participants (Tousignant, et al., 2006 & 2009). Finkekstein, et al., (2004) performed a randomized control study to evaluate patients' and clinicians' perceptions in regard to video conferencing augmenting visits for home care. Fifty three subjects were recruited and randomly assigned to one of three groups; traditional home health visits, traditional home health visits augmented with video conferencing and traditional home health visits augmented with video conferencing and in-home monitoring. A total of 567 video visits were performed in the study. Technical reporting forms were completed on 443 video visits. The mean technical quality ratings were 94.7%. Nurses involved in the video visits reported that 90.7% of the video visits were as useful as an actual home visit (Finkelstein, et. al, 2004). In a Cochrane review by Currell, Urquhart, Wainwright & Lewis (2010), an evaluation of current research literature was performed to assess the effectiveness of telemedicine in providing patient care compared to traditional face-to-face care. The conclusion was that, while research has shown the feasibility of providing patient care via telemedicine, there was insufficient evidence to evaluate the effect telemedicine has on outcome measures or cost effectiveness. The authors noted that randomized control trials evaluating the effectiveness of telemedicine are feasible and should be done whenever possible. They also concluded that there is urgent need for research on the "effectiveness, efficiency and appropriateness of telematics applications to healthcare" (Currell, et al., 2010, p. 11).

2.3.3 Cost effectiveness of telerehablitation

The utilization of telecommunication technology in the delivery of health care has been shown to be cost effective. A case report on the Veterans Health Administration's (VHA) national home telehealth program, Care Coordination/HomeTeleheath (CCHT) showed a significant decrease in medical expenditure with the utilization of telehealth compared to traditional home-based primary care. The annual cost of the CCHT per patient was $1600, compared to the VHA's home-based primary care annual cost of $13,121 (Darkins, et al., 2008). Hospital admissions for the cohort of 17,025 veterans enrolled in the study were compared to prior data. The cohort had a 23.31% reduction of hospital days after enrollment in CCHT, compared to a 4.6% decrease for patients in the VHA who were not enrolled in the study (Darkins, et al., 2008).

The National Association of Home Health (NACH) estimated that approximately 12 million people received home health care in 2010. The estimated medical expense for home health care in 2009 was $72.2 billion, with Medicare as the largest payer, covering 41% of the national home health care costs (NACH, 2010). Medicare fees for home health services for 2008 covered payment for 3.46 million clients at a cost of $4,938 per client. The average number of home health care visits per client was 35 (NACH, 2010). This averages to a medical expense of approximately $141 per visit. A pilot study by Tousignant, et al. (2006) on home telerehabilitation for elderly people showed a mean cost of $487 for 12 TR sessions over a four week period, averaging approximately $41 per visit. The Department of Health and Human Services (HHS) reported that 8.7% of Medicare beneficiaries who received home care in 2004 had a rehabilitation DRG code (HHS, 2004). Dick, Filler and Paven (1999) evaluated the cost savings of telemedicine consultations that were provided by a tertiary specialist to 140 children

at a clinical site that was 840 miles from the tertiary care center. A questionnaire was completed by the subjects to evaluate cost savings, comfort with the consultation and satisfaction. Parents of 98 of the children provided information in regards to the cost savings associated with using a telemedicine consult verses traveling to the tertiary care center to see the specialist. The average cost savings to parents due to elimination of travel expenses was $1318.00 (SD $677.00) (Dick, et al., 1999).

With the CDC estimating the population of people in the United States age 65 or older to increase from an approximately 35 million in 2000 to 71 million in 2030 (CDC, 2003), it is anticipated that there will be a proportionate increase in the number of people with chronic illnesses and disabilities that will require home health care. The utilization of TR for in-home rehabilitation therapy for the elderly could potentially result in a substantial decrease in Medicare expenditures for home health care.

2.3.4 Patient satisfaction with telerehabilitation

Results of studies have shown patients reporting high levels of satisfaction in the health care they receive by telecommunication. Dick, et al. (1999) reported that in his study on telemedicine consults for children, 71% of responses from the parents of the children reported complete satisfaction with telemedicine consultation. Comfort levels with the telemedicine consult increased significant from pre to post consultation. Fifty-eight percent of the parents reported being completely comfortable with the telemedicine consultation prior to consultation. The reporting of complete comfort with the telemedicine consultation increased to 77% following the completion of the consultation (Dick, et al., 1999). Tousignant, et al. (2009) reported patient

satisfaction levels of 94.7% ± 7.8 % out of a total score of 100% in his pilot study on telerehabilitation for patient's following knee arthroplasty surgery.

Schein, Schmeler, Saptona & Brienza (2010) study utilized real-time video-conferencing between a therapist who was a seating specialist and therapists and patients in a remote clinics to perform wheeled mobility and seating assessments. The results of the study showed a significant increase in patient satisfaction scores between pre and post evaluation and pre and post prescription. Based on a 5 point Likert scale questionnaire, with 5 as the highest level of satisfaction, overall mean patient satisfaction scores for both post evaluation and post prescription were 4.98 (SD = 0.16) (Schein, et.al., 2010).

Woods, et al. (1999) compared patient satisfaction between telemedicine to traditional clinical visits in adult patients with sickle cell disease. One hundred and twenty subjects were recruited from the Medical College of Georgia Sickle Cell Program in the state of Georgia. This program consisted of a clinic in Augusta Georgia, three outreach clinics and a telemedicine outreach network used to link healthcare professionals from the clinical sites to patients in rural areas of Georgia in an effort to provide increase in specialized care to patients. The recruitment of subjects was based on a convenience sample. Subjects were assigned to the group that corresponded with the type of clinic they attended (standard clinic vs. telemedicine). Sample size of each group was 60 patients. Patient satisfaction was determined using the Client Satisfaction Questionnaire (CSQ-8), a validated generalized questionnaire comprised of eight question answered using a four-point Likert scale to evaluate patient satisfaction. The subjects completed the questionnaire after a minimum of one visit. The results of the study showed that subject satisfaction was high in both groups with no significant difference. Out of a total possible score of 32, the mean score for the telemedicine and standard clinic groups was 28.82 (SD ± 3.06) and

29.32 (SD $\pm$ 3.06), respectively. Open ended negative comments from the telemedicine group were primarily in regard to concerns for confidentiality (Woods, et al., 1999).

A randomized control study by Finkelstein, et al. (2004) evaluated patient perceptions in regard to the use of video conferencing and in-home monitoring to augment visits for home care. Subject satisfaction was evaluated using the Home Care Client Satisfaction Instrument (HCCSI), a validated questionnaire for home healthcare satisfaction. Results of the study showed that subjects who were provided with standard home health care that was augmented with both video conferencing and home monitoring had the highest rate of satisfaction (Finkelstein, 2004). Louis, Turner, Gretton, Baksh & Cleland (2003) performed a systematic review of the literature on telemonitoring for the management of heart failure. Eighteen observational studies and six randomized control trails were reviewed. Of these studies, six observational studies looked at patient satisfaction with results showing that both patient compliance and acceptance of telemonitoring was high. One randomized control study reported high levels of patient satisfaction and improved quality of life (Louis, et al., 2003).

2.4 SELF-MANAGEMENT OF CHRONIC CONDITIONS

Chronic conditions result in seven out of ten deaths in the United States. As of 2005, 133 million people in the United States suffered from at least one chronic condition. This is projected to increase to 157 million people by 2020 (Bodenheimer, Chen & Bennent, 2009). This increase in the prevalence of chronic conditions is contributed to the increasing age of the population and an increase in risk factors (Bodenheimer, et al., 2009). The population within the United States is

aging at a rapid rate with predictions of people over the age of 60 increasing from 57 million in 2010 to 65.7 million by 2015 (HHS, 2010). The occurrence of people having multiple chronic conditions increases with age, with 25% of Medicare recipients having at least four chronic conditions (Coleman & Newton, 2005). This rise in chronic conditions is creating an increased financial burden on the health care industry with costs associated with the management of these chronic diseases accounting for 75% of all health care costs (HHS, 2010). The increase in prevalence of chronic conditions also results in an increased demand on the healthcare workforce. The current health care delivery system is focused on acute care. With the aging population and the increase in chronic conditions, the current health care delivery system is not meeting the public's needs. In order to meet public health care needs, a redesigning of the current health care system to provide a continuum of health care to people with chronic conditions is necessary (IOM, 2001). Recommendations for redesign of health care delivery systems by IOM include that patients be informed decision makers in their health care, health care should be customized according to patients' needs and values and health care should be readily available and provided not just by face-to-face visits but also by internet or telephone (IOM, 2001).

The Chronic Care Model (CCM) is an evidenced based framework developed by MacColl Institute for Healthcare Innovation to improve the health care delivery for people with chronic conditions. The CCM framework is composed of six components. These components include healthcare organization, community resources, self-management support, delivery system design, decision support and clinical information systems (Epping-Jordan, Pruitt, Bengoa & Wagner, 2004). The CCM framework has been utilized on over 1000 health care

organizations (Epping-Jordan, et al., 2004) and evidence has suggested that the implementation of this framework results in improved care and better health care outcomes for patients with chronic conditions (Coleman, Austin Brach & Wagner, 2009; Dorr et al., 2006). The World Health Organization, in an effort to address the global increase in chronic disease, expanded on the CCM and developed the Innovative Care for Chronic Condition (ICCC) framework. The intention for the ICCC is to provide countries with a framework that could be utilized to assist in the development of health care policies and the transformation of healthcare systems (Epping-Jordan, et al., 2004). The central idea of the ICCC framework is "optimal outcomes occur when a health care triad is formed that establishes a partnership among patients and families, health care teams, and community supporters" (World Health Organization, 2002, p. 7). In order for this partnership to succeed, all members involved in the triad must be educated, motivated, prepared and willing to collaborate with the other partners (World Health Organization, 2002). The ICCC also incorporates an additional level in its framework that focuses on legislation, policy development, finance, leadership and the development and allocation of human resources (Epping-Jordan, 2004). Both the CCM and ICCC are being implemented within multiple countries with ongoing research in regard to their effectiveness in addressing the health care of people with chronic conditions (Epping-Jordan, 2004). A focal point in the delivery of health care in both the CCM and ICCC is self-management support. Self-management is defined as "an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent with living with a chronic disease" (Glasglow, Davis & Funnell, 2003, p. 56 3). The emphasis of care in self-management of chronic conditions changes from the health care provider to the person with the chronic condition. The role of the health care provider is to educate and assist the patient is the development and implementation of a self-

management regimen that is tailored to the patient's needs (Bodenheimer, Lorig, Holman & Grumbach, 2002).

Lorig & Holman (2003) describe five core skills for self- management of chronic conditions. The first of these skills is problem solving. This is the ability to not only identify problems but to look at possible solutions to the problem. Decision-making is the second skill. Decision-making involves people having the knowledge to make daily decisions in response to the current status of their chronic condition. The third skill is an understanding of how to find and utilize appropriate resources. This could involve the use of the internet, library, community resources and support groups. The fourth skill is the ability to develop a partnership with your health care professionals in the planning and implementation of your care. Patient need to not only acquire the knowledge to appropriately evaluate and relay any changes in the status of their chronic condition, but to actively participate with health care professionals in tailoring their health care to meet their needs. The final skill is the ability to implement and evaluate a plan of self-care. Patients need to learn how to develop and evaluate short term measurable goals in regards to the self-management of their chronic condition (Lorig & Holman, 2003).

Self-management theory is grounded in the expectation that increasing a patient's belief in their ability to manage their illness will result in behavior change and better health care outcomes (Coleman, & Newton, 2005). This belief is referred to as their perceived self-efficacy. Self-efficacy is defined as "the confidence a person feels about performing a particular activity, including confidence in overcoming the barriers to performing that behavior" (Glanz, Rimer, & Lewis, 2002, p. 173). According to Albert Bandura's Social Cognitive Theory of Self-Regulation, a person's perception of their self-efficacy will impact their decisions in life, their

goals and how they respond to adversity. The more competent a person believes themselves to be, the higher goals they will set for themselves and the more determined they will be to overcome adversity in meeting those goals (Bandura, 1991). Research has shown a positive correlation between self-efficacy and health care outcomes. Results of a longitudinal prospective study by Finlayson, et al. (2011) showed that a higher general perception of self-efficacy correlated with a decrease in recurrence of venous ulcers. Jenkins & Gortner (1998) evaluated the correlation between self-efficacy expectation and post-operative walking behavior in 199 elderly cardiac surgery patients. The results of this prospective cohort study found a significant positive correlation between self-efficacy expectation and self-reported walking behavior. In a literature review by Strecher, Devellis, Becker & Rosenstock, (1986) of studies on self-efficacy and health care behaviors in regard to smoking, weight control, contraception, exercise and alcohol abuse, self-efficacy was a predictor of success of the behavioral intervention.

Self-management programs for chronic conditions have been shown to increase self-efficacy, improve health behaviors, (Lorig, et al.,2001), improve healthcare outcomes (Chodosh, et al., 2005; Lorg, et, al., 2006; Lorig, et al., 2001; DeWalt, et al., 2004) decrease Emergency Department and outpatient visits (Lorig, et al., 2001) and decrease the incidence and length of hospitalization (Bourbeau, et al. 2003). This suggests a positive benefit when combined with TR.

2.5 HEALTH LITERACY

The 1993 National Assessment of Adult Literacy (NAAL) survey results indicated that 90 million adults in the United States experienced difficulty understanding the health information they were given (Institute of Medicine, 2004). These results increased the awareness of both the government and health professionals of the significance literacy levels in regard to health education and healthcare outcomes. In 2003, a health literacy component was added to the NAAL survey making it the first large national survey to assess health literacy. Results of this survey showed that while 12% of adults had proficient health literacy and (53%) of adults in the United States have intermediate health literacy skills, there are 30 million adults (14%) with below basic health literacy and 47 million adults (22%) with only basic health literacy skills (U.S. Department of Education, 2006).

Healthy People 2010 defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions "(U.S. Department of Health and Human Services, 2000). Results from research evaluating the prevalence of inadequate heath literacy indicate that subjects with inadequate or marginal health literacy tended to be older, a minority, have lower incomes and less than a high school education (Schillinger, et al., 2002; Wolf, Gazmararian & Baker, 2005).

Inadequate health literacy has been shown to have a negative impact on a patient's ability to communicate with health care providers. Schillinger, Bindman, Wang, Stewart & Piette (2004) evaluated the quality of communication between 408 Spanish and English speaking patients and their physicians. The communication sub-scales of the Interpersonal Processes of

Care in Diverse Populations Questionnaire (IPC) were used to evaluate the subjects' perception of their communication with their physician. This tool focused on six areas of communication: clarity of information provided by the physician; time allowed to respond to the physician; explanations or care provided by the physician; explanation of self-care; empowerment; and decision making. The results of the study indicated that inadequate health literacy levels were associated with poorer quality of interpersonal communications in the areas of clarity, explanation of condition and care, and empowerment and decision making (Schillinger, et. al, 2002). A study by Wolf, et al. (2007) evaluated a subject's shame associated with low literacy. This study found that although 47.8 % of subjects with low health literacy and 19.2% with marginal health literacy expressed feelings of embarrassment and shame relating to their literacy levels and 90% of them reported it would be beneficial for doctors to know they had difficulty with medical words.

Numerous measures have been developed to evaluate the health literacy levels of patients. Two measures that are frequently used are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test for Functional Health Literacy in Adults (TOFHLA). The REALM measures word recognition and the TOFHLA measures reading and numerical comprehension (Baker, 2006).

Health literacy levels have been shown to impact subject's knowledge of their chronic disease. In a study by Gazmararian, William, Peel & Baker (2003) 635 Medicare patients who had asthma, diabetes, congestive heart failure or hypertension were evaluated on their knowledge of their chronic disease using previously designed knowledge questionnaires. Results of the study showed that subjects with inadequate health literacy had significantly lower scores on the

knowledge tests. Results of a study by Williams, Baker, Honig, Lee & Nowlan (1998) that involved 483 subjects from an urban hospital's emergency room and clinic also showed a correlation between inadequate health literacy and a decrease in the subjects' knowledge of asthma and their skill using their inhaler.

Studies have demonstrated that there is a negative association between inadequate health literacy and health care outcomes. A study by Schillinger, et al. (2002) evaluated the association between health literacy and A1C levels of 408 English and Spanish speaking adults. The results of the study found that there was a correlation between inadequate health literacy and the subject's ability to achieve good glycemic control. The study's results also showed a higher incidence of diabetic retinopathy in subjects who had inadequate health literacy levels. A multi-sight cross-sectional survey of 2923 Medicare patients demonstrated that inadequate health literacy was associated with poorer physical and mental health (Wolf, et al., 2005). Mancuso and Rincon's (2006) study looked at health literacy in relation to patients' assessment of their disease management. Interviews were performed on 175 patients with asthma. The study's findings indicated that patients with inadequate and marginal health literacy were significantly more dissatisfied in the status of their asthma, reported worse results in their care of their asthma and other medical conditions and were less involved in decision making concerning their medical care. DeWatt, Beckman, Sheridan, Lohr & Pignine (2004) performed a systematic review on the effects of literacy on healthcare outcomes. The results of the review showed that people with lower literacy were 1.5 to 3 times more likely to experience a negative healthcare outcome compared to people with higher literacy levels. Self-management programs that are tailored for patients with inadequate health literacy have been shown to overcome learning

barriers, increase self-management skills and reduce the rate of hospitalization and death (Paasche-Orlow, et al., 2005; DeWalt, et al., 2004).

In order to address health literacy disparity, health care professionals need to provide education materials that are appropriate for all health literacy levels. The average reading level of adults in United States is between the 5th - 8th grade levels (Vahabi & Ferris, 1995). Patient comprehension has been shown to increase with health information developed at 5th grade level (Vahabi & Ferris, 1995). Adult readers of all reading levels prefer and learn better with easy-to read instructions (Doak, C., Doak, L. & Root, J., 1996). The American Medical Association recommends that written material for patient education be developed at a 5th or 6th grade reading level. If health care practices have patient populations who have low literacy levels, the AMA recommends readability level of education materials is lowered to a 3rd to 5th grade level (Weiss, 2003).

Readability formulas have been developed to evaluate the grade level of a written text. Frequently used formulas are the Flesh Reading Ease Scale, Flesh-Kincaid Gunning Fog Index, SMOG and the Fry (Friedman & Hoffman-Goetz, 2006). The Flesh Reading Ease Scale, Kincaid-Flesh, Gunning Fog Index and Fry formulas use the number of polysyllable word and sentence length within a 100-word text to calculate a grade level of readability. The SMOG is based on the number of polysyllable words within 30 sentences (Friedman & Hoffman-Goetz, 2006). These formulas are limited because they assume that the increase in the number of syllables in a word increases its difficulty. They do not take into account that familiar multi-syllable words may be easier to comprehend than rarely used single syllable words. Different formulas applied to the same writing sample have also shown discrepancies with grade level

results, with the average score deviating as high as 41%. One recommendation to address this issue is to use the average of several formulas (Mailloux, Johnson, Fisher & Pettibone, 1995).

Electronic software packages have been designed to evaluate the readability level of written material. Mailloux, et al. (1995) performed a study to evaluate four programs: Corporate Voice, Grammatix IV, Microsoft Word for Windows and RightWriter. The Flesh Kincaid, Flesh Reading Ease and Gunning Fog Index formulas were evaluated in each program. Results showed that there were significant differences in each of the formulas in all software programs. The lowest grade level was provided by the Flesh Kincaid. The Gunning Fog Index had the highest grade level. Overall, the mean grade level of the formulas varied as high as 2.3 grades. There was no significant difference in overall grade level means produced by the Corporate Voice, Grammatrix IV and RightWriter software programs. The Microsoft Word software program results were a 0.8 – 1.3 grade level lower than the other software programs (Mailloux, et al., 1995). The recommendation made as a result of this study was to use an average readability level based on the results of several different formulas and several software programs in an effort to insure that one has achieved the desired readability level (Mailloux, et al, 1995).

Studies have shown that many patient educational materials have a much higher readability level than recommended by the AMA. The results of a review of the readability level of 426 different educational material on the American Academy of Orthopaedic Surgeons web site showed that mean Flesh Kincaid readability level of the material was a 10.43 grade level and that only 10 of the articles had a readability level of six grade or less (Sabharwal, Badarudeen & Kunju, 2008). Estrada, Hryniewicz, Higgs, Collins & Bryd (2000) evaluated the reading level of 50 patient brochures on anticoagulation therapy. The average reading level of the brochures

using the SMOG grade formula was a 10.7 grade level. No brochure had a reading level at the recommended 6th grade or below. D' Alessandro, Kingsley & Johnson-West (2001) evaluated 89 web based pediatric educational materials. Their findings also showed that the educational materials were above AMA recommendations, with a mean readability grade level for the Fry formula at 12th grade and the Smog formula mean readability grade level at 12.2. Although the Flesh Kincaid mean readability level was significantly lower at a 7.1 grade level, it still was above the recommended 6th grade or below readability level. The results of these studies and other studies on the readability levels of patient educational material indicate a need to educate health care professionals regarding health literacy and the appropriate readability level to use in the development of patient educational materials.

The readability level is not the only factor that determines the effectiveness of written material to address health literacy disparity. Authors of education material should also look at the suitability of the material. Suitability refers to the ability of the material to be understood and acceptable to the patient population it is targeting (Vallance, Taylor & Lavelle, 2008). Active voice, illustrations, short words and sentences and clear precise objectives should be used when developing education material. Words should be at least a 12 point font, both upper and lower case and consist of black letters on a white background. Subheadings and double spacing should be used to avoid cluttering of words. Avoidance of medical jargon and abstract concepts is also recommended (Mayer & Villaire, 2009).

The Suitability Assessment of Materials (SAM) was developed by Cecila Doak and Jane Root in 1993 as a method for evaluating the suitability of health educational material. The validation of SAM was completed by 172 health care professionals from various countries (Doak, et al., 1996). The SAM rates education material in using six criteria; content, literacy

demand, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness. There are 22 factors within the six criteria that are evaluated. Each factor receives a score of either superior (2 points), adequate (1 point), or not suitable (0 point). The scores are totaled and the overall material is rated on the percentage derived from the score of the educational material divided by the total possible score. Educational material with a score of 0 - 39% is given a rating of "inadequate suitability", 40 - 69% is given a rating of "adequate suitability" and 70% and above is rated as "superior suitability" (Doak, et al.1996, Vallance et al., 2008). SAM has been widely used to evaluate educational material related to a variety of diseases (Vallance, et al., 2008; Fagerlin, et al., 2004; Wallace, Rogers, Turner, Keenum & Weiss, 2006; Eames, McKenna, Worrall & Read, 2003; Taylor & Carson, 1998).

3.0 DEVEOPMENT OF THE SELF-MANAGEMENT EDUCATION PROTOCOL

3.1 METHOD

3.1.1 Content Development

Based on information obtained from review of literature from peer reviewed journals (Rockson, 2001; Foldi, 1998; Mayrovitz, 2009; Foldi, et al., 1989; Kerchner, et al., 2008; Szuba & Rockson, 1998; Petrek, et al., 2000, Learner, 1998), and the position statement from the National Lymphedema Network on the treatment of lymphedema (NLN, 2011), a self-management educational protocol was developed that incorporated current best practice for the treatment of chronic swelling/lymphedema. To address the potential limitations in ROM, and upper body strength and dexterity of an immobile population, an advanced pneumatic compression device was chosen in place of lower body MLD. Pneumatic compression devices have been shown to be effective in increasing lymphatic propulsion rates (Adams et al., 2010) and decreasing extremity volume (Klein, Alexander, Wright, Redmond & LeGasse, 1998; Wilburn, et al., 2006), Chronic edema is a prominent risk factor for infection (Kelly, 2002; Dupay et. al 1999; Baddour, 2006; Cox, 2006) and sedentary life style is a risk factor for type 2 diabetes (Wei, et al., 1999; Zhang, Solomon, Manson & Ho, 2006). In anticipation that some subjects may have chronic swelling of the feet, vascular issues or neuropathy, foot care was incorporated into the 10 steps.

This included education on loss of sensation and circulation to the feet, proper hygiene and inspection of feet, and appropriate footwear (American Diabetes Association, 2004). After identifying appropriate content, the next step was the development of a script for the protocol. The initial draft of the script, developed with input from three certified lymphedema therapists, was designed to encompass 10 learning goals for self-management of chronic swelling/lymphedema of the lower extremities. See Figure 1.0

STEP	GOAL
1	Understand basic pathophysiology of the vascular and lymphatic system, including warning signs of vascular, lymphatic and neurological damage.
2	Demonstrate proper limb hygiene, e.g., washing and drying technique and nail care.
3	Describe proper use of moisturizers and appropriate application.
4	Relate steps during skin inspection for changes such as redness, wounds, skins cracks, blisters and excessive dryness and increased hardness
5	Describe proper care for minor skin wounds.
6	Describe how to select appropriate footwear and clothing.
7	Demonstrate strategies to prevent/minimize swelling, including leg elevation, avoidance of excessive heat, and proper diet.
8	Demonstrate appropriate use of deep breathing and decongestive exercises.
9	Demonstrate appropriate application and care of an advanced pneumatic compression device and compression garments.
10	State signs and symptoms and appropriate action when complications develop, e.g., Deep venous thrombosis, pulmonary emboli, pulmonary congestion, edema and/or infection

Figure 1. 10 Steps to Healthier Feet and Legs

3.1.2 Readability

Once content was determined, the script was rewritten to reach a 5^{th} to 6^{th} grade readability level to address health literacy disparities that might be encountered in the targeted population. The

computer software RightWriter (Elite Minds, Inc.) was used to evaluate the readability level of the educational script. Right Writer employs two readability formulas, the Flesh Kincaid and the Gunning Fog Index and also evaluates for active versus passive voice and jargon. A second evaluation was completed using the Microsoft Word for Windows readability program.

3.1.3 Video Development

The final revised script was used to develop a series of videos for the TR-PUMPS protocol. A video was developed for each of the 10 steps, with the length of each video ranging from 1.5 to 11 minutes. The videos illustrated specific skills such as decongestive exercises and donning and doffing of compression garments. To establish content validity, the videos were viewed by eight additional board certified lymphedema therapists who anonymously ranked each video on accuracy and completeness of the information as well as the clarity of the presentation. A 5-point Likert scale (5 = strongly agree to 1 = strongly disagree) was used to determine the therapists' level of agreement with descriptive statements about the content of each video. See Figure 2.0.

Please respond to the following questions by placing a number in the box that matches your level of agreement.	Strongly Agree 5	Agree 4	Neither Agree nor Disagree 3	Disagree 2	Strongly Disagree 1
Step 1: Know about your feet and legs					
1. The basic anatomy and physiology are clearly explained					
2. Anatomy and physiology provide rationale for interventions at basic level					
3. The warning signs of poor circulation are accurate and complete					
4. The warning signs for chronic swelling are accurate and complete					
5. The warning signs for neuropathy are accurate and complete					
6. Co-morbidity is explained as well as the need for differential diagnosis					
Step 2: Wash & Dry Daily					
1. Rationale for daily washing is clearly explained					
2. Preparation for washing is accurate and complete					
3. Washing technique is accurate and complete					
4. Criteria for helper assistance and performance requirements are clearly explained					
5. Preparation for drying is accurate and complete					
6. Drying techniques are accurate and complete					
7. Precautions are accurate and complete					
8. Instructions to wash & dry both the affected and unaffected foot and leg in the same manner are clear					

Figure 2. Excerpts from the tool used to evaluate video content

The videos were made available electronically via a portal that subjects could access from their home computer. The videos were also used during teleconferencing to teach the 10 step program and to reinforce the teaching during review sessions. Some of the videos were subdivided into individual skills to enhance ease of viewing during TR.

3.1.4 Educational Booklet Development

In addition, a supplemental educational booklet was developed using the script created for the videos. The book was formatted in the same manner as the videos to match the 10 learning goals. Illustrations and still frames from the videos were used to augment the script. Following development, the educational booklet was evaluated for suitability using the Suitability Assessment of Materials tool (Doak, et al., 1996).

3.2 RESULTS

The educational scripts were rewritten until an average 5th grade readability level was obtained with the RightWriter and Microsoft Word for Windows software. Content validity of the educational videos was determined by eight experienced, board certified, lymphedema therapists. The mean score for the videos was 4.5 ± 0.35 with a range of 4.1 - 4.9. See Figure 3.0. The video content was deemed to be valid. Minor comments from the reviewers were incorporated to clarify or emphasize a point.

Table 1. Rating of lymphedema therapists on video content validity.

Learning Goal	1	2	3	4	5	6	7	8	9	10
Therapist Rating Mean	4	4.19	4.8	4.5	4.6	4.55	4.48	4.38	4.34	4.9
Mode	4	4	5	4	4	4	4	4	4	4

Ratings were derived from Likert scale of 5 = strongly agree to 1 = strongly disagree for each of the 10 videos in regard to the question, "Is this content appropriate for patient education on this topic?"

The educational booklet was evaluated for suitability utilizing the Suitability Assessment of Materials. A score of 77% was achieved, resulting in a superior rating.

4.0 EVALUATION OF SELF-MANAGEMENT EDUCATIONAL PROTOCOL

4.1 METHOD

4.1.1 Design

This present study was a component of a study funded by the National Institute on Disability and Rehabilitation Research, United States Department of Education (Grant # H133E090002). The parent study's aim was to evaluate use of TR to provide a self-management program for persons with chronic swelling/lymphedema and limited mobility within their homes. The parent study used a prospective, longitudinal single cohort design. This design allows for treatment effect evaluated over time.

4.1.2 Sample Population

The cohort was comprised of people with chronic swelling of the lower extremity(ies) who utilized a wheelchair or scooter as their primary means of mobilization within the community.

4.1.2.1 Inclusion criteria

- Age 18 – 80;

- Have chronic edema/lymphedema for greater than 3 months that does not resolve overnight; and
- Utilize a scooter or wheelchair for mobility within the community.

4.1.2.2 Exclusion criteria

- Visual acuity less than 20/100;
- Inability to apply and remove socks and pants or unavailability of a caregiver who could perform such tasks;
- Body dimensions too large for the proper application of the Flexitouch pneumatic compression device selected for use in this study;
- Medical history of congestive heart failure, peripheral artery disease, chronic renal disease, pulmonary edema, or pulmonary embolism;
- Active or recurrent cancer or currently receiving chemotherapy or radiation therapy;
- Current wound infection in the lower trunk or lower extremity(ies); and
- Diagnosed with deep vein thrombosis within the last six months.

4.1.3 Recruitment Protocol

Subjects were recruited from research registries associated with University of Pittsburgh Medical Center (UPMC) Physical Medicine and Rehabilitation Department, UPMC wound clinics, the Western Pennsylvania Lymphedema Therapists Network and lymphedema clinics outside the

UPMC network, including the Veterans Administration (VA) Medical Center. Recruitment involved contact with subjects via flyers placed in clinics, and contact with physicians and department managers to request referrals of patients who may benefit from participating in the study. Information of the study was provided to lymphedema therapists at the VA Medical Center, Pittsburgh, PA. When referring VA patients, therapists provided minimal verbal information about the study along with a contact number of a study investigator in accordance with the VA policy, *Guidance on Engagement and Referral of VAPHS Patients for Research Studies Conducted by non-VAPHS Entities.* This approach avoided engagement of VA employees in study as required by this institution's policies.

4.1.4 Screening Protocol

Initial screening of the subject was done by telephone. During the telephone interview, the subject was informed of the purpose of the study. Inclusion and exclusion criteria were reviewed with the subject and eligibility based on the subject's verbal report was confirmed. If the subject met the eligibility criteria and expressed an interest in participating in the study, a copy of the screening consent was emailed to the subject for their review.

A telephone call to verify the subject's interest in continuing the screening process was initiated two weeks following receipt of the initial screening. If the subject expressed willingness to continue with the screening process, an in-home screening was scheduled. The in-home screening was done by two investigators and consisted of the following:

a. Visual acuity was assessed utilizing the Snellen pocket vision chart. It was required that the subject have vision greater than 20/100 to participate in the study. This criteria was

based on the necessity of the subject to be able to accurately visualize the self-management educational booklet and the questionnaires used in the study.

b. The ability of the subject to visualize a spot on the bottom of his/her foot was evaluated to insure that he or she had the physical ability to perform a skin assessment of the feet.

c. The subject was observed to determine if they could apply and remove a trunk and leg sleeve that was similar to the advanced pneumatic compression garment. This could either be done independently or with the assistance of the caregiver. If it was necessary for a caregiver to apply the sleeve, confirmation was obtained that the caregiver would be available to apply and remove the advanced pneumatic compression garment on a daily basis.

d. The ability for the subject to safely transfer from a wheelchair or scooter to the bed either independently or with caregiver assistance was assessed.

e. Range of motion, sensation and strength was assessed.

f. Skin inspection and palpation of the lower extremities and trunk was performed by a trained therapist to validate the presence of chronic edema/lymphedema and assess for skin wounds or infections.

g. Body dimensions were measured to confirm that the subject's dimensions did not exceed the limitations of the advanced pneumatic compression garment. These measurements were also used to order the garment (if the subject entered the study).

h. Measurements for a compression garment were taken.

Assessment of the subject's bandwidth, via their internet provider or 4G cellular access, was performed to ensure their computer system met the minimal requirements of the Versatile and Integrated System for Telerehabilitation (VISYTER) (Parmanto et al., 2010). VISYTER was the software platform utilized for the telerehabilitation component of the study. If the subject did not have sufficient bandwidth via their internet provider or 4G access, a discussion was held regarding loaning of a laptop computer.

On the completion of the screening, if all criteria for inclusion into the study were met, the subject was given a copy of the study's informed consent form to review. The potential subject was asked to sign a medical information release form. This form was sent to the subject's primary care physician for verification of the subject's self-reported medical history. Upon the physician's verification that the subject had none of the exclusion criteria, the subject was considered eligible to participate in the study.

Telephone contact was made with the subject concerning their eligibility. Information was provided about the assessments, telerehabilitation intervention, length of the study, follow-up procedure, and compensation. If the subject confirmed his/her willingness to participate, the subject was scheduled for their initial assessment. See Figure 4.0.

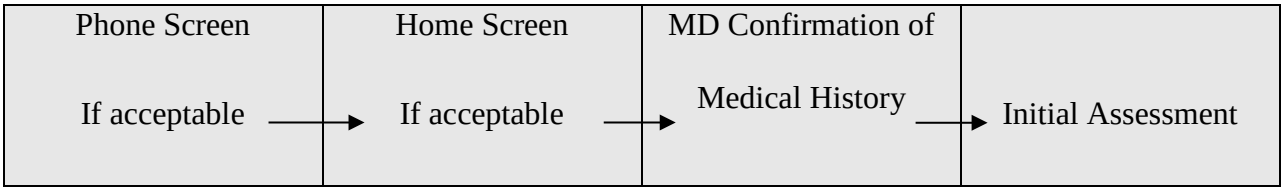


Figure 3. Screening Protocol

4.1.5 Implementation of Educational Protocol by TR

TR-PUMPS was implemented utilizing the Versatile and Integrated System for Telerehabilitation (VISYTER) software platform. VISYTER was developed by the Rehabilitation Engineering and Research Center on Telerehabilitation, School of Health and Rehabilitation Sciences, of the University of Pittsburgh, with funding provided by the National Institute for Disability and Rehabilitation Research. VISYTER is a secure system that provides users the ability for real-time teleconferencing with remote camera control, sharing of educational videos through Microsoft Windows Media Player and the ability to archive teleconferencing sessions and still images (Parmanto, et al., 2010). VISYTER has been demonstrated to be effective conducting remote face-to-face evaluations (Schein, Schmeler, Holm, Saptono & Brienza, 2010). VISYTER is a secure system that provides users the ability for real-time teleconferencing with multiple remote camera control, sharing of educational videos through Microsoft Windows Media Player and the ability to archive teleconferencing sessions and still images (Parmanto et al., 2010). Minimum computer requirements for VISYTER include "Pentium Dual Core processor 2 GHz with 2 GB of RAM and an NVIDIA GeForce 4 Series graphic card" (HARINFO, n.d.). VISYTER requires an internet connection with an upstream and downstream speed of approximately 1.5 Mbps for medium quality video.

The use of the VISYTER system involves first downloading the software onto a subject's home computer. Subjects were provided with a Clear One CHAT 60 speakerphone (ClearOne, Salt Lake City, UT). If no built in webcam was available, a Logitech HD C910 web cam (Logitech, Fremont, CA) was used for face-to-face videoconferencing. A second camera, the Logitech Orbit AF (Logitech, Fremont, CA), was also connected to the subject's computer for

use in skin and skill assessments. The Logitech Orbit AF provides clinicians with the ability to remotely control the camera's movement and zoom capabilities. The clinician at the remote computer site used a Logitech HD C910 web cam and a Logitech USB headset.

A personal user ID and password were assigned to the subject to enable them to log on to VISYTER. Each subject was assigned his or her own virtual clinic room. VISYTER's virtual clinic rooms, which are housed on the server, can only be accessed by authorized users. An assigned room administrator determined users' access and specific access capabilities that varied depending upon their role (Parmanto, et al., 2010). Training was provided to the subject on how to use the VISYTER software to connect to the remote clinician.

The VISYTER software was downloaded onto the subject's home computer. The subject was provided with remote cameras and a speaker to use during their six week TR intervention. A personal user ID and password was assigned to each subject to enable them to log on to VISYTER.

The subject and clinician connected to a VISYTER virtual clinic room in the Lymphedema Venue for their teleconferencing session. To assure privacy, the subject and investigators were the only people able to access the virtual clinic room that had been assigned to the subject for their six week intervention. During the initial session, each subject was asked to identify five specific occupational performance goals relating to the management of their chronic swelling/lymphedema using the Canadian Occupational Performance Measurement (COPM). A plan of action was developed in a collaborative effort by the subject and clinician. This evaluation included assessment of learning needs related to TR-PUMPS and potential barriers that could negatively affect ability to perform the self-management program.

Real-time videoconferencing occurred a minimum of one time per week for six weeks. The decision for the frequency of videoconferencing was a result of an agreement between the subject and the clinician, based on the subject's educational needs and availability. During videoconferencing, education was provided on management of chronic swelling of the lower extremities using the 10-step educational program. Educational videos were reviewed with the subject using the media sharing capabilities of the VISYTER software. The subject's comprehension and retention of the educational material provided by the program was evaluated by the subject performing return demonstrations and verbal recall. At the completion of the study periods, an evaluation of the subject's competency in each of the ten steps of the chronic swelling self-management program was documented utilizing the Competence in Self-Care & Self-Management (CSCSM). All video conferencing was archived for future evaluation. Once the study protocols was completed, the subject's access to VISYTER was deactivated. See Figure 4 and 5.

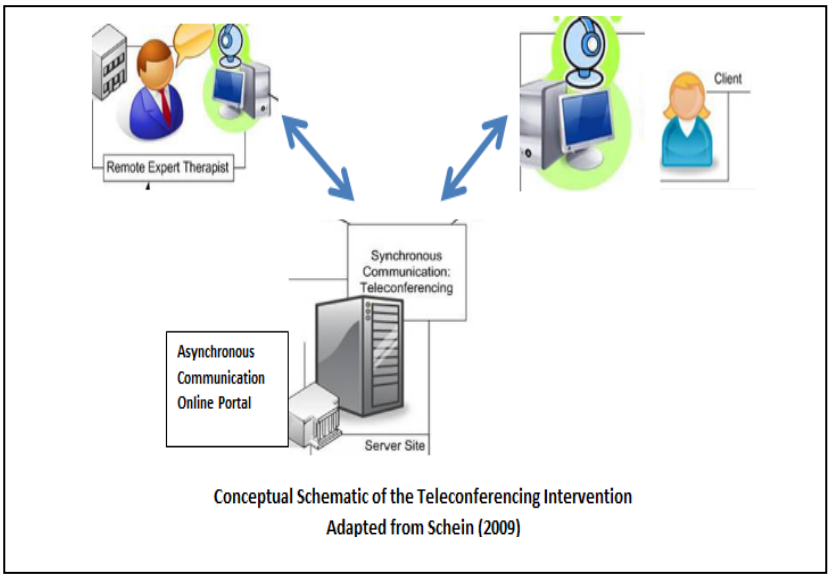


Figure 4. Conceptual Schematic of Teleconferencing Intervention

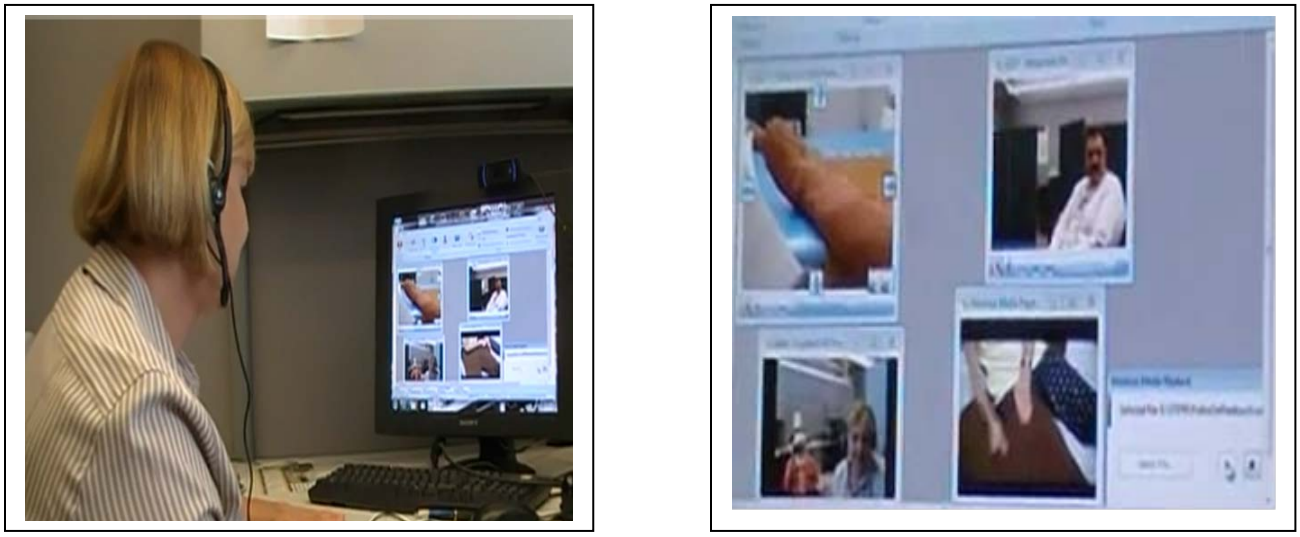


Figure 5. Simulated telerehabilitation session
Remote clinician (**left)**. Simulated telerehabilitation session (**right).** The **right panel, top left**, shows an image from video camera with remote control capabilities used for assessment; the **right panel, top right**, shows an image of a face-to face intervention; the **right panel, bottom left**, shows an image of what the participant observes from their camera; the **right panel, bottom right**, shows educational video used for client education

4.1.6 Assessment protocol

A battery of instruments were used to evaluate the effectiveness of the TR-PUMPS (see Table 2). These instruments had been shown to influence and predict the success of self-management educational programs and/or telehealth interventions or were developed to assess specific aspects of TR-PUMPS when no validated instruments were available.

4.1.6.1 Brief Test for Functional Health Literacy in Adults (Brief-TOFHLA)

The Brief-TOFHLA was administered at the time of the initial assessment to assess health literacy. The Brief-TOFHLA is a widely used, valid and reliable predictor of numeracy and

reading comprehension (Friedman & Hoffman-Goetz, 2006; DeWalt, et al., 2004). The Brief - TOFHLA utilizes a modified cloze method. The test consists of two reading passages where every 5th to 7th word is deleted and the subject was given a list of four words and asked to select the correct missing word. The first passage is about preparing for an upper GI series and written at a 4.3 grade level. The second passage is about the patient's rights and responsibilities when applying for Medicare and is written at a 10.4 grade level (Baker, Williams, Parker Gazmararian & Nruss, 1999). The reading grade levels for the two sections of the Brief-TOFLHA are calculated using the Gunning FOG Index. Subjects are given 7 minutes to complete the reading portion of the test. The numeric portion of the test is used to assess quantitative health literacy. It consists of 4 questions which the investigator presents verbally to the subject along with medicine bottles to read or cue cards (Baker, et al., 1999).

The maximum time allowed for the completion is 12 minutes. Questions are weighted to equal a total score of 100. The 36 cloze items are worth 2 points each and the 4 numeric questions are worth 7 points each. The test rates the subject's functional health literacy at one of three levels: inadequate (0-53), marginal (54-66) and adequate (67-100) (Baker, et al., 1999). In a study by Baker et al. (1999), 211 subjects completed both the Brief-TOFHLA and Rapid Estimate of Adult Literacy in Medicine (REALM). Using the Spearman's Rank Correlation, there was a 0.80 correlation between the Brief-TOFHLA and the REALM. Reliability analysis was performed using the Cronbach alpha reliability coefficient. The value for the Brief-TOFHLA reading portion was 0.97 and for the numeric portion 0.61 (Baker, et al., 1999).

4.1.6.2 Information Technology (IT) Familiarity Questionnaire

The IT Familiarity Questionnaire (Geyer, 2011) was utilized to evaluate the subjects' familiarity with Information Technology. This questionnaire was developed by a study investigator as no relevant validated tool could be located that was appropriate for use in this study. This tool consists of eight questions in a Likert scale format. The survey was administered to researchers in telerehabilitation and was found to have face validity.

4.1.6.3 Self-Efficacy for Managing Chronic Disease 6-Item Scale

Subjects perceived self-efficacy in managing their chronic edema/lymphedema was evaluated utilizing the Self-Efficacy for Managing Chronic Disease 6-Item Scale which was developed by Stanford University, Patient Education Research Center. It is composed of six questions that evolve around the subject's confidence in management of their chronic disease. The questions are rated on a Visual Analog Scale (VAS) of 1-10; higher numbers indicate a greater confidence level in the subject's management of their chronic disease. The total achievable score ranges from 6 to 60 and is determined by averaging scores for the 6 questions. The Self-Efficacy for Managing Chronic Disease 6-Item Scale (SE-6-Item) was evaluated in a study comprised of 605 subjects who had a chronic illness. Results demonstrated a mean score of 5.17 (SD 2.22). Internal reliability of the questionnaire was 0.91 (Stanford Patient Education Research Center n.d.; Lorig, Sobel, Ritter, Laurent & Hobbs, 2001).

4.1.6.4 Canadian Occupational Performance Measurement (COPM)

Subjects' occupational goals were determined using the Canadian Occupational Performance Measure (COPM), a standardized client centered outcome measure that was developed in a

collaborative effort by the Canadian Association of Occupational Therapists and the Canadian Department of National Health and Welfare. The COPM is formatted as a semi-structured interview between the therapist and the client or caregiver and focuses on the occupational domains of self-care, productivity and leisure.

The COPM is delivered as a four step process. The initial step involves identification of problems in performance in three occupational domains. Once these problems have been identified, the subject weighs the importance of each problem in regard to his/her life and is asked to identify the five most important problems from their personal perspective. The subject is next asked to rate his/her performance and satisfaction with performance in regard to each of these problems (Pollock, 1992). These scores are used as baseline scores prior to the initiation of the intervention and the intervention is tailored to address the five problems identified by the subject. Upon completion of the intervention, the subject again evaluates his/her performance and satisfaction with performance in the five identified problem areas. The change in pre and post intervention scores was utilized to evaluate the effectiveness of the intervention (Law, et al., 2005; Pollock, 1992).

The COPM is a validated measurement of occupational performance (Law et. al, 2005; Cup, Scholte, op Reimer, Thijssen & Kuyk-Minis, 2003) that has been shown to be a clinically useful and responsive measurement (Herman, Herzog, Jordan, Hofnerr & Levine, 2010; Eyssen, 2010) effective in identifying patient specific goals (Eyssen, 2010). The test retest reliability of the COPM is 0.89 for the performance scores and 0.88 for the satisfaction scores (Cup. et al. 2003). The reported minimal important difference (MID) for the COPM is a score change of 2.0 (Law et al., 2005). The COPM has been successfully utilized as a measurement of occupational

performance for different medical conditions including chronic edema and lymphedema (Hermann, et al., 2010; Knygsdand-Roenhoej & Maribo, 2011; Radlinger & Moulis, nd) and can be administered remotely via teleconferencing (Dryer, Dreyer, Shaw & Wittman, 2001).

4.1.6.5 Knowledge Test for Prevention and Care of Chronic Swelling

The Knowledge Test for Prevention and Care of Chronic Swelling (KT) was used to evaluate subjects' knowledge relating to prevention and managing of chronic edema of their lower extremities. The written test, which consisted of 20 multiple choice questions, was developed by two study investigators for use in the present study as a search of literature did not locate an appropriate relevant validated tool that could be used for this purpose. Each question was worth one point for a total possible score of 20. The KT was given pre and post TR intervention.

4.1.6.6 Competence in Self-Care & Self-Management (CSCSM)

The CSCSM is a research tool that evaluates the skill and knowledge of the subject based on the 10 step self-management educational protocol. The subject is scored by the educator through return demonstration of skills and verbal feedback of knowledge. Each step receives a separate score based on the number of skills in the step. The total possible score is 126 points. This questionnaire was developed study by two investigators (BF,MJG) as no relevant validated tool could be located that was appropriate for use in this study. Interrater reliability was established for the use of this tool. The study educator and two experienced certified lymphedema therapists viewed standardized videos of a subject performing each of the 10 Steps and scored the subject accordingly. These scores were analyzed using the intraclass correlation coefficient (ICC). The

ICC average measure was .979 (95% CI of .955 - .990), p = .000 and the ICC of single measures was .958 (95% CI of .955 - 980), p = .000.

4.1.6.7 Telehealth Usability Questionnaire (TUQ)

The Telehealth Usability Questionaire (TUQ), developed by Bambang Parmanto (2011), consists of 21 questions designed to address six components of usability: usefulness, ease of use and learnability, interface quality, interaction quality, reliability and satisfaction. Subjects complete a Likert scale (1 = disagree to 7 = agree) to rate their perception of the usability of TR-PUMPS as a self-management educational protocol.

4.1.6.8 Self-Reported, Self-Management Behaviors

An online self-report was completed weekly by the subjects during the treatment and follow-up phase of the study. The report was a 14 item Likert scale (1 = always true to 5 = never true) used by the subjects to report their level of adherence to the 10-step Lymphedema Self-Management program. The subject was also asked to provide information regarding any health care visits or hospital admissions during the study time period. Subjects accessed the report via the TR-PUMPS lymphedema portal developed by the Rehabilitation Engineering Research Center on Telerehabilitation.

Table 2. TR-PUMPS Evaluation Measures

TOOL	DESCRIPTION	VALIDATION	RATIONALE FOR USE
Brief-Test of Functional Health Literacy in Adults (TOFHLA)	Widely used, valid and reliable predictor of numeracy and reading comprehension (Friedman & Hoffman-Goetz, 2006; DeWalt, Beckman, Sheridan, Lohr, & Pignine, 2004; Gazmararian et al., 2003). Scoring format : Reading Comprehension: 36 close items worth 2 points each Numeracy comprehension: 4 questions worth 7 points each Total possible score = 100	Reliability Analysis: Reading portion - Cronbach alpha- 0.97 Numerical portion - Cronbach alpha-0.61 portion (Baker, et al., 1999)	Used to assess health literacy as a barrier to success of a TR educational intervention
Information Technology (IT) Familiarity Questionnaire	Used to assess extent of prior use and familiarity with IT. Scoring format = 8 questions in a Likert format (1=daily use – 3=never used) Total score = mean of scores on the 8 questions	Researcher developed No relevant tool available Face validity	Used to assess IT familiarity as a barrier to success of a TR educational intervention and satisfaction with TR
Self-Efficacy for Managing Chronic Disease 6-Item Scale	Evaluates the subject's perceived self-efficacy in managing their chronic disease. Scoring format: 6 questions in a Likert format (1=not at all confident – 10=totally confident) Total score = mean of scores on the 6 questions	Evaluated in a study comprised of 605 subjects who had with a variety of chronic conditions. Results demonstrated a mean score of 5.17 (SD 2.22). Internal reliability of the questionnaire was 0.91 (Stanford Patient Education Research Center; Lorig et al., 2001)	Used to evaluate change in perceived self-efficacy in managing chronic disease.

Table 2. (continued)

Canadian Occupational Performance Measure (COPM)	Clinically useful and responsive measure successfully utilized as a measurement of occupational performance for different medical conditions including chronic edema and lymphedema [Eyssen et al., 2011; Hermann et al., 2010; Knygsdand-Roenhoeg & Maribo, 2011; Wressel, Eeg-Olosson, Marcusson & Henriksson, 2002) Formatted as a semi-structured interview between the therapist and client or caregiver, it focuses on the occupational domains of self-care, productivity and leisure. Subject identifies 5 performance goals he wishes to focus on during intervention. Subject rates performance and satisfaction in achieving goals in a Likert scale format (1=not able to do – 10=able to do extremely well). Performance and satisfaction scores of all goals are totaled and then divided by number of goals to achieve final performance and satisfaction scores	Spearman's rho correlation Performance-0.89 and Satisfaction-0.88 (Cup, et al., 2003; Law, et al., 2005) Shown to be effective in improving patient participation in rehabilitation process (Wressle, et al., 2002).	Used to evaluate performance and satisfaction of performance in regard to subject identified goals. Can be efficiently administered remotely via teleconferencing (Dreyer, et al., 2001)
Knowledge Test for Prevention and Care of Chronic Swelling	Used to evaluate subjects' knowledge relating to prevention and management of chronic swelling of their lower extremity. Scoring format: Written test composed of 20 multiple choice questions (four choices for each question) Each question worth 1 point Total possible score = 20	Researcher developed. No relevant tool available Face validity.	Used to assess subjects' knowledge on care and management of chronic swelling. Given pre and post TR intervention

Table 2. (continued)

Competence in Self-Care & Management (CSCSM)	Evaluation of the skill and knowledge of the subject based on the 10 step self-management educational component. Scored by the educator through return demonstration of skills and verbal feedback of knowledge. Each step receives a separate score based on number of skills in step. Total possible score is 126 points.	Researcher Developed No relevant validated tool available	Used to evaluate effectiveness of TR in regard to specific self-management skills.
Telehealth Usability Questionnaire (TUQ)	21 questions that address 6 factors of usability: usefulness; ease of use and learnability, interface quality, interaction quality; reliability; and satisfaction. Scoring format: Likert scale (1=disagree – 7=agree) Final score is mean score of 21 questions; total possible score = 7	Study in progress for validation No relevant validated tool available.	Evaluates satisfaction with TR
Self-Reported, Management Behaviors	Subject reports their level of adherence to the 10-step self-management program. Also asks for information on any health care visits or hospital admissions. Online self-report format: 14 item Likert scale on adherence to program (1=Always true – 5=never true) Four questions on healthcare utilization Yes/No –if yes explanation of why Four questions on compression garments Yes/No Additional comment section Completed weekly during the treatment and follow-up phase	Researcher Developed No relevant validated tool available. Face validity	Used to evaluate subject adherence to the self-management program Identifies potential barriers subject encounters Provides information on health care utilization

4.1.7 Data Collection

The data collection protocol for the study is shown in Table 3. The measurement intervals involved in the current study are designated by grey bars. The Brief-TOFHLA and IT Familiarly Questionnaire (IT) were administered once at the baseline assessment (T_1). The Self-Efficacy

for Managing Chronic Disease 6-Item Scale (SE 6-Item) and the Knowledge Test for Prevention and Care of Chronic Swelling (KT) were administered prior to and following the TR intervention (T_1 and T3). The TeleHealth Usability Questionnaire (TUQ) and the Competence in Self-Care & Self-Management (CSCSM) were completed at the end of the six week TR intervention. The Canadian Occupational Performance Measurement (COPM) was given during the initial and final teleconferencing encounter. Data regarding Self-Reported Management Behaviors were obtained weekly during the 6 week TR intervention.

Paper documentation generated from the subject's participation in the study was locked in a file cabinet located in the Telerehabilitaion Lab in the Department of Rehabilitation Science and Technology, SHRS, University of Pittsburgh. All video conferencing was recorded and archived in a secure server for educational purposes.

Table 3. Timeline for study assessments and outcome measures

Week	1	2	3	4	5	6	7	8	9	10
TR				TR-1	TR-2	TR-3	TR-4	TR-5	TR-6	
Testing	T1		T2							T3
	Brief TOFHLA			COPM					COPM	
	IT								CSCSM	
	SE-6 item									SE-6 Item
	KT									KT
										TUQ
			SRB							

Test abbreviations = Brief-TOFHLA = Brief Test of Functional Health Literacy for Adults; SE-6-item = Self-Efficacy for Managing Chronic Disease 6-item scale; KT = Knowledge Test for Prevention and Care of Chronic Swelling; COPM = Canadian Occupational Performance Measure; IT = Information Technology Familiarity Questionnaire; TUQ = Telehealth Usability Questionnaire; CSCSM = Competence in Self-Care and Self-Management; SRB = Self-Reported Self-Management Behaviors.

4.1.8 Sample Size

The sample size of the study was N = 11. This sample size was determined using a power analysis with the alpha level of 0.05, a power of 0.80. No effect size for the COPM was found in the literature search for the population targeted in this study. On a Likert scaled of 1-10, the effect size of the COPM in prior studies ranged from 0.93 to 2.4 for the COPM performance measurement and 0.95 to 2.52 for the *COPM* satisfaction measurement. Using these data, a power analysis was performed using the *G*Power* power analysis software program. Results of the analysis indicated a sample size of 4 – 11 subjects was needed to achieve a power of 0.80.

A post-hoc analysis using *the G* Power* power analysis software program was done to determine if power of 0.80 was reached with this study. With a sample size of N = 9, the effect size for the COPM performance measurement was calculated to be 1.97 and the COPM satisfaction measurement effect size was 1.90. Based on these effect sizes, a sample size of 5 was needed to achieve a power of 0.80 with an alpha of 0.05 for a Wilcoxon signed-rank test. The actual power achieved for this study using the COPM measurement was 0.999 for the COPM performance measurement and 0.998 for the COPM satisfaction measurement.

4.1.9 Statistical Analysis

Statistical analysis was performed utilizing SPSS Statistical Analysis Software-Version 20. A descriptive analysis of all variables of interest was performed to assess data accuracy; evaluate distributions; and describe participant characteristics. Analysis for normal distribution utilizing the Kolmogorov-Smirnov was performed on all variables. Variables were normally distributed

for pre and post intervention COPM performance and satisfaction, pre and post intervention SE 6-ITEM, CSCSM, KT pre-intervention, KT change score, IT Familiarity and age. All other variables did not have normal distribution. Table 3 presents Aims 2-5, related hypotheses and the method used for statistical analysis. Aim 1 related to development of the educational protocol and therefore did not involve statistical analysis. See Table 4.

Table 4. Statistical analysis

Primary Aim 2: To determine if TR-PUMPS changes subjects' perceived self-efficacy in self-management of their lower limb(s) chronic swelling as measured by the Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale (SE-6 item). • H_A: As a result of TR-PUMPS there will be a significant change in the subjects' pre and post intervention perceived self-efficacy in the prevention and management of their chronic swelling. • $H_{O:}$ As a result of TR-PUMPS there will be no significant change in the subjects' pre and post intervention perceived self-efficacy in the prevention and management of their chronic swelling.	Paired t-test
Primary Aim 3: To determine if TR-PUMPS changes the subjects' perception of their performance and satisfaction with their performance in achieving their self-identified occupational performance goals as measured by the Canadian Occupational Performance Measure (COPM). • H_A: As a result of TR-PUMPS there will be a significant change in the subjects' pre and post intervention perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling. • H_O: As a result of TR-PUMPS there will be no significant change in the subjects' pre and post intervention perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling.	Wilcoxon Signed Rank Test

Table 4. (continued)

Primary Aim 4. To evaluate the relationship between the subjects' competence in self-care and self-management of their chronic swelling (CSCSM), their perceived self-efficacy in management of their chronic swelling (SE-6 item) and their performance and satisfaction with their performance of self-identified occupational performance goals (COPM). • H_A: As a result of TR-PUMPS there will be a significant relationship in the subjects' performance and knowledge in the care and management of their chronic swelling, their perceived self-efficacy in managing their chronic swelling and their perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling. • H_O: As a result of TR-PUMPS there will be no significant relationship in subjects' performance and knowledge in the care and management of their chronic swelling, perceived self-efficacy in managing their chronic swelling and their perception of their performance and satisfaction with their performance in achieving self-identified occupational performance goals in the self-management of their chronic swelling.	Parametric: Pearson's correlation coefficient Non-parametric Spearman's correlation coefficient
Primary Aim 5: To evaluate subjects' perceived usability of the remote delivery of TR-PUMPS through real-time interactive education and evaluation sessions as measured by the Telehealth Usability Questionnaire (TUQ).	Descriptive
Secondary Aims A number of parameters will be evaluated to determine if they had a significant impact on the outcome measurements of COPM, SE-6 item, CSCSM, and Telehealth Usability. These included the subject's initial knowledge of self-management of lower limb chronic swelling and selected demographic (age, education level, health literacy level, information technology familiarity_ and medical condition (stage of lymphedema, and previous treatment for their chronic swelling) variables.	Parametric: Pearson's correlation coefficient Non-parametric Spearman's correlation coefficient

4.2 RESULTS

4.2.1 Demographics of population

Thirteen subjects were recruited for the study. One subject withdrew the second week of the intervention, stating that she was unable to don the advanced pneumatic compression device used in the study herself and did not have a caregiver available to assist her. The second subject withdrew prior to the beginning of the intervention stating it was due to personal issues and time constraint. Table 4 presents demographic and medical condition data for the 11 subjects who completed the intervention.

Table 5. Participants' demographic characteristics (N = 11).

Subject	Sex	Age	Yrs of Education	Diagnosis	Yrs of Swelling	Previous CDT	Lymph edema Stage	INFECTIONS	
								PAST YEAR	PAST 5 YEARS
1	F	63	12+	Spina Bifida	47	Y	3	2	6
4	F	48	12+	Lipo-lymphedema Lymphedmatardia	6	Y	3	1	1
5	M	51	12	SCI, C5-C7	2	N	2	0	0
6	F	62	12	Head injury age 3 Decrease neruo-muscular function right side of body	20	N	2	1	3
7	M	43	12+	Multiple Sclerosis	3	N	2	0	0
8	M	79	12+	Chronic Venous Insufficiency Infection	3	Y	2	0	1
9	F	52	12+	Multiple Sclerosis	2	N	2	0	0
10	F	36	12	Life-long swelling Familial	36	N	2	0	1
11	F	64	12+	Multiple Sclerosis	2	N	2	0	0
12	F	54	12+	Multiple Sclerosis	2	N	2	0	0
13	F	50	12	Multiple Sclerosis	7	N	2	0	0

The 11 subjects' mean age was 54.5 years (SD ± 11.9, median 52 years, range 36-79 years). The majority (72.7%) were female. All subjects reported having at least a high school education and over half (63.6%) reported having pursued education beyond the high school level. The educational level of the study's population is higher than reported statistics of only 88 % of people without disabilities and 75% of people with disabilities having completed a high school education (National Council on Disability, 2007).

The majority (45.5%) were diagnosed with multiple sclerosis and the remainder with various other health conditions. Although the mean duration of chronic swelling/lymphedema was 11.8 years, there was a large variability reflected in the median (3 years) and range (2-47 years) of time with this health condition. Although the majority (81.8%) of participants had Stage II lymphedema, only 3 had used CDT previously. Five subjects reported previous infections, although most reported few infections.

4.2.2 Evaluation of self-efficacy in self-management of chronic leg swelling (SE 6-Item)

Mean scores on the SE 6-Item were 7.00 ± 2.53, range 1.33 to 10.00, pre-intervention and 7.52 ± 1.87, range of 4.17 – 10 post intervention. There was a normal distribution of scores. When analyzed using a paired t-test, there was no significant treatment effect for perceived self-efficacy (p = .605). See Table 5 and Figure 6.

Table 6. Paired- t test analysis of SE 6-Item scores (N = 11)

Variable	Time Obtained	Mean ± SD	Range	df	p
SE-6-Item	Pre-intervention	7.00 ± 2.53	1.33 – 10.00	10	.605
	Post-intervention	7.52 ± 1.87	4.17 – 10.00		

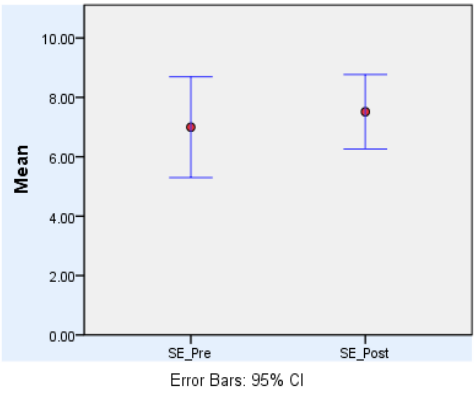


Figure 6. Error bar graph of pre and post intervention SE-6-Item scores

4.2.3 Evaluation of self-identified occupational goals (COPM)

Table 7 presents goals identified by the COPM instrument related to occupational domain, pre- and post-intervention performance scores, pre- and post-intervention satisfaction scores and the change score. The minimum important difference (MID) of this instrument is 2. Due to the fact that the COPM was introduced as a modification to the study, there were only nine subjects (subjects 5-13) that completed the COPM.

Table 7. Canadian Occupational Performance Measurement (COPM) scores

Subject	Goal	Occupational Domain	Pre COMP-P	Post COMP-P	Change Score COPM-P	Pre COMP-S	Post COPM-S	Change Score COPM-S
5	Improve ability in walking	Self-Care	5	5	0	3	3	0
	Improve with transfers out of bed	Self-Care	5	7	2	3	7	4
	Ability to go visit parents	Leisure	1	6	5	1	6	5
	Be able to wipe buttocks –standing stability	Self-Care	1	1	0	1	1	0
	Put on socks	Self-Care	1	7	6	1	7	6
	Mean Score of Goals		**2.6**	**5.2**	**2.6**	**1.8**	**4.8**	**3**
6	Prevent infections and keep swelling down.	Self-Care	8	10	2	4	10	6
	To be able to obtain and wear shoes	Self-Care	3	10	7	4	10	6
	To stay out of the hospital and ED	Self-Care	5	8	3	3	8	5
	To have foley catheter removed	Self-Care	3	7	4	1	7	6
	Obtain transportation so she could go shopping	Self-Care	1	10	9	1	10	9
	Mean Score of Goals		**4**	**9**	**5**	**2.4**	**9**	**6.6**
7	Prevent complications from swelling	Self-Care	4	8	4	3	8	5
	Improve in walking up steps	Self-Care	3	3	0	3	3	0
	Decrease overall fluid in body (body wt.)	Self-Care	4	6	2	3	6	3
	Decrease pain in legs	Self-Care	3	3	0	4	4	0
	Improve walking in community	Leisure	2	2	0	1	1	0
	Mean Score of Goals		**3.2**	**4.4**	**1.2**	**2.8**	**4.4**	**1.6**

Table 7. (continued)

8	Improve walking with cane	Self-Care	4	8	4	1	3	2
	More productive around home	Productivity	3	5	2	1	3	2
	Improve in mobility in sexual activity	Leisure	4	6	2	1	4	3
	Begin driving again	Self-Care	2	2	0	1	1	0
	Increase ability to play with grandchildren	Leisure	3	6	3	1	3	2
	Mean Score of Goals		**3.2**	**5.4**	**2.2**	**1.2**	**2.8**	**1.6**
9	Improve in walking	Self-Care	1	2	1	1	3	2
	Go back to work	Productivity	1	1	0	1	1	0
	Improve with transfers	Self-Care	3	4	1	1	5	4
	Begin to drive again	Self-Care	1	1	0	1	1	0
	Prevent complications from swelling	Self-Care	5	9	4	1	9	8
	Mean Score of Goals		**2.2**	**3.4**	**1.2**	**1**	**3.8**	**2.8**
10	Decrease/control pain in legs	Self-Care	4	8	4	2	8	6
	Increase ability to walk in community	Leisure	4	6	2	2	5	3
	Increase ability to stand to cook	Productivity	5	8	3	2	6	4
	Increase ability to shop	Self-Care	5	6	1	1	2	1
	Decrease pain in legs when driving long distance	Self-Care	5	8	3	2	5	3
	Mean Score of Goals		**4.6**	**7.2**	**2.6**	**1.8**	**5.2**	**3.4**

Table 7. (continued)

11	Prevent complications from leg swelling	Self-Care	3	8	5	3	8	5
	Decrease uncomfortable feeling in legs	Self-Care	3	8	5	3	8	5
	Improve appearance of legs	Self-Care	1	7	6	1	9	8
	Improve the fit on shoes	Self-Care	5	8	3	3	8	5
	Increase ability in walking	Self-Care	2	5	3	1	7	6
	Mean Score of Goals		**2.8**	**7.2**	**4.4**	**2.2**	**8**	**5.8**
12	Prevent complications from swelling	Self-Care	5	8	3	1	5	4
	Increase comfort in wearing shoes/socks	Self-Care	1	4	3	1	4	3
	Increase length of sitting without leg pain	Self-Care	2	4	2	1	4	3
	Improve appearance of legs	Self-Care	1	7	6	1	4	3
	Increase ability to do household chores	Productivity	1	6	5	1	5	4
	Mean Score of Goals		**2**	**5.8**	**3.8**	**1**	**4.4**	**3.4**
13	Increase ability to get out of bathtub	Self-Care	5	7	2	1	3	2
	Increase ability/comfort in wearing shoes	Self-Care	4	6	2	1	5	4
	Increase ability to walk up stairs	Self-Care	5	6	1	1	2	1
	Increase ability to walk to car	Self-Care	4	4	0	1	1	0
	Increase ability to take care of feet and legs	Self-Care	3	6	3	1	4	3
	Mean Score of Goals		**4.2**	**5.8**	**1.6**	**1**	**3**	**2**

Performance score: 1 = Not able to do - 10 = Able to do extremely well; Satisfaction score: 1= not satisfied at all – 10 = extremely satisfied. Definition of abbreviations: Pre COPM-P = Pre-intervention Performance, Post COPM-P = Post-intervention Performance, Pre COPM-S = Pre-Intervention Satisfaction, Post COPM-S = Post-Intervention Satisfaction
Minimum Important Difference: MID=2 (N=9)

The COPM rates performance and satisfaction goals on a Likert scale ranging from 1 = Not able to do it – 10 = Able to do it extremely well. Descriptive statistics showed that the median COPM performance pre-intervention score was 3.2, range 2.00 to 4.60, and median COPM performance post-intervention score was 5.8, range 3.40 to 9.00. For COPM satisfaction scores, the median pre-intervention was 1.80, range 1.00 to 2.80 and the post intervention median score was 4.40, range 2.80 to 9.00. All COPM scores had a normal distribution (See Table 6)

As the COPM used a Likert Scale for scoring, it produced ordinal data. This did not meet the assumption for parametric analysis, i.e., that data should be interval or ratio. The most appropriate statistical test was therefore judged to be the Wilcoxon signed-rank test. The Wilcoxon sign rank test result for COPM Performance score was Z = -2.670, p = .008 (two tailed) and the result for the COPM Satisfaction score was Z = -2.670, p = .008 (two tailed). Based on these results, the null hypothesis was rejected. See Table 8.

The difference between pre and post intervention median scores for the COPM Performance score was 2.6 and for the COPM Satisfaction score was 2.6. Both scores exceeded the reported minimal important difference (2.0) for this instrument. It should be noted, however, that 33% of the subjects did not achieve the MID score of 2.0 in COPM performance score and 22% did not achieve the MID in the COPM Satisfaction scores. A larger sample size may be indicated to evaluate the clinical significance of this intervention in regard to change in COPM.

Table 8. Pre and post intervention scores on the COPM (N=9)

COPM	Time Obtained	Median	Range	Z	p
Performance	Pre-intervention	3.20	2.00 – 4.60	-2.670	.008
	Post-intervention	5.80	3.40 – 9.00		
Satisfaction	Pre-intervention	1.80	1.00 – 2.80	-2.670	.008
	Post-intervention	4.40	2.80 – 9.00		

4.2.4 Evaluation of competence in self-care and self-management (CSCSM)

The CSCSM evaluated the subjects' skill and knowledge based on the 10 step self-management educational protocol. The CSCSM was added to the study as a modification once the study had started. Therefore only 10 subjects completed CSCSM. Scores were calculated by determining the percentage of correct items. Descriptive analysis showed a mean score of 94 $\pm$ 4%, range of 85% - 99%. CSCSM scores had a normal distribution. See Table 9.

Table 9. Competence in Self-Care & Self-Management (CSCSM) (N=10)

Subject	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Total	%
4	13/14	17/17	4/4	4/4	6/6	8/8	12/12	17/17	26/26	14/15	121/126	96
5	10/14	17/17	4/4	4/4	6/6	8/8	10/12	15/17	26/26	12/15	115/126	91
6	2/14	17/17	4/4	4/4	6/6	5/5	11/11	17/17	26/26	9/15	104/122	85
7	10/14	17/17	4/4	4/4	6/6	7/8	11/12	19/19	26/26	13/15	118/126	94
8	13/14	17/17	4/4	4/4	6/6	8/8	10/12	17/18	0/0	15/15	90/99	95
9	14/14	17/17	4/4	4/4	6/6	8/8	11/12	19/19	26/26	13/15	122/126	97
10	11/14	17/17	4/4	4/4	6/6	8/8	12/12	18/19	26/26	14/15	121/126	96
11	12/14	17/17	4/4	4/4	5/6	8/8	12/12	19/19	25/26	15/51	123/126	96
12	13/14	17/17	4/4	4/4	6/6	8/8	12/12	19/19	25/26	15/15	125/126	99
13	8/14	17/17	4/4	6/6	8/8	8/8	11/12	17/19	26/26	13/15	115/126	91

Interrater reliability was established for the CSCSM. Standardized videos of the 10 steps were viewed and the subject was scored by the study educator and two experienced certified lymphedema therapists These scores were analyzed using the intraclass correlation coefficient (ICC). The ICC average measure was .979 (95% CI of .955 - .990), p = .000 and the ICC of single measures was .958 (95% CI of .913 - .980), p = .000. See Table 10.

Table 10. Interclass Correlation of interrater reliability of Competence in Self Care and Self-Management (CSCSM)

	Interclass Correlation	95% Confidence Level	Significance
Single Measure	.958	.913 - .980	p = .000
Average Measure	.979	.955 - .990	p = .000

4.2.5 Evaluation of relationship between CSCSM, SE-6-ITEM, and COPM

Correlation analysis was performed using the Spearman's correlation coefficient to evaluate the relationship between the subjects' mean scores on the COPM, the SE-6 Item and CSCSM. The Spearman's correlation coefficient was judged to be the appropriate statistic due to the ordinal data from the COPM. This analysis indicated a significant positive correlation between COPM Performance change score and SE-6 Item post-intervention score (r_s = .706 p = .034). There were no other significant correlations.

Both the CSCSM and SE- 6 Item met the assumptions for parametric testing. Because parametric testing results in more power to detect differences, data were also analyzed using the Pearson's correlation coefficient. Results failed to show a significant correlation between mean score of the CSCSM and SE- 6 Item pre-intervention score (r = .487, p = .154) or the CSCSM

and SE-6 Item post-intervention score (r = -.279, p = .435). See table 10. The null hypothesis was accepted for all correlations with the COPM, CSCSM and SE 6- Item except for the correlation between the COPM Performance change score and SE-6 Item post-intervention score. See Table 11 and 12.

Table 11. Correlation analysis of COPM, SE-6 Item and CSCSM using Spearman's correlation coefficient

Variable	SE-6 Item Pre- Intervention	SE-6 Item Post-Intervention	CSCSM
COPM Performance Pre-Intervention	r_s = -.176 p = .651	r_s = -.285 p = .458	r_s = -.532 p =.141
COPM Performance Post-Intervention	r_s = -.353 p = .351	r_s = .336 p = .376	r_s = -.199 p = .607
COPM Performance Change Score	r_s = -.345 p = .364	r_s = .706 p = .034 *	r_s = -.102 p =.795
COPM Satisfaction Pre-intervention	r_s = -.315 p = .409	r_s = .519 p = .152	r_s = -.464 p = .209
COPM Satisfaction Post-intervention	r_s = -.594 p = .092	r_s = .561 p = .116	r_s = -.186 p = .632
COPM Satisfaction Change Score	r_s = -.504 p = .166	r_s = .513 p = .158	r_s = .038 p = .922

(N = 9)

Table 12. Correlation analysis of CSCSM and SE-6 Item using Pearson's correlation coefficient

Variable	SE-6 Item Pre-Intervention	SE- 6 Item Post-Intervention
CSCSM	r = .487 p = .154	r = -.279 p = .435

(N = 10)

4.2.6 Evaluation of telehealth usability

The Telehealth usability questionnaire (TUQ) evaluated the usability of telehealth using a Likert scale of 1 = disagree to 7 = agree. The TUQ consists of 21 questions that address six factors of usability: usefulness; ease of use and learnability, interface quality, interaction quality; reliability; and satisfaction. Descriptive analysis was completed for the total tool and each usability factor. The median score of the total TUQ was 6.67, range 4.90 – 7.00. TUQ factor scores can be seen in Table 11.

Table 13. Descriptive statistics for TUQ

Variable	Median	Range
TUQ Total Score	6.67	4.90 - 7.00
Usefulness	6.34	6.36 – 6.90
Ease of Use and Learnability	6.45	6.27 – 6.64
Interface Quality	6.59	6.45 – 6.64
Interaction Quality	6.68	6.45 – 6.91
Reliability	5.09	4.50 – 5.27
Satisfaction and Future Use	6.95	6.82 – 7.00

(N = 11)

4.2.7 Evaluation of Secondary Aims

A number of relationships were evaluated to determine if they had an impact on the outcome measurements of COPM, SE 6-Item, CSCSM, and TUQ. These included demographic characteristics (initial knowledge on self-management of lower limb chronic swelling, self-reported behaviors, age, education level, health literacy level, information technology familiarity) and medical condition (stage of lymphedema, and previous treatment for their chronic swelling) characteristics.

4.2.7.1 Relationship between IT Familiarity and TUQ

The IT Familiarity Questionnaire evaluates the subjects' familiarity using various types of IT technology on a Likert Scale of 1 = daily use for this activity – 3 = never use for this activity. The median score for IT Familiarity was 1.69, range 1.00 – 2.63. Correlation analysis was performed using the Spearman's correlation coefficient to evaluate the relationship between the subjects' IT Familiarity and their perception of telehealth usability determined from scores on the TUQ. The results of the analysis showed no significant correlation (r_s = -006, p = .987). See Table 14.

Table 14. Spearman's correlation coefficient analysis of IT Familiarity and TUQ Scores

Variable	Median	Range	r_s	p
IT Familiarity	1.69	1.00 – 2.63	-.006	.987
TUQ	6.67	4.90 – 7.00		

(N = 11)

4.2.7.2 Relationship between SE 6-Item scores to other variables

The relationship between the SE 6-Item and gender, education level, Brief-TOFHLA, IT familiarity, years of swelling, lymphedema stage and previous CDT use were analyzed using the Spearman's correlation coefficient. There was a significant negative correlation between the SE 6-Item pre-intervention mean score and previous use of CDT (r_s = -.681, p = .021). No other variables demonstrated a significant correlation to SE 6-Item scores. See Table 15.

Table 15. Spearman's correlation coefficient analysis for SE 6-Item to gender, education level, Brief-TOFHLA, IT Familiarity, years of swelling Lymphedema stage and previous CDT.

Variable	Gender	Education	Brief-TOFHLA	IT Familiarity	Years of Swelling	Lymphedema Stage	Previous CDT
SE 6-Item Pre-Intervention	r_s = .097 p = .776	r_s = .510 p = .109	r_s = -.080 p = .815	r_s = -.190 p = .575	r_s = -.016 p = .962	r_s = .449 p = .166	r_s = -.681 p = .021*
SE 6-Item Post-Intervention	r_s = -.065 p = .850	r_s = .179 p = .598	r_s = -.277 p = .409	r_s = .429 p = .188	r_s = -.005 p = .989	r_s = .373 p = .259	r_s = -.323 p = .333

(N = 11)

Both the SE 6-Item and age of the subjects had a normal distribution; therefore parametric correlation analysis was performed using the Pearson Correlation coefficient. There was no significant correlation between SE 6-Item scores and age of the subjects. See Table 16

Table 16. Pearson Correlation coefficient analysis of SE 6-Item and age

Variable	Age
SE 6-Item Pre-Intervention	$r = .333$ $p = .317$
SE 6-Item Post-Intervention	$r = .547$ $p = .082$

(N = 11)

Correlation analysis was done to evaluate the relationship between the results of the SE 6-Item and the KT (see Tables 15 and 16). The KT was added as a modification once the study had begun, therefore only 10 subjects completed the pre-post KT. The Pearson's correlation coefficient was used to analyze SE 6-Item and the KT pre-intervention and change scores. Due to the fact that the KT post-intervention scores did not have a normal distribution, the Spearman's correlation coefficient was used to analyze the correlation with the SE 6-Item. There was a significant positive correlation between the SE 6-Item pre-intervention scores and the KT mean change scores ($r = 678$, $p = .031$). There were no other significant correlations between the SE 6-Item and the KT. See Tables 17 and 18.

Table 17. Pearson correlation coefficient analysis of SE 6-Item and KT pre-intervention and KT change score

Variable	Knowledge Test Pre-Intervention	Knowledge Test Change Score
SE 6-Item Pre-Intervention	r = -.186 p = .607	r = .678 p = .031*
SE 6-Item Post-Intervention	r = .268 p = .455	r = -.124 p = .732

(N = 10)

Table 18. Spearman's correlation coefficient analysis of SE 6-Item and KT post intervention

Variable	Knowledge Test Post-Intervention
SE 6-Item Pre-Intervention	r_s = .302 p = .397
SE 6-Item Post-Intervention	r_s = -.044 p = .903

(N= 10)

4.2.7.3 Relationship between COPM scores to other variables

Correlation analysis was performed to evaluate the relationship of the COPM scores to age, education level, Brief-TOFHLA, IT Familiarity, gender, years of swelling, and KT using the Spearman's correlation coefficient. A significant positive correlation was seen between the COPM Performance pre-intervention score and years of swelling (r_s = .940, p = .000). There were no other significant correlations. See Tables 19 and 20.

Table 19. Spearman's correlation coefficient analysis of COPM to age, education level, Brief-TOFHLA and IT familiarity

Variable	Age	Education	Brief-TOFHLA	IT Familiarity
COPM Performance Pre-Intervention	r_s = -.377 p = .318	r_s = -.609 p = .082	r_s = -.127 p =.745	r_s = .156 p = .688
COPM Performance Post-Intervention	r_s = .202 p = .603	r_s = -.437 p = .240	r_s = -.039 p = .920	r_s = .403 p = .283
COPM Performance Change Score	r_s = .454 p = .220	r_s = -.262 p = .496	r_s = -.149 p =.702	r_s = .513 p = .158
COPM Satisfaction Pre-intervention	r_s = -.060 p = .879	r_s = -.088 p = .821	r_s = .004 p = .991	r_s = .000 p = 1.00
COPM Satisfaction Post-intervention	r_s = -.017 p = .966	r_s = -.348 p = .359	r_s = .035 p = .929	r_s = .278 p = .468
COPM Satisfaction Change Score	r_s = .218 p = .572	r_s = -.306 p = .424	r_s = -.013 p = .973	r_s = .339 p = .372

(N = 9)

Table 20. Spearman's correlation coefficient analysis of COPM and KT, swelling and previous CDT

Variable	Gender	Years of Swelling	Previous CDT	Knowledge Test Pre-Intervention	Knowledge Test Post-Intervention	Knowledge Test Change Score
COPM Performance Pre-Intervention	r_s = -.092 p = .815	r_s = .940 p = .000*	r_s = -.069 p = .860	r_s = -.393 p = .295	r_s = -.165 p = .672	r_s = .245 p = .526
COPM Performance Post-Intervention	r_s = -.552 p = .123	r_s = .503 p = .168	r_s = .138 p = .723	r_s = -.060 p = .878	r_s = -.035 p = .929	r_s = -.123 p = .753
COPM Performance Change Score	r_s = -.368 p = .330	r_s = .048 p = .901	r_s = .138 p = .723	r_s = .047 p = .904	r_s = -.104 p = .789	r_s = -.203 p = .600
COPM Satisfaction Pre-intervention	r_s = .326 p = .391	r_s = .272 p = .478	r_s = .140 p = .720	r_s = -.048 p = .903	r_s = .026 p = .946	r_s = -.172 p = .659
COPM Satisfaction Post-Intervention	r_s = -.321 p = .400	r_s = -.140 p = .718	r_s = .550 p = .125	r_s = -.009 p = .983	r_s = -.156 p = .689	r_s = -.456 p = .218
COPM Satisfaction Change Score	r_s = -.664 p = .061	r_s = .031 p = .937	r_s = .483 p = .188	r_s = .142 p = .716	r_s = -.191 p = .622	r_s = -.496 p = .175

(N = 9)

4.2.7.4 Relationship of CSCSM relationship to other variables

The relationship of CSCSM score was analyzed using Pearson's coefficient correlation for parametric measures and Spearman's correlation coefficient with nonparametric measures. There was a significant positive correlation between scores on the CSCSM and Brief-TOFHLA (r_s = .650, p = .026) and between the CSCSM score and educational level (r_s = .650, p = .042). There were no other significant correlations. See Tables 21. 22 and 23

Table 21. Spearman's correlation coefficient analysis of CSCSM to age, gender, Brief-TOFHLA, education level, years of swelling, lymphedema stage and previous CDT and KT post intervention

Variable	Gender	Brief-TOFHLA	Education	IT Familiarity	Years of Swelling	Lymphedema Stage	Previous CDT	KT Post
CSCSM	r_s = -.386 p = .271	r_s = .694 p = .026*	r_s = .650 p = .042*	r_s = -.492 p = .148	r_s = -.430 p = .215	r_s = .177 p = .625	r_s = -.088 p = .808	r_s = .528 p = .117

(N = 10)

Table 22. Pearson correlation coefficient analysis of CSCSM and age

Variable	Age
CSCSM	*r* = -.149 *p* = .681

(N = 10)

Table 23. Pearson correlation coefficient analysis of CSCSM to KT pre-intervention and KT change scores

Variable	Knowledge Test Pre-Intervention	Knowledge Test Change Score
CSCSM	*r* = .200 *p* = .580	*r* = .226 *p* = .531

(N = 10)

4.2.7.5 Knowledge Test on Care and Management of Chronic Swelling

The mean score of the Pre-intervention KT was 14.0 $\pm$ 3.3. The scores ranged from 8-18 and had a normal distribution. The Post-Intervention KT had a mean of 18.5 $\pm$ 2.0, median score 19, and a range of 14-20. The Post-Intervention KT score did not have a normal distribution. A Wilcoxon sign rank test was performed to evaluate treatment effect on the subjects' knowledge of care and management of chronic swelling. The results of the analysis showed a significant difference in the subjects' knowledge from pre to post intervention (Z = -2.456, *p* = .014).

4.2.7.6 Relationship between Brief-TOFHLA and Knowledge Test

The Brief-TOFHLA had a median score of 98 with a range of 39-100. The scores of the Brief-TOFHLA did not have a normal distribution. The Spearman's correlation coefficient was used for analysis for correlation. There was a significant positive correlation between the Brief-TOFHLA and the Knowledge Test post-intervention scores (r_s = .787 p = .007) See Table 24

Table 24. Spearman's correlation coefficient analysis for correlation between Brief TOFHLA and KT.

Variable	Knowledge Test Pre-Intervention	Knowledge Test Post-Intervention	Knowledge Test Change Score
Brief -TOFHLA	r_s = .073 p = .841	r_s = .787 p = .007*	r_s = -076 p = .835

4.2.7.7 Self-reported self-management behavior

Due to the limited adherence of subjects to the weekly self-reports, there was insufficient data for analyze.

5.0 DISCUSSION

A standardized self-management protocol was successfully developed for the self-management of chronic swelling of legs in people with limited mobility. The educational tools were validated for content and completeness. In an attempt to address health literacy disparities, the script for the educational tools was written at a 5^{th} grade level and had a superior suitability for the targeted population. Results showed a significant increase in the subjects' knowledge from pre to post intervention. The subjects were rated high in their Competence in Self-Care and Self-Management (CSCSM) of their chronic swelling with scores ranging from 85-99%.

Despite efforts to achieve a reading level that was easy to comprehend and therefore equivalent across participants, some differences remained. Results did however, show a positive correlation between health literacy level and the measure of CSCSM of chronic swelling of the legs (r_s = .694p = .026). There was also a positive correlation between education level and the CSCSM (r_s = .650, p = .042). Thus, participants with a higher health literacy score and educational level fared better in regard to the competency measurement.

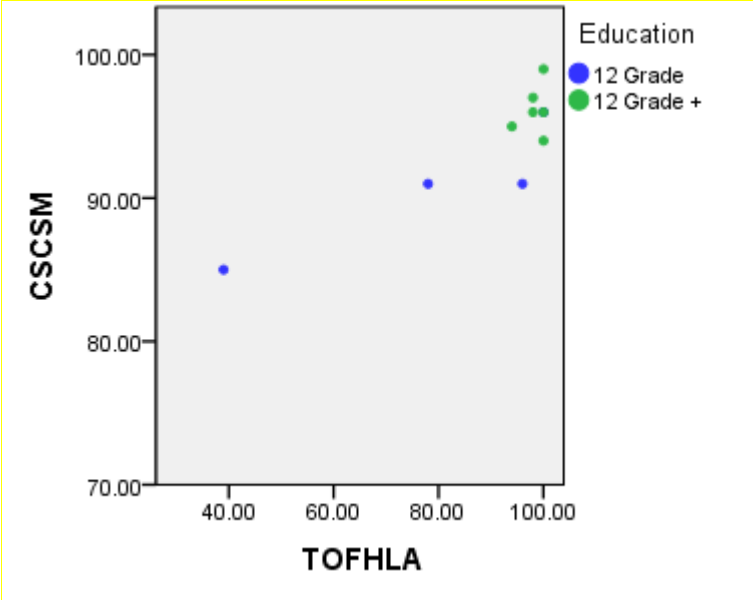


Figure 7. Correlation between CSCSM, TOFHLA and Education Level

Explanations for this finding likely relate to the small sample size and health literacy of participants. Of the 11 subjects, 10 subjects scored an adequate health literacy level on the Brief-TOFHLA. Only one subject received a score of inadequate health literacy. In part this score resulted from inability to complete the reading comprehension portion of the test within the allotted 7 minute time frame. The subject did state that she has difficulty reading, which would explain the low score she received on the written knowledge test. In regard to her score on the CSCSM tool, the low score primarily resulted from Step 1 of the 10 step self-management protocol. This step involved knowledge on basic pathophysiology of lymphedema. Her score was 2/14 compared to the other subjects whose scores that ranged from 8-14. During the TR sessions she was able to successfully instruct her caregiver on the appropriate way to perform skin hygiene, skin assessments, application of compression garments and minor wound care. As a result of these findings, an evaluation of the content and delivery of Step 1 of the self-management protocol should be considered with possible revisions that would better facilitate

comprehension of the pertinent educational material provided in the step. Conversely, it may not be possible to write text for this step of the protocol in manner that is easily understood by all participants given variability in education, reading speed and health literacy.

TR-PUMPS was hypothesized to significantly change the subjects' perceived self-efficacy in the prevention and management of their chronic swelling. Findings indicated no statistically significant difference between pre- and post-intervention SE-6-Item scores ($p = .605$). Therefore, the hypothesized change did not occur. These finding contrasts with previous studies that showed that self-management programs increase self-efficacy (Lorig, et al., 2001; Chodosh, et. al, 2005; Lorig, er al., 2006; DeWalt, et al, 2004).

There are several possible explanations for the small effect size of the SE 6-Item. First participants were provided with a large amount of educational information in regard to self–management of their chronic swelling within a relatively short period a time. Participants also had to make significant life-style changes including learning use of the pneumatic compression device and compression garments. These changes required learning new skills and reorganizing their day to make time for this therapy. To some, this may have been overwhelming particularly if they did not have previous experience with this modality and were not aware of the skills and time, self-management of their swollen legs encompassed. One participant related during her last video session, stating that while she was really confused at first, everything was starting to make sense. Her pre and post intervention self-efficacy scores reflected this statement as her SE 6-Item score decreased from 8/10 pre-intervention to a 4.7/10 post intervention, reflecting a decrease in self-efficacy.

To decrease this overwhelming feeling experts in the development of self-management programs suggest that education of a new skill be broken down to small steps that are reinforced until the patient becomes proficient before moving on to the next step. This approach has been found to increase patient's perceived self-efficacy in completing the skill (Lorig, 2001). Due to time constraints in their daily lives, the majority of the subjects wanted longer, less frequent sessions rather than the actual schedule with sessions that lasted between 1-1 ½ hours. Shorter, more frequent sessions may help to prevent feeling overwhelmed and increase perceived self-efficacy.

A second factor likely related to the small sample size and variability in pre and post intervention scores. The SE 6-Item utilized a Likert scale with a range of 1-10 as its measurement for self-efficacy. Participants mean pre- (7.00 $\pm$ of 2.53) and post-intervention (7.52 $\pm$ 1.87) scores were essentially equivalent but also included a large variance in range. There was also a large difference in age (36-79 years), time that participants had chronic swelling/lymphedema (2-47 years) and prior experience with CDT (3 yes; remainder no). A post-hoc analysis using *the G* Power* power analysis software program was done to determine if power of 0.80 was reached with this study in regards to the SE 6-Item. The effect size of the SE 6-Item was small (.16) resulting in a power of only .13 with 11 subjects. To reach a power of .80, sample size was calculated at 241. Therefore, there was an 87% chance of a Type II error occurring. In future studies, it would be beneficial to attempt to recruit a larger, more homogenous population.

A third factor may be a ceiling effect with this outcome tool. Two of the eleven subjects' pre-intervention SE-6-Item scores were 10, preventing any improvement. Both of these subject's

post-intervention score was lower than their pre-intervention score, suggesting that they may have overestimated their competency. Lack of initial knowledge by subjects who had no previous CDT on what was involved to manage their chronic swelling could also be responsible for high pre-intervention scores. Once they began the intervention, they may have realized how much they did not know in regards to the care of their chronic swelling, resulting in a lower post-intervention score. This could explain why there was a negative correlation with pre-intervention SE 6-Item and people who had previous CDT.

High pre-intervention self-efficacy scores could also be due to the fact that the study population used a single group design and recruited a convenience sample. People with higher self-efficacy levels are more confident in setting high goals and overcoming adversity (Bandura, 1991). Having high self-efficacy levels could have been a reason these prompted these participants to seek out and agree to participate in a study focused on self-management of chronic swelling.

During completion of this instrument, it appeared that several subjects had difficulty relating the questions of this generalized self-efficacy measure to their chronic condition which involved swelling in their legs. A generalized tool was chosen to be used for this study because no validated self-efficacy tool specific for lower extremity chronic swelling could be found. A solution to this would be the development and validation of a self-efficacy measurement that focuses on the self-management of chronic swelling.

TR-PUMPS was hypothesized to change the participants' perception of their performance and satisfaction with their performance in achieving their self-identified occupational performance goals in the self-management of their chronic swelling. COPM performance and

satisfaction scores improved significantly and were greater than the documented Minimal Importance Difference (MID) of 2.0 for the COPM. While both scores exceeded the reported MID for this instrument, it should be noted that a substantial minority did not achieve the MID score for performance (33%) or satisfaction (22%). A larger sample size may be indicated to fully evaluate the clinical significance of this intervention. The effect size of both the COPM Performance measurement and the COPM Satisfaction measurement were large; 1.97 and 1.90 respectively. These results support results of previous studies that found the COPM to be a clinically useful and responsive measurement (Herman, et al., 2010; Eyssen, 2010).

As previously, one of the reasons for this outcome may relate to the sample which varied greatly in regard to demographic and medical condition characteristics. Attempting to recruit a sample with more restrictive entry may help to address this problem. However, this may prove difficult as individuals diagnosed with this health condition vary greatly in their medical condition. The study did not include exclusion criteria related to the underlying diagnoses resulting in limited mobility, degree of mobility limitation, length of swelling or stage of lymphedema.

The majority of the participants needed caregivers to assist in some of the self-management tasks. The degree of caregiver engagement in the self-management care may have influenced the ability of subjects to change health behaviors that would promote success in the management of their chronic swelling. One participant stated that she is “at their mercy” when she discussed meal preparation and skin hygiene. Barriers seen in the delivery of TR-PUMPS when caregivers were involved included time constraints for teleconferencing due to caregivers’ availability and the need to educate multiple caregivers. One solution that addressed multiple

caregivers was the education of subjects in the instruction of caregivers on the 10 step educational protocol.

Income also affected subjects in getting necessary equipment to assist them in ADLs and IADLS. One participant stated that her minimal income resulted in the use of a food bank, thus limiting her ability to avoid processed and canned foods that are high in sodium, an essential component of the self-management protocol. Transportation issues have also been a barrier that has affected subjects in achieving their self-identified occupational goals. This varied greatly among the subjects depending on the degree of their mobility limitation, the type wheeled mobility device they used and whether they were dependent on public transportation.

A positive aspect of this diversity is that it increased the external validity of this study. External validity involves the generalization of research so that the study results can be used to predict results in the general population. Limited mobility affects a diverse population of people who have varying disease processes, degrees of mobility limitations, support systems and income. By diversifying the study population, the study gained increased potential to adequately evaluate how this education protocol can be effectively used by people with mobility limitations in the general population.

TR-PUMPS was hypothesized to result in a significant relationship between scores on the CSCSM, SE 6-Item and COPM. The CSCSM score was derived from the percentage of correct item scores applicable to management of their chronic swelling. Use of a percentage was chosen over a total score since items did not apply to each subject. When evaluating the relationship between the CSCMS and the SE 6-Item pre and post-intervention scores, there was no significant positive correlation between them. CSCSM scores reflected the subject's knowledge and skill level in performing the health behaviors related to the successful self-management of their

chronic swelling. The higher the score of the CSCSM, the more knowledgeable and efficient the subject was in the self-management skills. Performance accomplishments have been shown to be an effective way to increase perceived self-efficacy (Lorig, 2001); therefore it was assumed that a higher CSCSM score would correlate with a higher self-efficacy level.

Results of this study showed a small but not significant negative correlation between the CSCSM and SE 6-Item score (r = -279, p = .435), which indicates an opposite effect. These results do not support previous studies that have showed high self-efficacy scores correlate with improved health behaviors (Jenkins & Gortner, 1998; Finlayson, Edwards & Courtney, 2011; Strecher et al., 1096) or as stated before, that self-management programs increase self-efficacy (Lorig, et al., 2001; Chodosh, et. al, 2005; Lorig et al, 2006, DeWalt, et al, 2004). These results may reflect the previous issues discussed about the responsiveness of the self-efficacy tool and delivery of the educational protocol in regard to frequency and length of sessions.

Correlation analysis between the COPM and SE 6-Item resulted in a significant positive correlation between the COPM performance change scores and the post-intervention SE-6-Item scores (r_s = .706 p = .034). There were no other significant correlations between the COPM performance scores and SE 6-Item score or the COPM satisfaction score and the SE 6-Item. Self-management focuses on patient-centered care and the COPM is a tool that is utilized to facilitate that approach. Traditionally patient education has been defined by what the clinician feels is important for the patient to learn to succeed in the management of health care. This approach is based on the clinician being the teacher and the patient being the student. In self-management education, the goal is for the patient to be responsible for making decisions in regard to their health, identifying their own goals and actively collaborating with health care professionals in regard to the treatment and management of their health care. For this reason, the COPM was

chosen as an outcome as it requires patients to make decisions about goal setting for their health care. The results of the significant correlation between the COPM performance change scores and patient's self-efficacy of the management of their chronic conditions supports previous studies that have shown that use of the COPM improves patients' perception of their ability to manage their own care (Wressle, Eeg, Marcusson & Henriksson, 2002).

The study did not find a significant relationship between CSCSM scores and COPM performance change scores or satisfaction change scores. Self-management education involves more than learning about one's health condition and having the skills to manage this condition. It involves having patients identify their own specific goals in regard to managing and living with their chronic condition. For example, one participant's occupational performance goal was to be able to go shopping. She had not gone shopping for "years" due to the accessibility and high cost of transportation. Part of self-management education is to help patients identify and use community services. When this subject was provided contact information for the local paratransit service, she initiated communications and was able to find transportation for only $1.75. She was then able to go shopping with her daughter. Her performance score for this goal went from a pre-intervention score of 1 to a post-intervention score of 10. While accomplishing this goal increased her perception of her quality of life, it was not something that could be scored on a tool such as the CSCSM. In regard to the third hypothesis for this study, the null hypothesis was accepted in regards to finding a relationship between the COPM and the CSCSM and rejected in regard to a relationship between the COPM performance change and the SE 6-Item post intervention score.

An aim of this study was to evaluate the subjects' perceived usability of the remote delivery of TR-PUMPS through real-time interactive education and evaluation sessions as

measured by the Telehealth Usability Questionnaire (TUQ). The TUQ evaluated the usability of telehealth using a Likert scale of 1 = disagree to 7 = agree was used to evaluate the TR intervention using the VISYTER software platform. Descriptive analysis was performed on the subjects' scores of the TUQ. The mean score of the TUQ was 6.4155 (± 0.64374). The range of the scores was 4.90 – 7 9. The TUQ covers six usability factors: 1) usefulness, 2) ease of use and learnability, 3) interface quality, 4) interaction quality, 5) reliability and 6) satisfaction and future use.

The mean score and ranges for each factor were:

- Usefulness: Mean score was 6.67, range from 6.36 – 6.90.
- Ease of Use and Learnability: Median score was 6.34, range from 6.27- 6.64
- Interface quality: Median score was 6.45, range from 6.45 – 6.64.
- Interface Quality: Median score was 6.59, range from 6.45 – 6.64
- Reliability: Median score was 5.09 ,range from 4.50 – 5.27
- Satisfaction and Future Use: The mean score was 6.95, range from 6.82 – 7.0

The results of the TUQ indicated that the subjects' perception of the delivery of TR with real-time face to face interactive education and evaluation sessions using the VISYTER software platform was an acceptable way to receive self-management education. The lower score on the reliability likely relates to issues with connection and equipment that occurred during the sessions. The majority of the issues were handled either by the teleconferencing or by telephone and only three trips to the subjects' homes were necessary during the study. One trip was to reinstall VISYTER and the other two trips were due to the need to replace damaged remote

camera. Damage from the cameras occurred when they fell on the ground. While minor, these issues likely resulted in a lower rating for reliability.

A number of relationships were evaluated to see if they had a significant impact on the outcome measurements of COPM, SE 6-Item, CSCSM, and Telehealth Usability. These included initial knowledge on self-management of lower limb chronic swelling, self-reported behaviors, the subjects' age, education level, health literacy level, information technology familiarity, stage of lymphedema, and previous treatment for their chronic swelling. Correlation analysis to evaluate the relationship between the subjects' IT Familiarity and there perception of Telehealth Usability showed no significant correlation. This score may have been the result of unsuccessful traditional therapy. SE 6-Item pre-intervention scores had a positive correlation with knowledge test change scores. Higher self-efficacy scores have been related to better outcomes (Finlayson et al., 2011; Jenkins & Gotner, 1998). In regard to the COPM, there was a significant positive correlation in the COPM pre-intervention scores and years of swelling. Increase in the subjects' perception of their ability in their performance, particularly in the occupational domain of self-care, may be the result of previous treatment and the knowledge and skills they received from the previous treatment. Nevertheless, these results must be interpreted cautiously due to the number of analyses performed.

There were several limitations to this study. First, it was a single cohort study with no control group. Second, the study had a small sample size. A larger sample size may have decreased the variability and increased the effect size of variables such as the SE 6-Item. A third limitation is that the sample population was a convenience sample that may not be a true representation of the population being studied.

6.0 CONCLUSION

The evidence-based educational materials developed as part of the self-management program for lower limb chronic swelling/lymphedema in persons with limited mobility were found to be valid, accurate and complete with high ratings of clarity. The readability and suitability ratings indicated that the materials were appropriate for the level of health literacy in the study population. The self-management program described may be applicable to address to problems experienced by persons with other chronic conditions such as diabetes, heart failure and chronic obstruction pulmonary disease.

Results of the effectiveness of TR-PUMPS was demonstrated by the high scores on the subjects' skill and knowledge based on the 10 step self-management educational protocol (94% $\pm$ 4%, range of 85% - 99%) and the significant increase in the subjects' pre and post knowledge test (p = .014). Subject's self-identified operational performance goals (COPM) increased significantly in both their perceived performance of the goals and the satisfaction with the performance (p = .008). COPM performance score was 2.6 and for the COPM satisfaction score was 2.6. Both scores exceeded the reported minimal important difference (2.0) for this instrument. There was however on significant change in the subjects' self-efficiency scores on the management of their chronic swelling (p = .605).

The program was well received by subjects, addressing barriers associated with traditional care such as transportation and access to specialists. The results of the TUQ indicated that the subjects' perception of the delivery of TR with real-time face to face interactive education and evaluation sessions using the VISYTER software platform was an acceptable way to receive self-management education. The ability to observe subjects in their home environment enabled the team to assess and address potential physical barriers that could negatively affect the subjects' care and more quickly respond to potential problems before they become major challenges. This study supports telerehabilitation as we believe TR-PUMPS is a viable method of providing a home based self-management program on lower limb chronic swelling/lymphedema in people with mobility limitations and a means to decrease the burden associated with lifelong management of this debilitating condition.

APPENDIX A

BRIEF TEST OF FUNCTIONAL HEALTH LITERACY IN ADULTS

Short Test of Functional Literacy in Adults
STOFHLA
READING COMPREHENSION

HAND PATIENT THE READING COMPREHENSION PASSAGES TO BE COMPLETED. FOLD BACK THE PAGE OPPOSITE THE TEXT SO THAT THE PATIENT SEES ONLY THE TEXT.

PREFACE THE READING COMPREHENSION EXERCISE WITH:

> "Here are some other medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear just below it. I want you to figure out which of those 4 words should go in the blank, which word makes the sentence make sense. When you think you know which one it is, circle the letter in front of that word, and go on to the next one. When you finish the page, turn the page and keep going until you finish all the pages."

STOP AT THE END OF 7 MINUTES

PASSAGE A: X-RAY PREPARATION

PASSAGE B: MEDICAID RIGHTS AND RESPONSIBILITIES

PASSAGE A

Your doctor has sent you to have a _____ X-ray.

a. stomach
b. diabetes
c. stitches
d. germs

You must have an _____ stomach when you come for _____.

a. asthma
b. empty
c. incest
d. anemia

a. is.
b. am.
c. if.
d. it.

The X-ray will _____ from 1 to 3 _____ to do.

a. take
b. view
c. talk
d. look

a. beds
b. brains
c. hours
d. diets

THE DAY BEFORE THE X-RAY.

For supper have only a _____ snack of fruit, _____ and jelly,

a. little
b. broth
c. attack
d. nausea

a. toes
b. throat
c. toast
d. thigh

with coffee or tea.

After _____ , you must not _____ or drink

a. minute,
b. midnight,
c. during,
d. before,

a. easy
b. ate
c. drank
d. eat

anything at _____ until after you have _____ the X-ray.

a. ill
b. all
c. each
d. any

a. are
b. has
c. had
d. was

THE DAY OF THE X-RAY.

Do not eat _____.

a. appointment.
b. walk-in.
c. breakfast.
d. clinic.

Do not _____, even _____.

a. drive,	a. heart.
b. drink,	b. breath.
c. dress,	c. water.
d. dose,	d. cancer.

If you have any _____, call the X-ray _____ at 616-4500.

a. answers,	a. Department
b. exercises,	b. Sprain
c. tracts,	c. Pharmacy
d. questions,	d. Toothache

PASSAGE B

I agree to give correct information to _____ if I can receive Medicaid.

a. hair
b. salt
c. see
d. ache

I _____ to provide the county information to _____ any

a. agree
b. probe
c. send
d. gain

a. hide
b. risk
c. discharge
d. prove

statements given in this _____ and hereby give permission to

a. emphysema
b. application
c. gallbladder
d. relationship

the _____ to get such proof. I _____ that for

a. inflammation
b. religion
c. iron
d. county

a. investigate
b. entertain
c. understand
d. establish

Medicaid I must report any _____ in my circumstances

a. changes
b. hormones
c. antacids
d. charges

within _____ (10) days of becoming _____ of the change.

a. three	a. award
b. one	b. aware
c. five	c. away
d. ten	d. await

I understand _____ if I DO NOT like the _____ made on my

a. thus	a. marital
b. this	b. occupation
c. that	c. adult
d. than	d. decision

case, I have the _____ to a fair hearing. I can _____ a

a. bright	a. request
b. left	b. refuse
c. wrong	c. fail
d. right	d. mend

hearing by writing or _____ the county where I applied.

a. counting
b. reading
c. calling
d. smelling

If you _____ TANF for any family _____ , you will have to

a. wash	a. member,
b. want	b. history,
c. cover	c. weight,
d. tape	d. seatbelt,

_____ a different application form. _____ , we will use

a. relax
b. break
c. inhale
d. sign

a. Since,
b. Whether,
c. However,
d. Because,

the _____ on this form to determine your _____ .

a. lung
b. date
c. meal
d. pelvic

a. hypoglycemia.
b. eligibility.
c. osteoporosis.
d. schizophrenia.

Subject: _____ **Date:** _____

Brief TOFHLA – Numeric Portion

"These are directions you or someone else might be given at the hospital. Please read each direction to yourself. Then I will ask you some questions about what it means."

Prompt 1:

If you take your first tablet at 7:00 am, when should you take the next one?

Correct _____ Wrong _____

And the next one after that?

Correct _____ Wrong _____

What about the last one of the day, when should you take it?

Correct _____ Wrong _____

Prompt 4:

If this were you score, would your blood sugar be normal today?

Correct_____ Wrong_____

Prompt 5:

When is your next appointment?

Correct_____ Wrong_____

Where should you go?

Correct_____ Wrong_____

Prompt 8:

If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, when should you take it?

Correct_____ Wrong_____

If you forget to take it before lunch, what time should you take it?

Correct_____ Wrong_____

IX. A Brief Test to Measure Functional Health Literacy

A third alternative exists for persons wishing to measure both reading comprehension and numeracy, but not wanting to give the full TOFHLA or the short TOFHLA (reading comprehension only). In such circumstances, you should use the full TOFHLA materials, but just administer reading comprehension passages A and B and four numeracy items (# 1, 4, 5, & 8). This brief version of TOFHLA takes approximately 12 minutes to administer and yields reliable and valid information about the patient's functional health literacy. In a study of 211 patients given this version (Baker, Williams, Parker, Gazmararian, & Nurss, 1998), reliability (Cronbach's alpha) was 0.68 for the four numeracy items and 0.97 for the 36 items of the two prose passages. The correlation between this version of the TOFHLA and the REALM was 0.80. To facilitate scoring of this version, numeracy items are assigned a weight of 7 (giving a total of 28 possible points for the Numeracy section) and comprehension items are assigned a weight of 2 (giving a total of 72 points for the Comprehension section). The total score for this brief version of TOFHLA is 100. Literacy level scores are:

Inadequate Functional Health Literacy	0-53
Marginal Functional Health Literacy	54-66
Adequate Functional Health Literacy	67-100

For further information on this brief version of TOFHLA, see Baker, Williams, Parker, Gazmararian, & Nurss, (1999).

APPENDIX B

INFORMATION TECHNOLOGY FAMILIARITY QUESTIONNAIRE

IT Familiarity Questionnaire

Please circle the number that corresponds most closely to your use of your computer or smart phone to access the internet.

Rating:

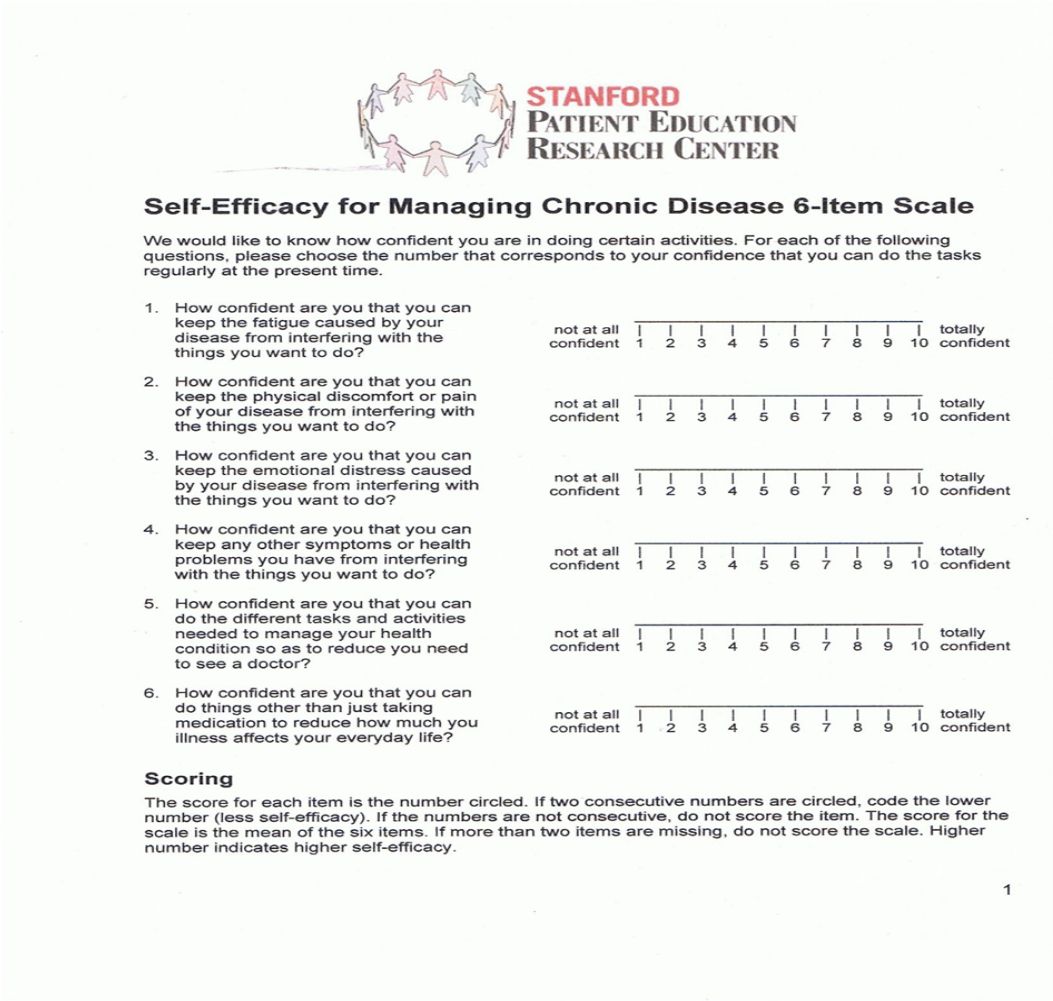
1= Daily use for this activity
2= Seldom use for this activity
3= Never use for this activity

1.	I use my computer or smart phone to send and receive email.	3	2	1
2.	I use my computer or smart phone to obtain information on a wide range of topics.	3	2	1
3.	I download applications from the internet to my computer or smart phone.	3	2	1
4.	I use my computer or smart phone to shop, manage my calendar and/or make travel arrangements.	3	2	1
5.	I use my computer or smart phone to bank and pay my bills.	3	2	1
6.	I use my computer or smart phone for social networking.	3	2	1
7.	I use my computer or smart phone to watch movies/videos, listen to podcasts and/or music, or share photos/images.	3	2	1

8. I use other forms of electronic technology such as eBooks (Kindle, NookBook) or tablets (iPad, LifeBook, etc.).	3	2	1

APPENDIX C

SELF-EFFICACY FOR MANAGING CHRONIC DISEASE 6-ITEM SCALE



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Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?
6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

not at all confident 1 2 3 4 5 6 7 8 9 10 totally confident

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

1

Characteristics

Tested on 605 subjects with chronic disease

No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	1-10	5.17	2.22	.91	NA

Source of Psychometric Data

Stanford/Garfield Kaiser Chronic Disease Dissemination Study. Psychometrics reported in: Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

Comments

This 6-item scale contains items taken from several SE scales developed for the Chronic Disease Self-Management study. We use this scale now, as it is much less burdensome for subjects. It covers several domains that are common across many chronic diseases, symptom control, role function, emotional functioning and communicating with physicians. For internet studies, we add radio buttons below each number. There are 2 ways to format these items. We use the format on this document, the other is shown on the web page. A 4-item version of this scale available in Spanish.

References

Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

This scale is free to use without permission

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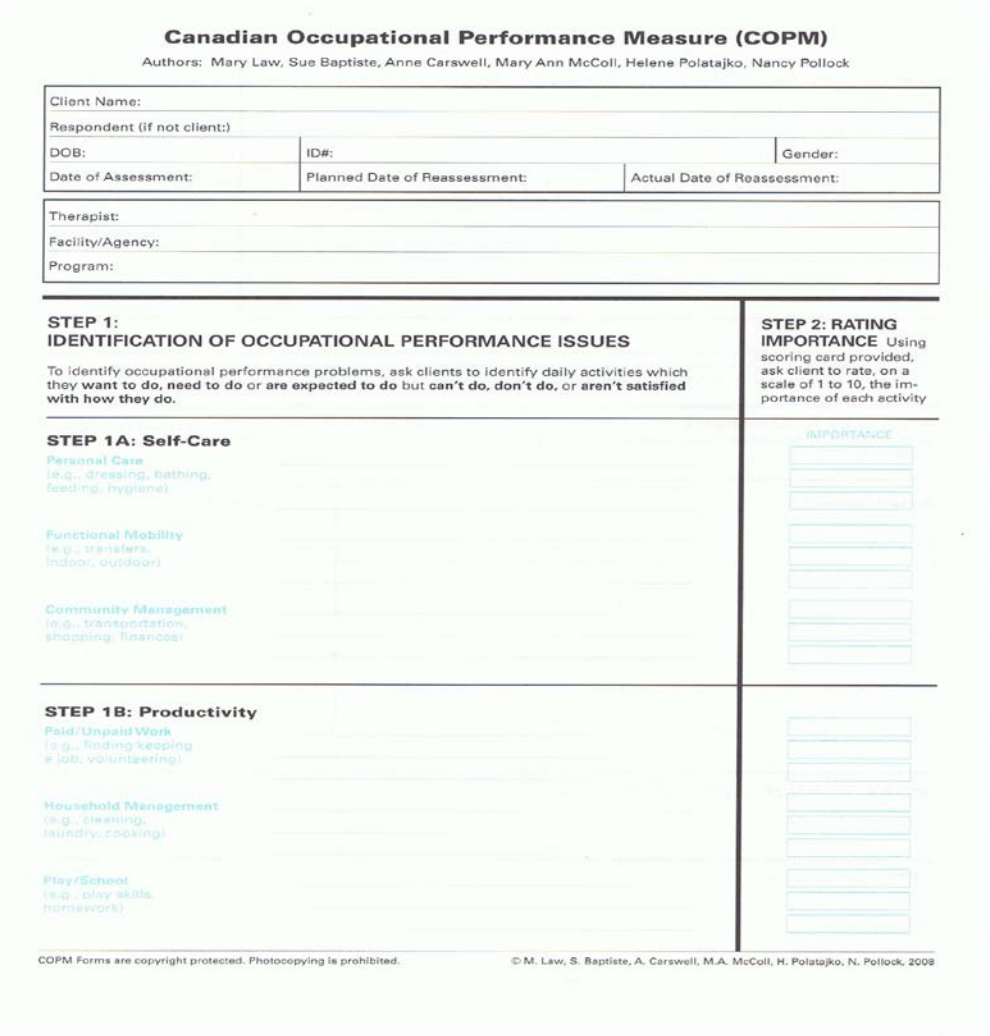
APPENDIX D

CANADIAN OCCUPATIONAL PERFORMANCE MEASURE



Canadian Occupational Performance Measure (COPM)

Authors: Mary Law, Sue Baptiste, Anne Carswell, Mary Ann McColl, Helene Polatajko, Nancy Pollock

Client Name:		
Respondent (if not client:)		
DOB:	ID#:	Gender:
Date of Assessment:	Planned Date of Reassessment:	Actual Date of Reassessment:
Therapist:		
Facility/Agency:		
Program:		

STEP 1:
IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES

To identify occupational performance problems, ask clients to identify daily activities which they **want to do, need to do** or **are expected to do** but **can't do, don't do,** or **aren't satisfied with how they do.**

STEP 2: RATING IMPORTANCE Using scoring card provided, ask client to rate, on a scale of 1 to 10, the importance of each activity

IMPORTANCE

STEP 1A: Self-Care

Personal Care
(e.g., dressing, bathing, feeding, hygiene)

Functional Mobility
(e.g., transfers, indoor, outdoor)

Community Management
(e.g., transportation, shopping, financial)

STEP 1B: Productivity

Paid/Unpaid Work
(e.g., finding/keeping a job, volunteering)

Household Management
(e.g., cleaning, laundry, cooking)

Play/School
(e.g., play skills, homework)

DOB: | ID#

STEP 1C: Leisure

	IMPORTANCE
Quiet Recreation (e.g., hobbies, crafts, reading)	
Active Recreation (e.g., sports, outings, travel)	
Socialization (e.g., visiting, phone calls, parties, correspondence)	

STEP 3: SCORING

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems.

STEP 4: RE-ASSESSMENT

At an appropriate interval for re-assessment, the client again scores each of the problems selected for performance and satisfaction.

Initial Assessment: Occupational Performance Problems:	PERFORMANCE 1	SATISFACTION 1	**Reassessment:** PERFORMANCE 2	SATISFACTION 2
1.				
2.				
3.				
4.				
5.				
SCORING:	PERFORMANCE SCORE 1	SATISFACTION SCORE 1	PERFORMANCE SCORE 2	SATISFACTION SCORE 2
Total score = Total performance or satisfaction scores / Number of problems (1–5)	=	=	=	=

STEP 5: COMPUTING CHANGE SCORES

CHANGE IN PERFORMANCE = Performance Score 2 — Performance Score 1 =

CHANGE IN SATISFACTION = Satisfaction Score 2 — Satisfaction Score 1 =

ADDITIONAL NOTES AND OBSERVATION:
Initial Assessment:

Reassessment:

Published by CAOT Publications ACE

APPENDIX E

KNOWLEDGE TEST

Care and Management of the Swelling in Your Legs

Please try to answers all the questions to the best of your ability.

1. The lymph system:
    a. Carries oxygen and food to the cells
    b. Removes fluid, protein, waste, and germs from the tissues
    c. Sends signals to your brain when your feet feel heat, cold or pain
    d. Do not know

2. Chronic swelling occurs because:
    a. Someone drinks too much fluid
    b. There is a problem with the blood getting to the legs
    c. Lymph fluid builds up in tissue faster than it can be removed
    d. Do not know

3. Washing of the legs and feet should be done:
    a. Only when the skin is visibly dirty so you do not dry out the skin
    b. Every day
    c. At least twice a week
    d. Do not know

4. When washing your legs and feet:
    a. Avoid using soap because it dries your skin
    b. Start with the feet and work your way up the leg
    c. Wash until the rinse water stays clean
    d. Do not know

5. When you dry your feet:
    a. Pat the skin gently
    b. Rub to get off all the dry skin
    c. It is not necessary to dry between the toes
    d. Do not know

6. When you inspect your skin:
    a. It is not important to wear your glasses
    b. Do not rely on a helper
    c. Look between the toes and in skin folds
    d. Do not know

7. When you moisturize your legs:
    a. Put on a thick layer that you can see
    b. The best time is right before you go to bed
    c. Do not moisturizer between your toes
    d. Do not know

8. If your physician says it is okay for you to trim your toenails, you should:
    a. Use scissors
    b. Cut your nails straight across
    c. Remove the thick skin at the base of the nails
    d. Do not know

9. Deep breathing helps to remove lymph fluid from your belly. When deep breathing:
    a. Your stomach should rise when you breathe out
    b. Your stomach should rise when you breathe in
    c. Breathe in twice as long as you breath out
    d. Do not know

10. Manual lymphatic massage helps to stimulate the lymph system. When you massage areas over lymph nodes to increase lymph flow:
    a. Gently stretch the skin towards the heart
    b. Rub your hand over the skin briskly
    c. Use forceful hand strokes
    d. Do not know

11. When taking care of minor skin injuries on your legs or feet you should:

a. Leave the injury uncovered to let it air out
b. Open all blisters to let them drain
c. Wash the area gently with soap and water
d. Do not know

12. You should wear shoes or hard sole slippers:
    a. Only when you go outside
    b. All of the time when you are out of bed
    c. As little as possible to prevent pressure on your feet
    d. Do not know

13. When buying shoes you should:
    a. Have both feet measured
    b. Buy flip flops for comfort
    c. Buy shoes with high heels
    d. Do not know

14. When shopping you are looking for foods that are low in salt. An example of a low salt food would be:
    a. Canned vegetables
    a. Lunch meat
    b. Fresh fruit
    c. Do not know

15. Elastic stockings are used to keep fluid from coming back into your legs. You should:
    a. Wear the stockings all of the time, day and night
    a. Put the stockings on in the morning and take them off at bedtime
    b. Wear the stockings only if you notice your legs are getting bigger
    c. Do not know

16. When raising your legs to help prevent extra fluid from building up in your legs. You should:
    a. Avoid using a small pillow under your knees
    b. Make sure your heels are off the supportive surface
    c. Always raise both legs at the same time
    d. Do not know

17. You have noticed that your foot has become numb, cold and pale. You should:
    a. Put them in hot water to warm them
    b. Tap your foot forcefully on the floor it increase blood flow
    c. Avoid putting heat on them and call the doctor
    d. Do not know

18. It is evening and you begin to have chest pain and shortness of breath. You should:
    a. Lay down and see if it goes away
    b. Call 911 and go to the emergency room
    c. Go to bed and call your doctor in the morning if it does not go away

d. Do not know

19. If you notice that your leg starts to feel hot and is red and painful you should:
    a. Continue using compression and call your doctor
    b. Walk on it if possible to increase blood flow
    c. Do not use compression and call your doctor
    d. Do not know

20. You have not iced a difference in your wound. You would call the doctor when:
    a. The wound is increasing in size
    b. There is a decreased in drainage
    c. The odor has decreased
    d. Do not know

APPENDIX F

COMPETENCE WITH SELF CARE & SELF MANAGEMENT

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
Step 1: Understand your body Essential facts (5) a. Cells need oxygen & food to produce energy for activity b. Cells create waste when producing energy c. The blood carries food & oxygen to the cells and removes waste d. The lymph system removes excess fluid, protein, fat, waste, dirt and germs from the body e. Damage to the blood or lymph system causes health				Possible total = 14

problems: low blood flow & eventual cell death, swelling that doesn't go away with infections, and loss of feeling Early signs of problems Essential facts (9) a. Problem: Lack of blood flow What you see • Coldness • Numbness				

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject

• Slow/no healing a. Problem: Chronic swelling What you see • Present > 3 mo • Remains after elevation at night • Frequent infections a. Loss of sensation in feet or legs • Lack of feeling in toes and feet • Sores, cuts that don't hurt • Burning, stabbing, pins & needles, feels asleep etc. Step 2: Wash and Dry Daily Essential Facts (2) a. Daily washing is important to remove dirt & germs b. Swollen feet & legs are prone to infection				Possible total = 17

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
Essential Skills: Wash (7) a. Clean water and cloth (has not been used for other body parts) b. Check temperature with hand to make sure it's not too hot/cold c. Wash only from top of leg to feet/toes d. Wash between toes & folds e. Rinse with clean water from top of leg down to toes; dispose of rinse water f. Repeat (c-e) until rinse water is clear; you may need to wash more than once g. Use a different cloth for each pass and each leg Essential Skills: Dry (3) a. Start from top and work down b. Pat not rub c. Dry between toes & folds Essential Facts: Nail care (5) a. Doctor's permission to cut nails? b. Clippers not scissors c. Cut straight				

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
a. Use emery board to shape b. Don't remove cuticle Step 3: Moisturize Essential skills (4) a. Best time to moisturize is after washing b. Don't use too much c. Don't put between toes and skin folds d. Don't put on open skin Step 4: Skin Inspection Essential skills (4) a. Position themselves and environment for good visualization (light, glasses, mirror, aid) b. Look between toes, around nails, in folds c. Look for dry, broken, cracked, reddened, moist, leaky, sores, blisters, thickened skin (callus) d. Know the difference between your normal skin and skin changes				Possible total = 4 Possible total = 4

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
Step 5: Take care of minor skin injuries Essential Facts (6) a. Stop any bleeding by applying light pressure until it stops b. Wash area gently with soap, pat dry and cover with a dressing c. Wash & dry daily until healed d. Call doctor if new redness or increased swelling, pain, warmth e. Do not open blisters Carry a first aid kit Step 6: Wear shoes that fit properly and avoid tight clothes Essential skills (8) a. Never go barefoot b. The shoe must fit the foot a. avoid high heels, pointed toes b. measure both feet c. Shoe must protect (hard sole)				Possible total = 6 Possible total = 8

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
d. Wear shoe that doesn't make feet sweat e. Shake out shoe before donning f. Wear clean cotton socks g. Avoid constricting socks elastic waist bands, belts, etc h. Don't cross your legs Step 7: Prevent swelling Essential skills (5) a. Raise affected leg (one at a time) b. Knee bent slightly – supported c. Heel off surface d. Show area (s) to examine for increased pressure from leg elevation e. Raise foot of bed if tolerated Essential facts (5) Low salt foods a. Foods high in protein b. Plenty of water c. Fiber				Possible total = 12

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
a. Calories/Serving b. Avoid heat c. Wear compression stockings when flying Step 8: Deep breathing and exercise Essential Facts (2) a. Before Flexitouch System use to maximize effect b. Do when & wherever possible Essential Skills a. Deep Breathing (4) • In nose; out through mouth • 1:2 ratio of inhale/exhale time • Inhale stomach goes out • Exhale stomach goes in • Chest remains level				Possible total = 19

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
a. Massage (8) • Above collarbone i. Direction- down-central ii. Force-light iii. Frequency 6-10/min iv. Repeat- 5-10xs • Armpit (hand behind head) i. Direction-up-central (heart) ii. Force-light iii. Frequency 6-10/min iv. Repeat- 5-10xs b. Breathing w head motion (2) • Nodding (inhale up/exhale tuck chin) • Rotation (inhale as turning; exhale on return) c. Breathing w arm motion(fingers to shoulders)(2) • Apart (inhale)/together (exhale) • Circular (inhale up past ears/ exhale back and down) Step 9: Compression to reduce swelling and prevent return Flexitouch System Essential Facts (3)				Total possible = 26

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
a. Preparation of trunk to accept fluid from legs b. Duration of cycle (1 hr.) c. Cause increased urination as fluid leaves legs and goes into circulation Essential Skills a. Donning leg piece (5) • Toes do not show • Never sit or lie on tubing- keep on outside • Top edge ends at knee • Fasten from toe to knee • Smooth out wrinkles b. Donning thigh/belly piece (3) • Notch of belly piece is at crotch • Wrap knee to thigh • Wrap belly c. Safe Use (4) • Turn on, check setting (L1), press start , and complete entire cycle (1 hour) • Keep phone nearby				

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
• Turn off when cycle complete • Cover open skin areas to prevent drainage onto FTS a. Doffing (4) • Unwrap belly first, turn back velcro tabs to prevent tangling • Loosen tabs on thigh leg pc. – do not completely unwrap • Slide leg piece off • Store garment and power unit safely (avoid kinking the tubing; minimize damage) b. Care of Device (2) • Do not immerse in water • Sponge clean with mild detergent; air dry				

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
Edema wear/Stocking Essential Skills (5) a. Apply in the AM and remove in PM b. Smooth out wrinkles c. Do not fold over unless instructed by therapist d. Observe for new swelling in toes or above top edge Ask for smaller size if too loose Step 10: Be smart about your feet and legs Essential Facts (7) What action would you take in the following situations a. Chest pain or difficulty breathing • Call 911 b. Sudden weight gain of more than 4 lbs. in 2 days • Call Dr				Total possible: 15

Step	Date	Performs Satisfactory	Needs Improvement	Comments/Recommendations for subject
a. New onset of hot red or painful feet or legs • Take temperature • Avoid walking • Don't use compression • Call Dr. b. New open blisters or sores on feet or legs • Wash, dry ,cover sores • Call Dr. c. New onset of cold, numb, pale feet or legs • Avoid external heating • Call Dr. d. Worsening of sore as in increased: pain, size, drainage, odor • Wash, dry, cover sore • Take temperature • Call Dr. e. Fever, Chills, Nausea, headache or soreness in your glands for longer than a day • Take temperature • Call Dr.				

APPENDIX G

TELEHEALTH USABILITY QUESTIONNAIRE

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TELEHEALTH USABILITY QUESTIONNAIRE (TUQ)
January 2012

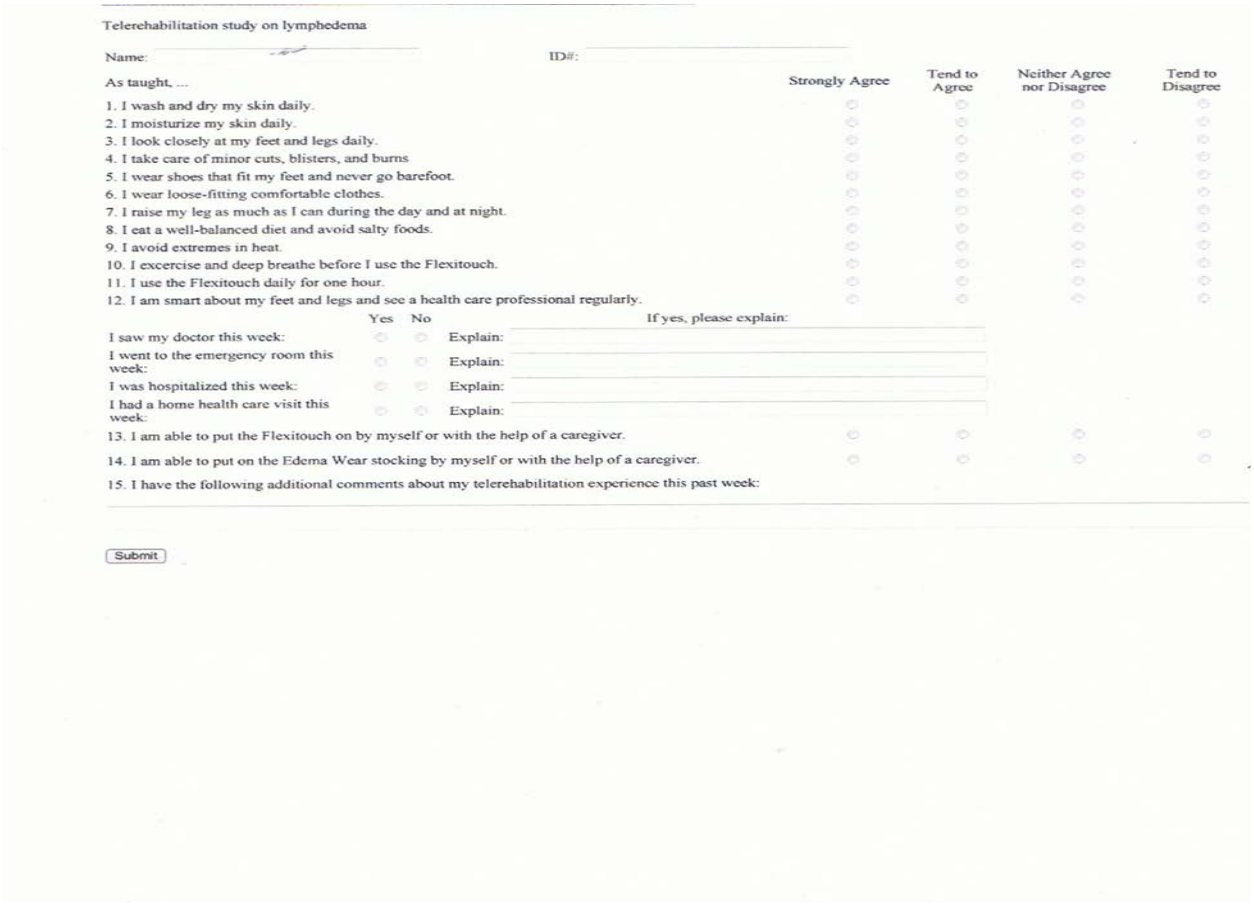
		N/A		1	2	3	4	5	6	7	
1.	Telehealth improves my access to healthcare services.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
2.	Telehealth saves me time traveling to a hospital or specialist clinic.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
3.	Telehealth provides for my healthcare need.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
4.	It was simple to use this system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
5.	It was easy to learn to use the system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
6.	The way I interact with this system is pleasant.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
7.	I like using the system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
8.	The system is simple and easy to understand.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
9.	This system is able to do everything I would want it to be able to do.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
10.	I can easily talk to the clinician using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
11.	I can hear the clinician clearly using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
12.	I felt I was able to express myself effectively.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
13.	Using the telehealth system, I can see the clinician as well as if we met in person.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
14.	I think the visits provided over the telehealth system (using videoconferencing) are the same as in-person visits.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
15.	Whenever a problem occurred with the system, I could fix it easily and quickly.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
16.	I feel comfortable communicating with the clininician using the telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE

17.	Telehealth is an acceptable way to receive healthcare services.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
18.	I would use telehealth services again.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE
	Overall, I am satisfied with this telehealth system.	☐	DISAGREE	☐	☐	☐	☐	☐	☐	☐	AGREE

Please provide comments about the telehealth system:

APPENDIX H

SELF REPORT OF SELF-MANAGEMENT BEHAVIORS



Telerehabilitation study on lymphedema

Name: ID#:

As taught, ...	Strongly Agree	Tend to Agree	Neither Agree nor Disagree	Tend to Disagree
1. I wash and dry my skin daily.	○	○	○	○
2. I moisturize my skin daily.	○	○	○	○
3. I look closely at my feet and legs daily.	○	○	○	○
4. I take care of minor cuts, blisters, and burns	○	○	○	○
5. I wear shoes that fit my feet and never go barefoot.	○	○	○	○
6. I wear loose-fitting comfortable clothes.	○	○	○	○
7. I raise my leg as much as I can during the day and at night.	○	○	○	○
8. I eat a well-balanced diet and avoid salty foods.	○	○	○	○
9. I avoid extremes in heat.	○	○	○	○
10. I excercise and deep breathe before I use the Flexitouch.	○	○	○	○
11. I use the Flexitouch daily for one hour.	○	○	○	○
12. I am smart about my feet and legs and see a health care professional regularly.	○	○	○	○

	Yes	No	If yes, please explain:
I saw my doctor this week:	○	○	Explain:
I went to the emergency room this week:	○	○	Explain:
I was hospitalized this week:	○	○	Explain:
I had a home health care visit this week:	○	○	Explain:

13. I am able to put the Flexitouch on by myself or with the help of a caregiver.	○	○	○	○
14. I am able to put on the Edema Wear stocking by myself or with the help of a caregiver.	○	○	○	○

15. I have the following additional comments about my telerehabilitation experience this past week:

Submit

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