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# Quality of Life Occupational Therapy Measurement Tool for Patients with Lymphedema/Chronic Venous Edema

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QUALITY OF LIFE OCCUPATIONAL THERAPY MEASUREMENT TOOL  
FOR PATIENTS WITH LYMPHEDEMA/CHRONIC VENOUS EDEMA

by

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A Scholarly Project

Submitted to the Occupational Therapy Department

of the

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in partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

Grand Forks, North Dakota  
May 12, 2007





This Scholarly Project Paper, submitted by Marsha Waind in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

*Jan Stube*

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Faculty Advisor

*May 12, 2007*

\_\_\_\_\_  
Date



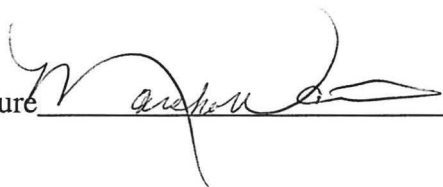
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Title                      Quality of Life Occupational Therapy Measurement Tool  
                                  for Patients with Lymphedema/Chronic Venous Edema

Department                Occupational Therapy

Degree                     Master's of Occupational Therapy

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## ABSTRACT

The objective of this project was the development of a tool in the form of a patient questionnaire to be used by Occupational Therapists (OT) treating patients with lymphedema/chronic venous edema. This questionnaire was designed to identify life factors beyond limb volume reduction and activity independence that correlate with the patients' perceptions of an improved quality of life, therefore promoting Health Related Quality of Life (HRQoL).

Literature reviewed supported the premise that attainment of the typical OT goals of activity completion will not accomplish the desired result of lymphedema treatment, nor will lymphedema goal attainment of reduced limb measures achieve long-standing patient satisfaction. The Occupational Therapy Framework (AOTA, 2002) and the Ecological Model of Occupation (Dunn et al., 2003) constructs were applied to address patient specific factors to be included in the treatment planning for patients with edema/lymphedema.

A HRQoL measurement tool, called the Lymphedema/Chronic Venous Edema Patient Questionnaire, was developed to be used by lymphedema trained occupational therapists as an outcome measure of patient satisfaction after treatment. Further, through clinical use of this questionnaire, Health Related Quality of Life is more likely to be an intentional outcome of the occupational therapy lymphedema treatment process.

## CHAPTER I

### INTRODUCTION

Lymphedema is the abnormal collection of protein rich interstitial fluid due to a dysfunction in the body's lymphatic system (Zuther, 2005). Chronic Venous Edema is long standing fluid retention due to seepage of lymph fluid out of an incompetent venous system into the surrounding tissues. Both pathologies can cause legs and feet to swell significantly, sometimes attaining massive proportions. The fluid filled limbs suffer from infections and un-healed wounds which weep onto clothing, are costly to heal and may become life-threatening situations. The enlarged limbs cause changes in the lives of these patients. Consider the life factors of an extremity that has become so large the patient is unable to lift it onto a bed, feet that no longer fit into shoes, the inability to stand or walk for reasonable periods of time. The loss of mobility, vitality and the ability to enjoy life's chosen activities, indeed life's occupations, are a result of this condition that can be avoided with treatment and self-maintenance programming developed by a trained lymphedema therapist.

In the United States, trained lymphedema therapists may be occupational or physical therapists, massage therapists or nurses. Each discipline approaches the treatment of patients with a history of professional expertise and experience. Lymphedema therapists who are also occupational therapists are trained in the specialized skills of task analysis, cognitive processing, and the psychosocial

application of daily life factors affecting each patient's personal ideation of their needs. The most desirable goal of the active treatment phase as well as the self-maintenance phase of lymphedema care is the reduction and maintenance of the circumferential limb measures. The successful outcome of occupational therapy (OT) treatment in lymphedema treatment is the integration of the life changes necessary to maintain the reduced measures while maintaining or improving the patient's quality of life (QoL). The skill set of an occupational therapist includes identification of opportunities for change, analysis of personal requirements necessary to attain identified goals, and plan development with the patient to bring about the change. The plan successfully integrates changes into a life plan that not only reduces the measures of edema in a limb, but reduces the personal impact of the edema and the lifelong routines necessary to management it.

These treatment activities and the time for completion may take one hour to several hours each day. Daily self-management in a typical lymphedema patient will alter existing performance patterns of the patient. New patterns must be developed and integrated into the daily activity demands. According to the American Occupational Therapy Association Practice Framework (AOTA, 2002, p. 611), "Engagement in occupation includes both the subjective (emotional or psychological) aspects of performance and the objective (physically observable) aspects of performance." The dedication to completion of an intensive daily self-management program comes only with the purposeful plan to dedicate the time and energy to it and the practice of a newly formed daily routine.

Success of the daily treatment program will reap improved protocol outcomes measured by reduced limb volume, closed wounds, and increased joint mobility. These patient factors are important as they may lead to an increased activity level and involvement in life's array of opportunities. However, the psychosocial implications of a misshapen limb clothed in a compression garment can have a debilitating effect on the patient and their life activities.

In two respected books on lymphedema treatment techniques and management (Zuther, 2005; Kasseroller, 1998), the most desirable outcome is limb volume reduction. There is no mention of QoL as an outcome measure. Although reduction in the limb size is regarded as the foremost aim of treatment, lymphedema practitioners recognize the importance of the patient's acceptance of the condition as a factor in a changed lifestyle.

It is important to assess the patient's feelings regarding his lymphedema, his body image, his ability to carry out the tasks, and his dedication to the time commitment of the daily self-care.

#### Purpose of the Scholarly Project

The focus of this scholarly project is a QoL measurement tool for patients who have edema/lymphedema in the occupational therapy treatment of lymphedema. The tool was developed to guide the occupational therapist to recognize and address in treatment the patient's functional limitations, their feelings regarding altered personal image, and their personal measure of their health related quality of life (HRQoL).

Qualitative work has identified both psychological and physical problems

associated with the condition and their impact on the quality of life of those with edema/lymphedema. (Augustin, Bross, Foldi, Banscheldt, & Zschocke, 2005; Muscari, 2004; Pereira de Godoy, Braile, De Fatima Godoy, & Longo, 2002; Sitzia, & Sobrido, 1997; Voogd, Ververs, Vengerhoets, Roumen, Coebergh, & Crommelin, 2003). My interest and intent for this scholarly project is a review of HRQoL tools and comparison of the assessment fields with those of interest to Occupational Therapy.

### Theoretical Framework

The Ecological Model of Occupation (Dunn, Brown, & Youngstrom, 2003) serves as a reference for the development of the tool. The OT theory identifies four major constructs of person, context, task, and performance. This model of occupational therapy practice underscores the uniqueness of patient circumstances and the effects of those circumstances on the occupational performance. This framework is ideal when considering the necessary scope of treatment and life long changes necessary to maintain the health of a patient with lymphedema.

The core constructs of the Ecological Model relate to the individual and change according to the environment. A person's constructs relative to a task is different at home, work, or play (Dunn, et al, 2003). This is true of a lymphedema patient: their personal requirements for health and vitality, their edema/lymphedema change in different settings, different times, and even different weather.

The occupational/lymphedema therapist must design a treatment program and a maintenance program that successfully meets the core constructs of the patient and the task of management of this condition while addressing the quality of



life of each patient. Using the Ecological Model of Occupation and its core constructs, the clinical application of a HRQoL satisfaction questionnaire will facilitate therapists to address these issues for their patients who have lymphedema.

The Practice Framework (AOTA, 2002, p. 611) defines occupational therapy treatment and goals with the statement, “Occupational therapists and occupational therapy assistants understand engagement from this dual and holistic perspective and address all the aspects of performance (physical, cognitive, psychosocial, and contextual) when providing interventions designed to support engagement in occupations and in daily life activities. The Outcomes Process in the Practice Framework (2002) focuses on two concepts that are important to apply to lymphedema care: (a) engagement in occupation, and (b) participation in context. Engagement in occupation supports participation, both of which are meaningful and purposeful to the person and their life situation. This OT process speaks to activity or the engagement in occupation as the act that brings personal fulfillment to the person (AOTA,2002). Does the engagement in the activities, habits, routines that maintain the lymphedema measures and skin health improve or bring satisfaction to a patient’s personal life situation? This was the question of interest to me as an occupational therapist. I developed my scholarly project’s HRQoL measurement tool for patients with lymphedema/chronic venous edema.

Success of OT an treatment program is typically measured by an increase in independence in the area of tasks/activity through rehabilitation or compensation. In the treatment of patients with lymphedema/chronic venous edema, success in this

measurement of success will not reach the desired result of most patients with lymphedema.

According to expert opinion of lymphedema therapists, the most desired outcome in a lymphedema treatment protocol is limb reduction. The accepted protocols for treatment address only treatment and management of limb volume and skin integrity. Yet, the research points to a different conclusion; that limb volume reduction does not correlate with a patient's perception of an improved quality of life. There is a need for a patient assessment that includes other life factors beyond limb reduction and activity independence. This tool will identify issues and direct the treatment to meet the needs of the patient for limb reduction as well as the life satisfiers that are disrupted by lymphedema/chronic venous edema.

#### Current Occupational Therapy for Lymphedema

Occupational therapists that treat lymphedema understand and respect the clinical relevance of the factors of person, context, task, and performance in the success of any edema/lymphedema treatment regime. Lymphedema is not cured, but managed. The activities, routines, and habits used to maintain a healthy limb while coping with the burden of an altered body image and lifestyle must be integrated into life that maintains HRQoL. It is the premise of this project that attainment of the typical OT goals of activity completion alone will not accomplish the desired result of lymphedema treatment. Nor will lymphedema goal attainment of reduced limb measures achieve long standing patient satisfaction. Quality of life is the optimal therapeutic goal as well as an appropriate outcome of treatment

Satisfaction with one's body and life situation must be accomplished to truly measure success of the lymphedema treatment process. "Comfortable in your own skin" is a phrase that could have much deeper meaning for a patient with chronic edema/lymphedema. Occupational therapists are skilled at formulating an excellent self-management program for the patient and his/her family to complete. But only when the impact of these changes are factored into the patients' lifestyle and their HRQoL are we truly successful at treatment.

Following the active treatment phase, it is the management skills of the individual patient or involved family member that will determine the long-term success of limb volume reduction. These skills must include good coping strategies and problem-solving methods, as the therapist is not a daily source of information and encouragement to continue the self-management techniques necessary to be successful in managing limb volume.

It is within the scope of occupational therapists treating lymphedema to address the satisfaction of life with an enlarged limb. However, the Practice Framework (AOTA, 2002) does not lead us toward that ultimate goal. The Model of Ecological Occupation addresses tasks and person in context, but, again, does not address quality of life, verbatim. In addition, the founders of lymphedema practice and methodology do not discuss quality of life and life satisfaction with the condition of chronic edema/lymphedema (Zuther, 2005).

### Quality of Life

Included in this project are the key concepts of quality of life and health related quality of life. The concept of quality of life (QoL) first appeared in the

literature in 1978 by a psychologist named Flannagan researching the human experiences related to well-being. He surveyed 3000 Americans and the areas of material well-being, personal development and fulfillment, relations with other people, recreation, and social, community and civic activities. Health did not surface as an independent qualifier (Wood-Dauphinee, 2001).

Health-related quality of life (HRQoL) narrows the concept to address an individual's ability to attain reasonable levels of functional performance and self-perceived well-being following illness or injury. In review of the literature, HRQoL incorporates actual and patient perceived physical, mental, social, and role functioning, including current status and anticipated status given the effects of the disease process.

### Terminology

For purposes of this scholarly project, the following terms and definitions are used.

Cellulitis- diffuse, acute infection of the skin and subcutaneous tissue; streptococcal in nature, tends to spread rapidly (Zuther, 2005, p.247).

LE - Lymphedema is defined as the abnormal accumulation of water and proteins principally in the lymphatic subcutaneous tissues occurring when the system's transport capacity falls below the body's normal lymphatic load. (Zuther, 2005, p.46)

CDT - Complete decongestive therapy is the non-invasive, multicomponent approach to treat lymphedema and related conditions (Zuther, 2005, p. 101). It includes a four-step approach to treatment: manual lymph drainage, compression therapy, skin care, exercise.

Compression therapy - use of specific bandage materials or compression garments or a combination to prevent the accumulation of fluids in the tissues due to the loss of elasticity of the cutaneous tissues from edema/lymphedema. (Zuther, 2005, p.125)

Compression bandages - short-stretch bandages (60% extensible) used during the decongestive phase of treatment providing “high working pressure” and “low resting pressure.” Working pressure is the tissue pressure created against the resistance during muscle activity while the resting pressure is the pressure exerted without muscle contraction. Bandages effect improved muscle pump action and reduction of lymph fluid stagnation in the tissue space. These bandages reduce risk of tourniquet effect typically produced with a long-stretch bandage (ACE<sup>®</sup>) which has a high resting factor on the lymph and blood vessels. (Zuther, 2005, p.168)

Compression garments- form fitting elastic custom or pre-made garments manufactured in a variety of materials worn after decongested with the intent to maintain reduction; come in compression measured in millimeters of mercury from 10mmHg to >60mmHg and are worn daytime hours for life. (Zuther, 2005, p.192)

CVDL - Chronic venous disorder of the Leg- umbrella term of various clinical presentation of chronic venous disease including venous symptoms, edema, skin changes, varicose veins, venous ulcers. The 1993 VEINES (Venous Insufficiency Epidemiologic and Economic

Studies) task force identified CVDL as an important public health problem, based on its prevalence, cost, and impact on quality of life. (Launois, et al, 1996, p. 539)

CVI - Chronic venous insufficiency-the advanced stage of venous disease characterized by incompetent veins and poor quality muscle pump action causing blood to pool in the legs and feet. Insufficient venous return results in elevated blood capillary pressure, causing and increase in net filtrate. Over time, lymphatic system develops mechanical insufficiency. (Zuther, 2005, p. 74)

HRQoL- Health-related quality of life. The measure of factors related to health issues denoting life satisfaction. (Sitzia & Sobrido, 1997, p. 373)

Lymph- a thin watery fluid originating in organs and tissues of the body that circulates through the lymphatic vessels and is filtered by the lymph nodes. It is primarily made up of lymphocytes. (Zuther, 2005, p. 252)

Lymphangitis- an inflammation of one or more of the lymphatic vessels, usually resulting from a streptococcal infection (Zuther, 2005, p. 253).

MLB-Multi-layered bandaging is a component of the decongestive phase of treatment. The procedure uses a combination of padding materials and low stretch bandages to provide external support to the

outstretched skin and tissues. This enables lymph fluid to enter the larger lymph collectors and drain to the vessels. (Zuther, 2005, p168)

Papilloma-epithelial tumor of skin or mucous membrane (Zuther, 2005, p. 258).

QoL -Quality of Life: A person's dynamic appraisal of his or her life satisfactions (perceptions of progress toward one's goals), self-concept (the composite of beliefs and feelings about oneself), health and functioning (including health status, self-care capabilities, and role competence), and socioeconomic factors (e.g., vocation, education, income) (AOTA, 2002, p.633).

#### Summary

This project will start with the review of the research literature and demonstrate the need for a clinical tool to be utilized by occupational therapists treating lymphedema/chronic venous edema that will enhance patient satisfaction with treatment outcomes and improve their quality of life in relation to their lymphedema. Studies by Voogd et al. (2003) and Sitzia and Sobrido (1997) have measured the lack of correlation between limb volume reduction and life satisfaction scores. The Occupational Therapy Framework (AOTA, 2002) and the Ecological Model of Occupation (Dunn et al., 2003) theorize that our individual concept of self, including skills, cognition, self in context determines our choice of activities, including health maintenance. It is within the scope of occupational therapists to address these factors and include them in the treatment of

edema/lymphedema patients measuring an improved HRQoL factor for their patients.



## CHAPTER II

### REVIEW OF LITERATURE

#### What is Lymphedema?

According to the National Cancer Institute, “Lymphedema (LE) is the accumulation of lymph in the interstitial spaces, principally in the subcutaneous fatty tissues, caused by a defect in the lymphatic system. It is marked by an abnormal collection of excess tissue proteins, edema, chronic inflammation, and fibrosis. Lymphedema is a frequent complication of cancer and its therapies, and can have long-term physical and psychosocial consequences for patients” (2004, p.1). The National Lymphedema Network (NLN, 2006) in their Position Statement on Lymphedema treatment describes LE as “a chronic condition characterized by the abnormal accumulation of interstitial fluid due to insufficiency of the lymphatic system”. Lymphatic dysfunction may be related to primary malformation of the lymphatic system, or to secondary causes” (2006, p 1).

There are two types of Lymphedema, Primary, and Secondary (NCI, 2004). Physical abnormalities or disease originating in the lymphatics causes primary LE. Lymphedema is divided into two classes: congenital and acquired conditions. Weiss and Spray (2002) report it occurs in approximately 1 in 10,000 people by the age of 20 years, with women affected more often than men.

Secondary lymphedema is caused by surgery, trauma, or disease not originating in the lymphatics. It has been reported that lymphedema in the lower extremity and trunk to be approximately 20% among patients undergoing groin dissection for primary skin tumors and up to 70% of patients having undergone radical lymph node dissection for prostate cancer (Weiss & Spray, 2002; Sitzia & Sobrido, 1997).

The World Health Organization estimates that lymphatic filariasis affects over 120 million people in the tropics and subtropical areas of the world. It is the leading cause of permanent and long-term disability of that area. A parasitic filarial worm is transmitted through insect bites and causes inflammation of the lymphatic system leading to destruction of the lymph nodes (Zuther, 2005). The lymph nodes acting as filters become a dam structure for the lymph fluid, which restricts the flow of fluid out of the limb. Elephantiasis is the eventual outcome.

According to Zuther (2005), regardless of genesis, lymphedema is always a progressive condition and is without a cure. Typical progression includes increasing girth of the limb or body part, thickening of the skin with growths known as papillomas, changes in the body contour by exaggerated skin folds and lobules all of which may limit mobility, clothing options, and body image. This leads to a reduction in functional skills and daily activities, including work or gainful employment. Psychosocial health is affected early in the course of progression due to these bodily changes and resultant restrictions of activities and functions (NLN, 2006). Medical complications caused by the stagnant pool of fluid include recurrent

tissue infections and non-healing wounds leading to serious illness and loss of work time as well as functional limitations (NLN, 2006).

### Chronic Venous Insufficiency and Edema

Edema is the collection of the transudate fluid of the body consisting of water and electrolytes (Artzberger, 2005). Edema lasting longer than 3 months is generally considered chronic (Artzberger, 2005). This type of edema is less viscous, becomes harder to pit, and can progress to fibrosis, poor skin health and ulceration (Clark-Moloney, O'Brien, Grace, Burke, 2005).

Chronic venous insufficiency (CVI) indicates the deficient return of venous blood flow in the lower extremities usually through valvular reflux. The venous insufficiency and its skin complications do not depend on previous incidents of deep venous thrombosis (DVT) (Yuwono, 2000).

### Chronic Venous Edema and Lymphovenous Insufficiency

Chronic Venous Edema may be a precursor condition to lymphedema. As the vein walls become incompetent, the body fluid pressures cause the lymph to enter the surrounding tissue space. Unlike blood flow, lymph flow relies on intermittent changes in interstitial pressures and subsequent contraction of lymphatic collecting vessels. It is likely that contractility fails in lymphedema, so that lymph drainage becomes dependent on passive processes (Badger, Peacock, & Mortimer, 2000).

Zuther (2005) describes 4 stages of progression (classified 0-3):

Stage 0 has no symptoms as the body activates its systems and responds to the increased fluid load by increasing transport of the fluids.

Stage 1 demonstrates mild edema as the lymphatic load overwhelms the transport capacity. In this stage, the edema will recede during sleep as the system can “catch up” to the overload.

Stage 2 progresses with increased pressures of the blood capillaries and lymph collectors causing edema and pain. Skin changes are evident, as skin turns more fibrotic from the protein leakage.

Stage 3 is considered severe. The swelling decreases oxygen and nutrient delivery to the tissues resulting in local hypoxia and necrosis. Typical signs of elephantiasis are evident. Ulcerations, pigmentation of the skin, and pain may develop in extremities that show minimal swelling.

Venous ulcers affect up to 2.5 million patients a year in the United States. These chronic wounds severely affect patients’ quality of life because of impaired mobility and substantial loss of productivity. They result in frequent hospitalizations, resulting in substantial costs and morbidity. The incidence rate of recurrent ulceration after wound healing with non-operative methods has been reported at 37% and 48% at years 3 and 5 (Brem, Kirsner, & Falanga, 2004). Lower extremity lymphedema and chronic ulceration is a major health issue and a significant health related quality of life (HRQoL) factor for many people.

#### Typical Assessment and Treatment Protocol

Evaluation includes peripheral volumetric measurements of the limb as a primary tool for assessing treatment effectiveness (Weiss & Spray, 2002). This method is time-consuming and difficult to carry out for the less mobile patient or in a small clinic space. Circumferential measures of the limb at predetermined spots are

effectively used to gauge the severity and mark improvements. These measures act as a comparison to subsequent measures and the normal limb, if the edema is unilateral. ABI or ankle brachial index is used identify the presence of peripheral arterial disease in the lower extremities. A Doppler device is used to listen for the systolic blood pressure and the resting ankle brachial pressure index measured at  $\geq 0.9$  indicates normal arterial blood flow (Clark-Moloney, et al. 2005). A physician may also order Duplex ultrasonography tests to check for venous occlusion or venous reflux.

Treatment of edema/lymphedema patients has changed considerably in the last 25 years. Complete Decongestive Therapy (CDT) has only recently been utilized in the United States for treatment. CDT consists of several treatment components delivered in two phases. The intensive phase components are skin and nail care, manual lymph drainage (MLD), compression therapy, and decongestive exercises. Manual Lymph Drainage has been practiced in Europe since Dr. Vodder first presented his paper on MLD in 1936 (Kasseroller, 1998). It is defined by the specific massage technique, which mobilizes fluid along lymphatic pathways through the body. Daily massage treatments are followed by multilayer low-stretch wrapping (MLB) of the limb. Daily exercises specifically mobilize the lymph circulation and are performed twice a day. The typical course of active intensive treatment lasts 14 days with the primary goal of limb volume reduction.

Patient self-management is phase two. The components are similar to the intensive phase but self-management is the primary goal. Changes to the program may include daytime compression garment wear and nighttime wraps. A lifelong

program is devised usually consisting of daytime compression stocking, nighttime wrapping procedure, and a specific exercise program to mobilize the lymph fluid.

In a study comparing treatment plans of MLB followed by compression stocking with those using compression stocking alone, the reduction in limb volume by MLB followed by hosiery was approximately double that from hosiery alone and was sustained over the 24-week period. The mean overall percentage reduction at 24 weeks was 31% for MLB versus 15.8% for hosiery alone (Badger et al., 2000). Although time consuming and cumbersome, multilayer bandaging as an initial phase of treatment for lymphedema patients, followed by hosiery, achieves greater and more sustained limb volume reduction than hosiery alone.

#### Other Indicators of Successful Treatment

Passik and McDonald (1998) identified an avoidant coping style as a significant predictor of adjustment difficulties for women with lymphedema. He stated that swelling in the dominant hand causes greater psychological distress than in a non-dominant hand for those women with upper extremity lymphedema. Further, the garments lead to decreased social activity participation. He suggests identification of those who are at greater risk for developing psychological problems may improve the outcomes of treatment and management of the condition.

Dennis (1993) reported a qualitative study of a very small sample of 9 women with post Breast Cancer lymphedema. She noted that factors for what she classified as a successful outcome include a small amount of swelling and a secure, active lifestyle. Factors linked to a poor outcome include extensive swelling, poor health, poor coping skills, and poor support networks.

There was a greater decrease in quality of life (QoL) scores post-treatment for patients with lymphedema in one or both lower extremities when compared to those patient with swelling in either upper extremity (Weiss & Spray, 2002). This decrease suggests that CDT treatment improved QoL more dramatically in leg lymphedema patients than in arm lymphedema patients by means of measuring physical improvement.

In the Weiss and Spray (2002) study, patients with peripheral lymphedema completed a QoL survey pre- and post-treatment. Percent of edema volume reduction was calculated for each patient with only one affected limb. QoL scores differed significantly between pre- and post- treatment in all areas of inquiry. Patients with lower extremity lymphedema had significantly greater mean improvement in QoL scores compared with patients with upper extremity lymphedema. There was no correlation between percent edema volume reduction and post-treatment QoL improvement. This study suggests that significant improvements are made in the QoL of patients exhibiting peripheral lymphedema following CDT, which is not necessarily correlated with limb volume reduction.

#### Quality of life and Lymphedema Measurement

According to Wood-Dauphinee (2001), the concept of quality of life (QoL) first appeared in the literature in 1978 by a psychologist named Flannagan researching the human experiences related to well being. The term health-related quality of life (HRQoL) narrows the concept to address an individual's ability to attain reasonable levels of functional performance and self-perceived well-being following illness or injury.

HRQoL has been described as the effect that a medical condition or its treatment has on a person. Most outcome questionnaires operationally define quality of life according to the World Health Organization definition of health by assessing at least 3 domains of well-being: physical, emotional, and social. The questionnaires are completed by patients and may be classified as either generic or condition-specific. Generic questionnaires are designed to be used by anyone, allowing health status comparisons across groups of patients as well as people without disease or impairment. They are not responsive to clinical change (Wood-Dauphinee, 2001).

Condition-specific HRQoL measures focus on the area routinely followed by physicians as markers of the disease process which are also areas typically treated by clinicians. These products tend to be of value clinically to gauge the effect of disease specific treatment on the QoL. The use of these instruments along a timeline may indicate progression or severity of the disease or condition of the patient (Wood-Dauphinee, 2001).

#### *Generic Measures*

SF-36: Medical Outcomes Study 36-Short-Form is the most often seen tool in the research literature. It is a generic questionnaire that measures 8 health domains related to physical functioning, social functioning, and mental health, with higher scores representing a more favorable health status. It uses a scale from zero (extremely bad) to 100 (excellent). A score of 50 represents the national average for adults who are healthy, whereas a score of 40 is 1 standard deviation below the national norm (Wilson, Hutson, & VanStry, (2005).



NHP: Nottingham Health Profile is the most widely used British-designed instrument for the assessment of HRQoL and is best regarded as a measure of distress in the physical, emotional, and social domains. It has 38 items covering six domains. They are pain, sleep, emotional reactions, energy, social isolation, physical mobility (Augustin et al., 2005). When used before and after treatment, the NHP becomes an effective outcome measurement tool. Before the Sitzia (1997) study, the NHP was not previously found in the literature as used with chronic edema, but is considered particularly suited to elderly or chronically ill subjects and for that reason may be sensitive for the issues of chronic edema.

European Organization for Research and Treatment (EORTC) QLO-C30:

This is increasingly seen in the literature as a recognized and validated quality of life evaluation tool. It has thirty questions that make up five functional scales: physical, emotional, cognitive, social and role functioning. Symptom scores include: pain, fatigue, sleep, nausea/vomit, appetite, constipation, diarrhea, dyspnea. Body image scores examine: attractive/feminine, appearance, feel whole, cosmetic result, and scar issues. Lifestyle scores address: feeling insecure, contact with people, daily habits. The “Other worries” category includes financial future health, partner relationship, sexual relationship, and sexual activity. The global QoL is an overall self-assessment of their quality of life. Responses are aggregated and transformed along a 100-point scale (Engel, Kerr, Schlesinger-Raab, Sauer, & Holzel (2003).

*Condition-Specific Measures*

FLIC: The Functional Living Index-Cancer is also known as the Manitoba Functional Living Cancer questionnaire. This questionnaire contains 22 items with a

7-point Likert-type linear analog scale. A total score of the sum of the 22 items gives scores with higher numbers indicating better health status. Studies have broken the measures into 5 health dimension of physical functioning, mental functioning, social functioning, general health/well-being, and gastrointestinal symptoms (Wilson et al., 2005).

CIVIQ: The CIVIQ is a 20-item questionnaire designed specifically to measure health in patients with chronic venous disease. It has four domains: psychosocial, physical functioning, social functioning, and pain. Lower scores from this questionnaire reflect better quality of life (Clark-Moloney et al., 2005).

ULL-27: This is a tool specific to upper extremity lymphedema and has three dimensions: physical, psychological, and social withdrawal (Morgan, Franks, Moffatt, 2005).

FACT-B: Functional Analysis of Cancer Treatment-Breast. The FACT-B contains four subscales: physical, social, emotional, and functional well-being plus a breast cancer concern scale. This tool has been proven to discriminate between breast cancer patients on different breast cancer treatments and at different stages of disease. Five additional items were developed to form an “arm subscale.” The five questions of the arm subscale relate to: swelling or tenderness, painful movement, poor range of arm movements, numbness, and stiffness. This new tool was used to measure differences in patient satisfaction following surgery in two groups: sentinel node biopsy with node sampling and traditional axillary clearing (Coster, Poole, & Fallowfield, 2001).

FLQA-1: This is a questionnaire specific for lymphedema. The FLQA-1 is

based on the FLQA vein questionnaire (FLQA-V). The tool consists of 92 items with the scales for: physical status, everyday life, social life, emotional well-being, treatment, satisfaction, and profession/household (Augustin, Bross, Foldi, Banscheldt, & Zschocke (2005).

### Lymphedema and Quality of Life

Lymphedema affects QoL. Patients with lymphedema experience impaired QoL especially in the areas of physical mobility, energy, and pain. These have a profound impact on the patients' well-being and on everyday life (Augustin et al., 2005).

In the study by Sitzia and Sobrido (1997), the NHP was used to measure HRQoL receiving conservative treatment for limb lymphedema. Two important results must be recognized. First, conservative treatment for limb lymphedema did result in a measurable improvement in the HRQoL and three of the six subscales were statistically significant (i.e., energy, pain and physical mobility) with the last showing the largest change. Secondly, change in the gross volume of the limb correlated with no change on the QoL scores of the NHP. Several studies have also found a lack of correlation between HRQoL scores and limb volume.

Objective measurements typically used to indicate severity of arm lymphedema in women following lymph node dissection do not correlate with the impact on daily life activities and psychological involvement caused by the disease and this method of treatment (Voogd et al., 2003). This article bears out the lack of

correlation between lymphedema measures for severity and the impact of lymphedema on quality of life in the breast cancer survivor.

Ridner (2005) found that that the perception of limb size influenced the reported symptoms experienced more than the objective arm volume. This study suggests lymph volume reduction treatments may provide inadequate relief of symptoms reported by breast cancer survivors with lymphedema and that those symptoms result in a poorer QoL.

Voogd et al. (2003) conducted a study to explore measurements of arm circumference and shoulder abduction as indicators of QoL after axillary lymph node dissection for invasive breast cancer. They concluded that the objective measurements typically used to indicate severity of arm lymphedema in those women following lymph node dissection do not correlate with the impact on daily life activities and psychological involvement caused by the disease and this method of treatment.

Coster et al. (2001) designed the FACT-B+4 to assess the impact of arm morbidity on patients following breast cancer surgery. They found that lymphedema patients reported a poorer quality of life and the scores were significant along the continuum of rehabilitation over a twelve-week period. Those with arm problems experience poorer long-term QoL (Engel, Kerr, Schlesinger-Raab, Sauer, & Holzel (2003). If arm problems improve, however, quality of life improves. Yet, the negative impact on quality of life persists for several years.

The physical changes caused by lymphedema alter patient's roles within the family, work, and society through their body image, sexuality and emotional well-

being. The consequences of lymphedema are defined as pain, altered sensations and function, need for non-tailored, large-sized clothing and shoes, repeated, persistent infection, fatigue, altered interpersonal relationships, functional disability, self-image alterations (Muscari, 2004). Acceptance of the diagnosis is difficult by both professionals and patients. Patients typically do not want to recognize issues with their limbs and avoid wearing compression garments. These same patients will deny symptoms to their primary caregivers (Muscari, 2004).

De Godoy (2002) compared QoL of patients with upper and lower extremity lymphedema to similar control group without lymphedema. His study cites several physical and emotional factors related to peripheral lymphedema including increased weight of the edematous limb with restricted motion aggravated by fibrosis and joint contracture, and altered sensitivity and embarrassment during social interactions. Areas tested included vitality, pain, general state of health, physical aspects, mental health, physical capacity, emotional aspects and social aspects.

The FLQA-I (Augustin et al 2005) was used to compare patients with lymphedema, CVI, and healthy persons. The findings demonstrated that patients with lymphedema showed significant reductions of QoL in all scales compared to patients with early stage chronic venous insufficiency, a disease known to be associated with little QoL impairment. The QoL reductions of the lymphedema patients were comparable or even mildly higher than the QoL of patients with venous leg ulcer. Clinical results of markedly impaired QoL follow other studies cited and point to clinical treatment focus on measures consistent with chronically ill patients, e.g. pain reduction, skin care, relaxation, and psychological treatment.

## Lower Extremity Chronic Edema/Lymphedema and QoL

Leg ulcers have a major impact on quality of life. Venous ulcers account for annual losses of more than 2 million workdays in the United States. A significant number of patients had moderate to severe symptoms, principally pain, related to leg ulcer; 81% believed that their mobility was adversely affected by the ulcer, and 68% of patients reported that the ulcer had a negative emotional impact on their lives (Brem et al., 2004).

Eighty-one percent of patients with venous stasis ulcers experienced decreased mobility, and 57% reported that their mobility was severely limited. As a result, 68% of these patients with impaired mobility experienced fear, anger, depression, and social isolation (Clark-Moloney et al., 2005). Complications associated with venous ulcers were gait changes, pain, infection, cellulitis, malignant wound changes, and dermatitis (Brem et al., 2004). Words used by the patients to describe life with a leg ulcer included: pain, loss of mobility, disturbed sleep, offensive smell, fear, social isolation, anger, depression and negative self-image (Clark-Moloney et al., 2005).

Iglesias, Birks, Nelson, Scanlon, and Cullum (2005) completed a study using The Hyland Questionnaire with 387 patients with chronic leg ulcers. It addressed more personal daily issues from the patient's perspective such as sleep discomfort, time spent thinking about the ulcer, and time involved in ulcer care. Themes that recur in the responses were: restrictions to

social, leisure and work activities, the hope and despair experience throughout the healing process, the restrictions ulceration places on clothing and footwear.

Edema, in its many forms and span of severity, causes a measurable physical and psychological impact on the lives of these patients. The literature review reveals many HRQoL measures specifically developed for the diagnosis group.

Occupational therapists, both those trained in lymphedema management and those who are not, treat the physical and psychological limitations of edema/lymphedema. HRQoL measures are not typically used in occupational therapy treatment planning or outcome measures. A patient questionnaire was developed for the patient with edema/lymphedema treated in occupational therapy. Using the themes identified in accepted QoL disease specific measures, the questionnaire will generate relevant patient information for the occupational therapy plan of care. The tool will assist the patient and therapist and act a guide to reach functional outcomes of edema/lymphedema management and a higher quality of life.

## CHAPTER III

### METHODOLOGY

This master's scholarly project addresses the need for a patient questionnaire that provides information relative to Health Related Quality of Life (HRQoL) issues of the patient with lymphedema/chronic venous edema. Questionnaire results will assist the occupational therapist in establishing relevant treatment goals facilitating the desired outcome of improving limb health as well as improving the HRQoL of the individual.

The basic steps in instrument construction described by DePoy and Gitlin were utilized (1998, p. 208). Of the seven steps outlined in the text, the first six were completed for this project. The steps are:

1. Literature review for relevant instrumentation already available
2. Identify the theory as basis for the instrument
3. Operationalize the concepts or constructs within the instrument
4. Conceptually define the concepts or constructs within the instrument
5. Select and refine the instrument format
6. Translate the concepts into instrument items and appropriate response choices
7. Test the instrument

#### Research Review

A review of the concepts of health, quality of life, and health-related quality



of life revealed international concepts used by the World Health Organization (WHO, 2001) and medical based service outcome measures. The literature search revealed validated quality of life (QoL) tools measuring QoL within diseases such as cancer, filarisis, and chronic venous insufficiency (CVI).

The research review also revealed QoL measures utilized by medical providers specific to health issues. These are classified as HRQoL measures and often are formulated to capture information specific to disease or condition related factors. Their purpose may be a measurement of the resultant HRQoL following the treatment of the disease. The purpose of these instruments is a measurement of the patients' HRQoL with treatment for the condition compared to the HRQoL without treatment.

A review of edema/lymphedema literature related to quality of life had evidence of studies that were concerned about measuring the HRQoL of patients with edema/lymphedema and had projects demonstrating different measures. Only one was specific in addressing the effect of conservative lymphedema therapy and the effects on the patients' life activities (Weiss & Spray, 2002). However, the tool was used at the end of treatment to validate an improved QoL following treatment. A review of accepted edema/lymphedema treatment protocols and the outcome measures of QoL had very little discussion of application and only a mention of the measures of the impairments on the QoL of patients with lymphedema.

The OT literature relative to patient outcomes or life satisfaction was found to

be non-productive for this project because here is little discussion of QoL as it relates to patient and their OT treatment. Michener and Leggin (2001) reviewed eleven patient instruments designed to assess a patient’s function and disability. They comprehensively discussed design and validity in the measurement of a patient’s function and disability, however the scales were not tied to the patients’ concept of HRQoL. The focus of OT literature seems to be on task and participation in occupation, with little discussion on life satisfaction. Consequently, it was determined that there is a definite need for an outcome measure that emphasizes HRQoL to be used by occupational therapists who work with patients who have lymphedema.

#### Theory and Concept for HRQoL Tool Development

The Model of Ecological Occupation (Dunn, Brown, & Youngstrom, 2003) provided the structure of occupational therapy theory for development of the HRQoL tool. Each item was weighed for relevance as compared to the four constructs of the model. The delineation of the topic of each question was compared to the relative constructs in the table below. The HRQoL tool demonstrated a good balance in each of the constructs. See Table 1 below.

Table 1. Ecological Model of Occupation and Items on the HRQoL Measurement

|             |   |
|-------------|---|
| Person      | pain; energy/vitality; worry; feel confident in knowledge   |
| Task        | climbing, walking, standing, sitting, squatting, in/out of car, bathing, dressing, grooming, washing, standing during activity, ability to wear clothes/shoes |
| Context     | feelings of disability; impact on life; time of management/treatment  |
| Performance | in the context of work/job, care of home and family; social/leisure activities; relationships/sexuality   |

## Tool

During development of the HRQoL instrument considerations for clarity of the questions, social desirability of the questions, and format or design was factored for optimal instrument design. The tool was distributed to lymphedema trained therapists for their review. Their feedback provided information regarding content validity. Based on their experience with lymphedema and patient interactions in the clinical setting, several measurement tool items were restated to clarify the intent and operationalize the constructs within this instrument.

## Format

Development of a new measure for testing in a research based project is a specialty area in the research world (DePoy & Gitlin, 1998). Commonly the instruments are developed for use in a single study and designed to capture a narrow selection of information.

In the research review, several HRQoL questionnaires were published. These instruments have been validated and published widely. These questionnaires are felt to be worthy for measurement of significant value. After consideration of the format, scale, and structure, each item for this project was constructed based on the four constructs of the Ecological Model of Occupation (Dunn, 2003). Once the items were felt to be representative of the idea, the tool was reformatted for a more visually appealing presentation.

## Summary

A HRQoL measurement tool, called the *Lymphedema/Chronic Venous Edema Patient Questionnaire*, was developed to be used by lymphedema trained

occupational therapists for a treatment planning device. The HRQoL Measurement Tool is presented in the following Chapter IV.

## CHAPTER IV

### THE PATIENT QUESTIONNAIRE

The 23 items on the *Lymphedema/Chronic Venous Edema Patient Questionnaire* were designed to address the areas of performance areas, performance skills, performance patterns, context, activity demands, and client factors from the OT Practice Framework (AOTA, 2002) most often limiting success in lymphedema/edema patient self-management. These items concurrently fit the criteria of the four constructs of the Ecological Model of Occupation (Dunn, Brown, & Youngstrom, 2003).

#### Clinical Protocol

The questionnaire will be presented to the patient with lymphedema/chronic venous edema just after registration and admission on the initial occupational therapy visit. Explanation of the intent and use of the tool will be given verbally as well as in written format on the introduction page of the document. The patient will have adequate time to complete the tool with assistance provided as needed. The therapist will review the answers with the patient to clarify issues and generate discussion of significant findings that may impact treatment. Although not part of this scholarly project, the use of this questionnaire as an outcome measurement tool would be a valuable option to validate the skilled treatment and patient education in the self-management of the condition.

The interaction that occurs between therapist and patient while reviewing the completed questionnaire will disclose the areas of individualized need in the four constructs of person, context, task, performance for treatment planning purposes (Dunn et al., 2003). These constructs will be addressed as goal statements in the treatment planning process. Addressing these areas in treatment will improve patient treatment outcomes as well as patient satisfaction in the management of their condition and life activities.

Further development of the tool for validation will follow these steps:

- Development of construct validity by obtaining expert (OT) opinion on the concepts within the instrument
- Testing the instrument with a client population

To validate the instrument with a client population the following steps would occur:

- Establish internal consistency by running Cronbach's Alpha on data collected
- Establish convergent validity by running instrument results again with other similar instruments already in the clinical realm
- Establish test-retest reliability and responsiveness to change by administering instrument to same group of clients on 2 occasions and running Pearson's  $r$  correlation testing on patient data collected

In summary, the primary purpose of the tool for this scholarly project is to identify treatment goals and patient outcomes regarding the lymphedema issues that impact the patients' HRQoL. The *Lymphedema/Chronic Venous Edema Patient Questionnaire* is presented in the following pages.

Dear Patient,

Thank you for your time and cooperation in completing this questionnaire. The results will help us both understand how this condition affects your everyday life and the activities of life important to you. The effects of lymphedema on you and your activities are important factors in developing a program of treatment and ongoing self-management that will fit into your daily routine.

Lymphedema/chronic venous edema cannot be healed, but it can be managed. Treatment will help you reach your goal of self-management. The treatment techniques will reduce the size of your limb, but the ultimate outcome of treatment is a satisfying life style with a smaller and pain free limb. Treatment will focus on the design of a self-maintenance program that maintains the limb-size reduction attained in treatment and enables you to achieve a satisfying lifestyle with lymphedema/venous edema.

Please answer as honestly as you can and feel free to ask any questions you have.

Thank You

M.Waind, 2007



## Lymphedema/Chronic Venous Edema Patient Questionnaire

Circle the number that best describes the intensity of the experience or feeling listed.

|     | <b>Scale</b><br><b>1 = none or not at all</b><br><b>2 = a little</b><br><b>3 = moderately</b><br><b>4 = very</b><br><b>5 = impossible to do/absolutely</b> | not at all | a little | moderately | very much | A great deal |
|-----|--|------------|----------|------------|-----------|--------------|
| 1.  | Recently, to what degree have you felt <b>pain or discomfort</b> in your limb?   | 1          | 2        | 3          | 4         | 5            |
| 2.  | To what extent does your limb swelling take away <b>energy or vitality</b> from everyday experiences?  | 1          | 2        | 3          | 4         | 5            |
| 3.  | How <b>embarrassed or self-conscious</b> are you because of your limb?   | 1          | 2        | 3          | 4         | 5            |
|     | <b>Currently, to what extent does your limb swelling problems bother/limit you while doing the activities listed below?</b>                                |            |          |            |           |              |
| 4.  | <b>Walking briskly</b>   | 1          | 2        | 3          | 4         | 5            |
| 5.  | <b>Climbing Steps</b>  | 1          | 2        | 3          | 4         | 5            |
| 6.  | <b>Standing in line</b>  | 1          | 2        | 3          | 4         | 5            |
| 7.  | <b>Sitting with legs down</b>  | 1          | 2        | 3          | 4         | 5            |
| 8.  | <b>Squatting to pick up groceries</b>  | 1          | 2        | 3          | 4         | 5            |
| 9.  | <b>Getting in/and out of a car</b>   | 1          | 2        | 3          | 4         | 5            |
| 10. | <b>Bathing</b>   | 1          | 2        | 3          | 4         | 5            |
| 11. | <b>Dressing</b>  | 1          | 2        | 3          | 4         | 5            |
| 12. | <b>Grooming</b>  | 1          | 2        | 3          | 4         | 5            |
| 13. | <b>Standing</b> for a time such as to wash or shave  | 1          | 2        | 3          | 4         | 5            |

|     | <b>Scale</b><br><b>1 = none or not at all</b><br><b>2 = a little</b><br><b>3 = moderately</b><br><b>4 = very</b><br><b>5 = impossible to do/absolutely</b> | <b>not at all</b> | <b>a little</b> | <b>moderately</b> | <b>very much</b> | <b>a great deal</b> |
|-----|--|-------------------|-----------------|-------------------|------------------|---------------------|
| 14. | Currently, does swelling limit your work or involvement in the <b>care of your home and family</b> ?   | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 15. | Currently, to what extent does the size of your limb/feet limit the <b>clothes/shoes you can wear</b> ?  | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 16. | Currently, to what extent does your limb swelling interfere with your <b>relationships/sexual experiences</b> ?  | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 17. | Currently, how much does your limb swelling affect any <b>social or leisure activities</b> you take part in or would like to take part in?                 | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 18. | Currently, do you feel bothered or limited in your <b>work (job)</b> because of your limb swelling problems?   | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 19. | Currently, how much of a problem is the treatment/care of your limb (for example: taking <b>time or making your life more complicated</b> )?               | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 20. | To what extent does your lymphedema/swelling make you feel like a <b>handicapped person</b> ?  | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 21. | I am <b>worried</b> often about my lymphedema returning or getting worse.  | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 22. | I am confident that I am able to <b>complete the routine</b> I have learned in therapy to keep the swelling out of my limb.                                | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
| 23. | I would rate the level of impact of my <b>lymphedema/swelling on daily life</b> as   | <b>1</b>          | <b>2</b>        | <b>3</b>          | <b>4</b>         | <b>5</b>            |
|     | Your comments are welcome here:  |                   |                 |                   |                  |                     |

## CHAPTER V

### SUMMARY

The purpose of the this scholarly project was to develop a clinical tool in the form of a patient questionnaire that would identify occupational therapy treatment goals and desired patient outcomes regarding the individualized lymphedema issues that impact the patients' HRQoL.

In the literature search it was revealed that primary lymphedema and secondary lymphedema/chronic venous edema is a condition occurring in significant numbers causing serious illness, functional limitations and incidence of psychosocial health impairments (NLN, 2006). The literature search also showed that there was no correlation between the percent of edema volume reduction and post-treatment HRQoL improvements, yet the accepted clinical protocols for treatment persist in focusing on limb volume reduction as a benchmark of success (Weiss & Spray, 2002).

The tool developed for this scholarly project is a patient questionnaire designed to identify the activities, personal needs and desires of the patient with lymphedema/chronic venous edema so that these issues are addressed in the occupational therapy treatment planning process. Therefore, HRQoL is more likely to be an intentional outcome of the occupational therapy lymphedema treatment process.

Future use of the tool may include use as an outcome measurement tool if the same questionnaire was administered at discharge and a qualitative comparison was made. Validation of the tool is not addressed in this study and would be a good option for further research. Yet, as the tool is designed currently, it is of value for the occupational therapist treating patients with lymphedema/chronic venous edema since there is no similar product available.

This scholarly project has been an interesting venture into the world of QoL and HRQoL measures, especially as they relate to occupational therapy. Presently, much of the research and literature of the occupational therapy profession does not address HRQoL. In fact, the current professional view of treatment and scope of practice addresses occupation or activities of living. The sense of satisfaction with one's life, not related to the idea of completing a goal or task is not addressed in the occupational therapy professional literature. I found this to be incongruent with the health organizations' and clinical measurement tools and am concerned that the occupational therapy profession will soon be out of step with the general health-related holistic attitude to health maintenance.

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