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EXPLORATION OF FACTORS ASSOCIATED WITH PATIENT ADHERENCE IN UPPER EXTREMITY REHABILITATION: A MIXED-METHODS EMBEDDED DESIGN

DISSERTATION

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Health Sciences at the University of Kentucky

By

Enrique Victor Smith-Forbes

Lexington, Kentucky

Co-Directors: Dr. Dana M. Howell, Professor of Occupational Therapy and Dr. Timothy

L. Uhl, Professor of Athletic Training

Lexington, Kentucky

2015

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ABSTRACT OF DISSERTATION

EXPLORATION OF FACTORS ASSOCIATED WITH PATIENT ADHERENCE IN UPPER EXTREMITY REHABILITATION: A MIXED-METHODS EMBEDDED DESIGN

Adherence is considered a prerequisite for the success of exercise programs for musculoskeletal disorders. The negative effects of non-adherence to exercise recommendations impact the cost of care, and also treatment effectiveness, treatment duration, the therapeutic relationship, waiting times, the efficiency of personnel and use of equipment. Adherence to therapeutic exercise intervention is a multifaceted problem.

The World Health Organization (WHO) established the multidimensional adherence model (MAM). The MAM describes five interactive dimensions (socioeconomic, health-care team and system, condition-related, therapy-related, and patient-related factors) that have an effect on patient adherence.

The first purpose of this dissertation was to explore the MAM dimension of condition-related factors to determine the Quick Disabilities of the Arm Shoulder and Hand (QDASH) minimal clinical important difference (MCID) for three distal upper extremity conditions. The second purpose was to explore the MAM dimension of personal factors to learn from individuals who expressed incongruence between their QDASH and GROC scores; how they described their perceived change in therapy. The third purpose was to explore the MAM dimension of therapy-related factors to examine the effect of patient-therapist collaborative goal setting on patient adherence to treatment and QDASH outcomes.

Results demonstrated in the first study that diagnosis specific MCID's differed from the global MCID using multiple diagnoses. In the second study results demonstrated that



patients expect to have a dedicated therapist who they can trust to work collaboratively with them to establish goals and spend time with them to achieve these goals. In the third study, our first hypothesis was not supported for all three measures of adherence. The median for home exercise program diary adherence was found to trend towards significance by 8.7 percent favoring the experimental group Mann-Whitney U (p < .100). Our second hypothesis was not supported. The experimental group receiving collaborative goal setting intervention had similar QDASH mean change scores 45.9 ± 27.6 compared to the control group 46.1 ± 23.8 , Mann-Whitney U (p < .859).

KEYWORDS: Compliance, Distal Radius Fracture, Patient-centered Care, QuickDASH, Canadian Occupational Performance Measure

Enrique V. Smith-Forbes	
Student's signature	

April 13, 2015
Date



EXPLORATION OF FACTORS ASSOCIATED WITH PATIENT ADHERENCE IN UPPER EXTREMITY REHABILITATION: A MIXED-METHODS EMBEDDED DESIGN

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DEDICATION

I dedicate this dissertation in loving memory of my mother Elsie E. Edwards.



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CHAPTER 1

INTRODUCTION

The term adherence has been described in the literature with multiple interchangeable words. These include cooperation, compliance, engagement, concordance, and partnership. Adherence entails an "active, voluntary and collaborative involvement by the patient in a mutually acceptable course of behavior to produce a preventative or therapeutic result" (p. 20). Patient adherence is one of the most unpredictable, yet modifiable single factors that may influence clinical outcomes and effective healthcare.^{3,4} Adherence is considered an important prerequisite for the success of exercise programs for musculoskeletal disorders.⁴ Patient non-adherence to a therapeutic treatment plan of care can negatively reduce treatment benefits, affect recovery, increase the risk of disability, and bias assessment of treatment efficacy. 5,6 Non-adherence in acute hand injuries, or upper extremity (UE) rehabilitation, can result in complications requiring more difficult secondary surgical procedures, and increased costs from hospitalizations and loss of productivity. Because adherence is voluntary, it may be challenging for therapists to find ways to engage the patient in performing the exercise program.

The concept of adherence differs from compliance. While adherence is defined as "the extent to which a person's behavior corresponds with *agreed* recommendations from a healthcare provider," the term compliance has been described as the degree to which patients *obey* and follow through with prescriptions and proscriptions delineated by their treating health practitioner. ^{2,4} Contrary to adherence, compliance is rooted in the biomedical model and does not take into account all aspects of the patient, which is one



of the hallmarks of the occupational therapy profession and the hand therapy specialty.

Compliance has been associated in the literature with physician control.

Often

"noncompliance" implies patient blame for negative outcomes, instead of analyzing and understanding factors that impact the patient's engagement in therapy.

Adherence, on the other hand, implies patient collaboration with health care provider recommendations, and accounts for factors and conditions, which may influence a patient's ability to engage in therapy. Thus with adherence, better outcomes can be achieved as the patient follows agreed recommendations from a healthcare provider.

Adherence to exercise is essential to obtain good clinical outcomes. There is consistent evidence in the literature of the beneficial effects of exercise on main clinical outcomes such as physical function, quality of life, and pain. 10-12 Notwithstanding its importance, overall adherence to clinic-based exercise programs is usually reported to only be 50%, 13,14 and is often worse for unsupervised home exercise programs (HEP). 15 Adherence for unsupervised HEPs in acute hand therapy has been estimated 75% or more. 16 Despite the greater level of adherence, patients in acute hand therapy have higher related risks as reduced adherence is more likely to result in associated secondary surgical procedures, longer recovery times, increased disability and an increased burden on healthcare resources. 17,18 The overall cost of upper extremity (UE) musculoskeletal disorders (MSD) in the United States has been estimated to be US\$ 6.1 billion per year. 19 The negative effects of non-adherence to exercise recommendations not only impact cost of care, but also treatment effectiveness, treatment duration, the therapeutic -relationship, waiting times, efficiency of personnel and use of equipment. 20,21 Non-adherence may also



be responsible for non-significant research outcomes within a clinic-based research setting.²²

Multidimensional Adherence Model

Adherence to therapeutic exercise intervention is a multifaceted problem. The World Health Organization (WHO) conducted a critical review of the adherence literature, in order to address the complexities of adherence, and established the multidimensional adherence model (MAM).⁴ The MAM describes five interactive dimensions that have an effect on patient adherence (Figure 1.1). These five MAM dimensions are:

- (1) *Socioeconomic factors*: include unemployment, low education level, poverty, low socioeconomic status, long distance from treatment center, culture and lay beliefs about illness and treatment, family dysfunction, illiteracy, unstable living conditions and high cost of transportation.⁴
- (2) *Health-care team and system-related factors:* include overworked healthcare providers, lack of incentives and feedback on performance, short consultations, inability to provide community support, poorly developed health services with inadequate or non-existent re-imbursement by health insurance plans and poor medication distribution systems.⁴
- (3) *Condition-related factors*: represent the injury or illness-related demands faced by the patient. These include level of disability, severity of the disease, rate of progression, co-morbidities and the availability of effective treatments. Their effect depends on how they influence the patient's risk perception, priority to adhere, and importance of following treatment.⁴



- (4) *Treatment-related (or therapy-related) factors:* these include duration of treatment, complexity, previous treatment failures, frequent changes in treatment, the immediacy of benefit, side effects, and interference with lifestyle, and the availability of medical support to deal with these factors.⁴ Finally, but not least,
- (5) *Patient-related factors:* these include the individual's resources (psychological, sensory and physical) lack of information and skills related to self-management, problems with self-efficacy, attitudes, perceptions, beliefs, motivation, expectations and lack of support to attain behavioral changes.^{4,8}

This model departs from the traditional medical view of compliance, and potentially applying blame to the patient, as it does not place the primary focus on patient-related factors; noting that "it is a misconception that adherence is a patient-driven problem" ⁴(p.27). This model more equally shares responsibility with both patient and clinician and external factors affecting both parties. The MAM is now utilized to guide research. The MAM represents a gold standard for understanding the factors that influence adherence.

Measurement of Exercise Adherence

Determining accurate measures of exercise adherence can be challenging, particularly in HEPs. Home programs are multi-dimensional and include completing exercises and physical activity correctly, at agreed dose and in multiple settings.²³

Currently, no gold standard measures of adherence to HEPs exist.²⁴ The use of outcome measures provides an avenue to quantify patient adherence with HEPs.



Health system/
HCT-factors

Social/economic factors

Condition-related factors

Therapy-related factors

Patient-related factors

HCT.Health-care team

Figure 1.1 The World Health Multidimensional Adherence Model (MAM)

"Reproduced, with the permission of the publisher, from *Adherence to Long-Term Therapies: evidence for Action*, Geneva, World Health Organization, 2003 (Fig. 3, Page 27. http://www.who.int/chp/knowledge/publications/adherence_report/en/ accessed 04 October 2014)"

Outcome measures are frequently used in UE rehabilitation practice, ²⁵ and are a means of understanding adherence to HEPs. Two outcome measures typically used in UE rehabilitation are the Quick Disabilities of the Arm Shoulder and Hand (QDASH)²⁶ and the Global Rating of Change (GROC) scales, ²⁷ a generic global scale. The QDASH is the short form of the 30-item DASH, and uses 11 items to measure physical function and symptoms in persons with any or multiple musculoskeletal disorders of the upper limb. In contrast to the QDASH, the GROC scale allows patients in UE rehabilitation to personally identify what they consider important about their recovery from UE deficits. The GROC scale accesses important and relevant information additional to standardized pain and disability instruments, such as the QDASH.²⁸ The GROC scale asks that a person assess his or her current health status in relation to a previous time-point typically at the beginning of care to determine if they are same better or worse from initial intervention. The magnitude of this change is scored using a Likert or visual analog scale



that varies from 3-15 points.²⁹ Both the GROC scale and the QDASH have been found valid and reliable.^{26,27,30,31}

The value of administering both the QDASH and the GROC scales is that they measure different constructs. Given that a patient's GROC is likely to include constructs different from those measured by the QDASH, a perfect correlation between the two instruments would not be expected.³² However, it is a reasonable assumption to have consistency between the directions of both forms; in other words, if one instrument shows patient progress, the other instrument would as well. Incongruence in directionality between both forms may be an indication of underlying factors affecting the patient's adherence.

Incongruence between the QDASH and the GROC may relate to the patient's perception of their treatment success in UE rehabilitation. After orthopedic intervention to UE, objective parameters have often been used to quantify intervention outcomes, such as range of motion, strength, and radiological findings. One study found optimal cutpoints to distinguish satisfaction from dissatisfaction; satisfaction occurred when patients had recovered 65% of their grip strength, 87% of their key grip strength, and 95% of the wrist arc of motion, as measured as percent of their uninjured wrists. However numerous studies have found that objective parameters do not necessarily correlate with patient's perception of treatment success. He patient's perception of treatment success falls within the MAM dimension of personal factors. Exploring this dimension should shed light on the patient's high expectation of treatment outcome beyond what is functionally necessary.

In recent years subjective outcome variables after intervention have become



increasingly important such as: function, activities of daily living (ADL), quality of life, and patient satisfaction.³⁶ Hand therapy research has described a discrepancy between subjective outcome assessments and objective outcome measures such as range of motion and strength, after a variety of orthopedic interventions. Some of these interventions have been: metacarpophalangeal arthroplasty in rheumatoid arthritis, 37 impairment and disability after severe hand injuries with multiple phalangeal fractures,³⁴ arthroplasty for advanced osteoarthritis of the trapezio-metacarpal joint of the thumb, ³⁵ outcome assessment after distal radius fractures in aged patients, 38 and injured workers undergoing carpal tunnel release.³⁹ Patient's perception of treatment success has been found to be multifactorial regarding treatment outcomes or overall satisfaction.³⁶ Although some authors found no significant correlations from strength and range of motion (ROM), to patient satisfaction, 35,37 Chung and Haas found in patients with surgical treatment for distal radius fractures, significant moderate correlations between strength and satisfaction with strength; key pinch strength and satisfaction with strength; and between arc of wrist motion and satisfaction with wrist motion.³³

It is important to note that objective improvement does not equate to patient perception of improvement. Goldhahn et al.³⁸ recommended the use of subjective and objective measures when treating distal radius fractures. A multidimensional approach of improvement is necessary to determine if a patient perceives they are improved. In addition, measures from both the clinician and the patient need to be examined for congruency, to have a more holistic perspective on the patient's outcome. The WHO MAM dimension of patient-related factors that examines the patient's wants, needs, expectations and motivation to adhere to treatment lends itself to learn first-hand from the



patient and explore any incongruence between the patient's subjective and objective findings in treatment outcomes. To the knowledge of the authors, there is no qualitative study in hand therapy that has examined this concept of incongruence between objective and subjective findings from the patient's perspective.

Minimal Clinical Important Difference

One way to assess the incongruence in directionality is by determining the Minimal Clinical Important Difference (MCID) for the QDASH. The MCID represents a change in score on a standardized assessment that is perceived to be beneficial or harmful by the patient. He MCID can be calculated using multiple approaches. He MCID for the QDASH can be calculated utilizing the GROC as an anchor to determine the level of consistency in directionality. The MCID calculated this way provides a specific threshold of the amount of change a patient needs to achieve in treatment to consider it a meaningful change, taking into account the other factors captured by the GROC.

The MCID for the QDASH using collective UE diagnoses has been estimated by identifying those patients who have improved and comparing them to those who have not improved. 16,42-45 (see Table 1.1). However, the results of these studies have generated a wide range of MCID (8-20), which represents 10-20% of the 100-point scale and suggests the QDASH may have poor responsiveness. One potential explanation for this variance may be due to the fact that a single diagnosis was not used in these previous studies. The MCID may vary among diagnoses and that may be why the previous literature had generated varying results. This provides a strong rationale for examining MCID among separate diagnoses.

The MCID, which is amount of change a patient needs to achieve in order to



realize an improvement in treatment, may be a factor affecting patient adherence. The global adherence evidence indicates that the patient's motivation to engage in treatment is based on the value or (cost/benefit ratio) a patient places on following a regimen,

Table 1.1 Diagnoses of Upper Extremity Dysfunction Used to Determine the Minimal Clinical Important Difference

•	Mintken et al, 2009	Polson et al, 2010	Sorensen et al, 2013	Franchignoni et al, 2014
MCID Method	ROC	Anchor based	Anchor based	Triangulation/ROC
MCID points	8	19	14	15.91
Total Subjects	101	35	102	255
% Conditions per joint				
Shoulder				
Shoulder Pain	100.0%	0.0%	0.0%	0.0%
Rotator Cuff (RTC) Injury	0.0%	48.6%	0.0%	20.0%
Biceps or RTC Tendinitis	0.0%	0.0%	0.0%	12.6%
Shoulder Instability	0.0%	5.7%	0.0%	7.1%
Shoulder Impingement	0.0%	0.0%	0.0%	8.2%
Fracture Humerus	0.0%	2.9%	0.0%	5.9%
Shoulder Arthritis	0.0%	0.0%	0.0%	3.9%
Fracture Clavicle	0.0%	2.9%	0.0%	0.0%
Shoulder Caspsulitis	0.0%	2.9%	0.0%	0.0%
Shoulder Prosthesis	0.0%	0.0%	0.0%	0.8%
Total	100.0%	62.9%	0.0%	58.4%
Elbow				
Lateral Epicondylitis	0.0%	14.3%	12.8%	0.0%
Cubital Tunnel Syndrome	0.0%	0.0%	10.8%	0.8%
Elbow Fracture	0.0%	0.0%	0.0%	5.1%
Elbow Tendonitis	0.0%	0.0%	0.0%	3.1%
Medial Epicondylitis	0.0%	0.0%	2.9%	0.0%
Radial Tunnel Syndrome	0.0%	0.0%	1.0%	0.0%
Total	0.0%	14.3%	27.5%	9.0%
Wrist				
de Quervains	0.0%	8.6%	9.8%	0.0%
Carpal Tunnel Syndrome	0.0%	0.0%	11.8%	5.9%
Fracture wrist	0.0%	5.7%	0.0%	9.0%
Osteoarthritis DRUJ	0.0%	0.0%	9.8%	0.0%
Tendonitis	0.0%	5.7%	1.0%	0.0%
Total	0.0%	20.0%	32.3%	14.9%
Hand				
Trigger Digit	0.0%	0.0%	25.5%	0.0%
Osteoarthritis Hand	0.0%	0.0%	14.7%	0.0%
Flexor/exten Tendon Inj.	0.0%	0.0%	0.0%	8.2%
Fracture Carpal/finger	0.0%	0.0%	0.0%	3.1%
Thumb Strain	0.0%	2.9%	0.0%	0.0%



Table 1.1 (continued)

Dupuytren's (Surgery)	0.0%	0.0%	0.0%	1.2%
Total	0.0%	2.9%	40.2%	12.6%
Multi-joint				
Fracture Multiple	0.0%	0.0%	0.0%	2.0%
CRPS	0.0%	0.0%	0.0%	1.6%
Nerve Injury	0.0%	0.0%	0.0%	1.2%
Tendonitis	0.0%	0.0%	0.0%	0.4%
Total	0.0%	0.0%	0.0%	5.1%
Grand Total	100.0%	100.0%	100.0%	100.0%

MCID= minimal clinical important difference, DRUJ= distal radio-ulnar joint, CRPS = complex regional pain syndrome, ROC = receiver operator characteristics

and the degree of confidence in being able to follow through with treatment.⁴⁶ Patients may perceive conditions with a larger MCID to have a higher cost in terms of time investment for recovery and this may weigh heavier on their decisions to adhere or not to treatment.

It is important to note that the MCID for the QDASH has been established using a pool of diagnoses and only individually for shoulder conditions. The literature is lacking exploration of the QDASH MCID for diagnosis specific *distal* UE conditions and warrants further examination. Learning the QDASH MCID specific diagnoses thresholds will help clinicians better understand the amount of change a patient needs to obtain per condition. This specific threshold will serve as part of the puzzle to help clinicians adjust the patient's plan of care to accomplish goals that are meaningful to the patient, in other words, patient-centered functional goals. This exploration falls within the MAM dimension of condition-related factors, comprised by the level of disability, disease progression, availability of effective treatments, the rate of the disease, severity of the disease, and co-morbidities.

Collaborative Goal Setting

The MAM dimension of health-care team and systems that focuses on trust and



consistency of the provider, and the MAM dimension of therapy-related factors that includes the delivery of the intervention, such as frequent changes to treatment pathway are the MAM dimensions least investigated in the literature. 8,47 O'Brien has indicated many of the factors that can promote adherence are within the clinician's control and not addressing them is a missed opportunity. 8 The support and positive feedback from the therapist and the development of a patient-therapist relationship may also increase adherence. 47,48

The role of collaborative goal setting in hand therapy has been minimally studied. ⁴⁹ In occupational therapy, the client-centered approach describes the collaboration of the patient and therapist in establishing goals and a plan of care that is meaningful to the patient. ⁵⁰ One instrument often used to capture a client's perspective of function is the Canadian Occupational Performance Measure (COPM). ⁵¹ The COPM is an individualized, client-centered outcome measure, and its reliability and validity is well established. ⁵² A study utilizing the COPM ⁵³ to establish client-centered care, measured functional outcomes after outpatient occupational therapy for clients who had UE injury or surgery. ⁴⁹ The study found clients made strong positive gains in functional measures following 6-8 weeks of treatment. ⁴⁹ Nevertheless, this approach utilizing the COPM has not been investigated focusing on one specific UE condition.

The combined roles of goal setting, from a patient-centered perspective, on patient adherence in distal radius fractures have not been thoroughly explored.⁵⁴ A prospective cohort study analyzing patient-centered care and distal radius fracture outcomes, concluded that at baseline communication between the clinician and the patient was perceived most favorably, and partnership was improved by three months.⁵⁴



In a systematic review that examined the effectiveness of goal planning in rehabilitation, strong evidence was found that prescribed, specific, challenging goals can improve immediate patient performance in some specific clinical contexts, and some limited evidence was identified that goal planning can influence patient adherence to treatment programs. Another systematic review, examining the influence of the therapist-patient relationship on treatment outcomes in physical rehabilitation, found the therapeutic alliance between a patient and a treatment provider to be positively correlated with treatment adherence and outcome in both general medicine and psychotherapy settings. 56

A recent review recommended the QDASH and the patient reported wrist evaluation (PRWE) questionnaires as preferred clinical outcomes for distal radius fracture conditions. ⁵⁷ This review found the QDASH and the PRWE as reliable, valid and feasible to measure function in distal radius fractures. ⁵⁷ The absence of pain and restoration of function were agreed as the common treatment goals to be measured in future clinical trials to obtain homogeneity of outcomes. Utilizing the QDASH and the COPM to explore the effect of patient-therapist collaboration to establish goals and how this alliance affects patient adherence and outcomes, will speak to the MAM therapy-related factors of complexity, immediacy of benefit, interference with lifestyle and the therapists' availability for support. ⁴ All of these factors are yet to be investigated in hand therapy, utilizing a patient-centered perspective with distal radius fractures conditions.

Significance of the Study

Demonstrating improved patient adherence with treatment outcomes in UE rehabilitation is important. The US government, in an effort to attest for patient function, created the Middle Class Tax Relief and Jobs Creation Act of 2012 (MCTRJCA; Section



3005(g)). ⁵⁸ Therapists are now required to report to Medicare patient functional outcomes in the form of non-payable G-code and severity/complexity modifiers for patient functional status. Considering this, the ability to measure change in function and to determine differences in characteristics between those patients who adhere to treatment and those who do not is of great importance to clinicians and clinic managers, and insurance providers as they strive to maximize the effectiveness of care delivery. Patient adherence to treatment may be a major determinant in the patient's treatment outcome and the patient's satisfaction with outcomes may play a role in the patient's decision to adhere to hand therapy treatment.

Many patients with UE deficits present with functional impairments; in fact one study on shoulder pain found that upon initial evaluation 60% of patients had difficulty performing functional tasks. ⁵⁹ The studies presented in this dissertation will add to the body of knowledge on patient function by providing valuable information on patient adherence for the assessment and implementation of UE rehabilitation programs. In the first study, obtaining diagnosis specific thresholds for what is clinically meaningful to the patient will enhance confidence in interpreting patient change scores for clinical decision-making. Obtaining these diagnosis specific thresholds will expand therapists' confidence in knowing they have achieved on their QDASH patient specific meaningful targets. In the second study, learning why patients present with incongruence towards treatment will provide clinicians practical tools to help counter non-adherence to treatment. Finally, the third study will help guide clinical practice as clinicians will be informed of the effect of collaborative goal setting on patient adherence and to what extent collaborative goal setting makes a difference on functional outcomes expressed by QDASH scores.



PROBLEM

There are three problems this dissertation seeks to address. First, in hand therapy objective measures such as ROM and grip strength, along with functional activities, are typically utilized by the therapist to track patient progress. However, the patient's perception of improvement and function is also an important consideration, and their perspective may differ from that of the clinician. Therefore, it is desirable to use instruments that are meaningful and responsive to intervention, and capture the patient's perspective. The QDASH utilized in concert with the GROC can achieve this aim. To date, only Sorensen et al. 43 have calculated the MCID for the ODASH in distal UE conditions. Their study used multiple non-operative diagnoses of the forearm, wrist and hand and arrived at a 14-point MCID. However, this MCID is relatively general. We do not know how responsive the QDASH is to changing scores during rehabilitation of individual distal UE conditions. The question remains uncertain if the QDASH responds the same, better or worse for specific distal upper extremity pathologies. Taking a clinimetric exploration of the QDASH from this perspective will address the MAM dimension of condition-related factors, which examines factors such as the rate of progression and co-morbidities of the condition.

Secondly, in therapy the QDASH and the GROC are commonly used in concert, clinical observation indicates that there is incongruence in directionality between forms. We refer to incongruence as one form improving while the other form does not. This incongruence may affect the patient's decision to adhere or not adhere to treatment recommendations provided by the therapist and require further investigation to determine the factors affecting patient's responses to these common forms. Therefore, exploring the



patient's attitudes, beliefs, perceptions and expectations, in order to expand on what is already known within the MAM dimension of patient-related factors, can provide insight into the patient's decisions to adhere or not to therapy. A value added will be to first hand learn from these patients in their own words about these experiences.

Third, limited research has been done in acute hand therapy on adherence, which is a key component to rehabilitation. While there are several systematic reviews addressing chronic adherence or compliance in hand therapy, ^{60,61} to our knowledge, there is just only one review on acute hand therapy, and this review is on orthosis (splint) adherence. ¹⁶ In addition, patient adherence to general exercise and particular to hand therapy exercise has focused primarily on patient factors. ⁴⁷ While the role of adherence with treatment for a specific condition (distal radius fractures), ⁶² has been studied in hand therapy, the combined roles of adherence to home program and collaborative goal setting has not been examined. There is a need in hand therapy for further research to identify the barriers introduced by therapists (therapy-related factors) and health organizations (healthcare-team and systems related factors). ^{8,47} These two poorly explored MAM dimensions have potential to affect patient adherence with treatment.

PURPOSE AND AIMS

This dissertation was an investigation of patient adherence to UE rehabilitation programs and its impact on patient care and outcomes utilizing the WHO MAM's theoretical perspective. The first purpose was to explore the MAM dimension of condition-related factors to determine the QDASH's minimal clinical important difference (MCID) for three UE conditions. The second purpose was to explore the MAM dimension of personal factors to learn from individuals who expressed



incongruence between their QDASH and GROC scores; how they described their perceived change in therapy. The third purpose was to explore the MAM dimension of therapy-related factors to examine the effect of patient-therapist collaborative goal setting on patient adherence to treatment and on QDASH outcomes.

Specific Aim 1: Determine the MDC and MCID thresholds for the QDASH using a triangulation of distribution-and anchor-based approaches for the conditions of post-surgical distal radius fracture, non-surgical lateral epicondylitis, and surgical carpal tunnel release. This Aim will test one hypotheses 1) We hypothesized that there would be a greater MCID score needed using the QDASH for the three specific pathologies compared to the previous literature in which multiple diagnoses were combined to calculate QDASH MCID that ranged between 8-20 point and 18 points on the QDASH website.

Specific Aim 2: To answer the question "How do UE patients with an incongruence between the QDASH and GROC outcome scores describe their perceived change in therapy?" From this Aim we will 1) Learn about the patient's experiences and expectations of rehabilitation. 2) Learn about the patient's decisions to adhere and comply with rehabilitation guidelines.

Specific Aim 3: Examine the effect of patient-therapist collaborative goal setting on improved patient adherence to treatment and functional outcomes. This aim will test two hypotheses 1) Collaborative goal setting intervention will result in better adherence as measured by self-reported adherence, therapist-reported adherence, and attendance rate compared to a control group. 2) Collaborative goal setting intervention will result in



better self-reported UE function as measured by the QDASH scores compared to the control group.

OPERATIONAL DEFINITIONS

Adherence: an active, voluntary, and collaborative involvement by the patient in a mutually acceptable course of behavior to produce a preventative or therapeutic result.²

Compliance: the degree to which patients *obey* and follow through with prescriptions and proscriptions delineated by their treating health practitioner.²

<u>Canadian Occupational Performance Measure (COPM):</u>
⁶³ an individualized, client-centered outcome measure designed to capture a client's self-perception of occupational performance (or function), and its reliability and validity is well established. ⁵²

Global Rate of Change (GROC) scale:²⁷ a generic global scale asks that a person assess his or her current health status in relation to a previous time-point typically at the beginning of care to determine if they are same better or worse from initial intervention.

Hand Therapy: a specialty practice area of occupational therapy that primarily focuses on treating orthopedic-based upper-extremity conditions to improve the functional use of the hand and arm.⁶⁴ Certified hand therapists can either be physical or occupational therapists.

Home Exercise Program (HEP): refers to exercises provided by the therapist for the patient to adhere to on their own time outside of the clinic environment.

Incongruence: an inconsistency in directionality expressed by the patient in two subjective forms.

<u>Minimal Clinical Important Difference (MCID):</u> represents a change in score on a standardized assessment that is perceived to be beneficial or harmful by the patient.⁴⁰



Minimal Detectable Change (MDC): the smallest change in score on a standardized assessment that can be distinguished beyond random error.⁶⁵

Mixed-methods Embedded Design: utilizes qualitative and quantitative data to answer different research questions. This is in contrast to Triangulation design where the intent is to converge two different data sets to answer the same question. In Embedded design, either the qualitative or quantitative data sets are embedded within a larger design. 66

Occupational Therapy: a profession that uses the therapeutic use of daily activities (occupations) to help people across the lifespan participate in the activities they want and need to do. 67

Occupational Science: occupational science (OS) is defined as the study of humans as occupational beings. 68 OS emerged out of occupational therapy, as a discipline to study occupation and provide the science it requires. OS focuses on the "doing," which is a broad holistic concept not studied previously by any science. 69

Patient-centered care: providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions. Many models identified in the literature, medical (patient-centered medicine), nursing (patient-centered care), occupational therapy (client-centered care), psychology (client-centered counseling), and health and business management (customer-focused service).

<u>Patient satisfaction:</u> refers to the patient's satisfaction with treatment outcomes.

<u>Sport Injury Rehabilitation Adherence Scale (SIRAS):</u>⁷¹ an instrument designed to assess adherence during clinic-based sport injury rehabilitation sessions. The SIRAS has been used in hand therapy research.⁶²



Therapeutic alliance: the relationship between patient and therapist traditionally viewed as an important determinant of treatment outcome and is considered central to the therapeutic process. 54,56,72

<u>UE Rehabilitation:</u> involves rehabilitation of the entire upper extremity, from fingertips to the shoulder.

ASSUMPTIONS

It will be assumed that:

- Participants will understand the QDASH and GROC scales and will provide honest answers that reflect their true functional level.
- Participants will provide honest answers referring to their home exercise diary,
 Session Rating Scale (SRS), and Canadian Occupational Performance Measure
 (COPM).
- 3. Rehabilitation providers will provide honest answers when completing rehabilitation intake forms and measures of patient adherence.
- 4. Regarding qualitative data, it is assumed that the researcher remained objective during the course of the study and that participants provided accurate information regarding their experience.

DELIMITATIONS

- 1. Participants will be males and females between the ages of 18 and 89.
- 2. Participants in the third study were delimited to post-surgical distal radius fracture patients.
- 3. Occupational therapy or hand therapy prescriptions were not controlled in this



study.

LIMITATIONS

The studies were conducted in outpatient hand therapy clinics in a city of the Southeastern United States; therefore the results of this dissertation may only be generalized to those groups of patients and individuals with similar characteristics to this sample.⁷³

CHAPTER 2: REVIEW OF THE LITERATURE

INTRODUCTION

The purpose of this review was to: 1) discuss the known factors that positively and negatively influence exercise adherence using the WHO MAM as a framework, 2) discuss the commonly used measures of exercise adherence, 3) from an occupational therapy perspective hypothesize how exercise adherence might impact patients recovering from hand therapy deficits, and 4) examine from an occupational science perspective the occupations involved in the QDASH, since this instrument is utilized in all three studies.

FACTORS AFFECTING EXERCISE ADHERENCE

The global evidence on healthcare adherence has demonstrated that one-dimensional approaches to enhance treatment adherence, such as self-management education, tend to have modest results, whereas multi-level approaches targeting more than one factor with multiple interventions have been shown to be most effective. The Multidimensional Adherence Model (MAM) takes into account five distinct and interacting dimensions of the individual. These dimensions are social and economic, health system-related, condition-related, therapy-related and patient-related. The following evidence-based factors impacting exercise adherence are presented according to the five-dimensions of the MAM. (See Table 2.1).



Social and Economic

Socioeconomic factors reported in the global literature that have an impact on adherence is comprised among other factors of: low socioeconomic status unemployment, high cost of transportation to mention, unstable living conditions, family dysfunction, long distance from treatment center, low education level, illiteracy, poverty, and culture and lay beliefs about illness and treatment.⁴

Socioeconomic factors have not been consistent predictors of adherence in the hand therapy or the global healthcare literature. Nevertheless, there are some indicators of socioeconomic factors affecting general exercise adherence, although not of our population of interest. In a study on shoulder rotator cuff repair, smoking status was the only socioeconomic factor significantly associated with adherence to HEP (P = .00432; coefficient, 9.867). Ethnicity has been found as a predictor for treatment attendance at a resistance-training program and continued resistance training at nine months follow-up, for knee osteoarthritis (OA) participants. However, the authors did not clarify which ethnic groups were more or less likely to be adherent with the exercise program. Being unmarried has been found as a predictor for adherence to a one-year HEP in inflammatory rheumatoid arthritis (RA) disease participants.

In a study on women with fibromyalgia, unemployment at baseline significantly predicted those who engaged in exercise behavior in the first three months. At baseline, the predictor variables correctly classified 71.02% of the participants. In addition, educational level (high-school or lower) significantly predicted those who maintained exercise behavior after participating in an exercise class. The addition of the predictor variables improved the correct classification to 76.1%. ⁷⁷ In another study, therapists



estimated lower back pain (LBP) participants who pursued compensation to be less adherent to clinic based treatment activities than their non-compensable counterparts.¹⁴

Restricted social or family support was associated with non-adherence in multiple ways.⁴⁷ In a study of participants undergoing knee surgery for OA, the effectiveness of the spousal interactions depended largely on the quality of support provided by the spouse.⁷⁸ Another systematic review on chronic hand conditions, that included RA, found peer support groups to be effective.⁷⁹

In a study on participants with RA/OA, having the support of friends for exercise positively predicted exercise behavior nine months after participating in an exercise class. ⁸⁰ Having poor social support predicted poor attendance with resistance and aerobic exercise programs for participants with knee OA, ⁷⁵ while having a larger social support network predicted those who exercised regularly at baseline or who started performing regular exercise during the 18-month follow-up period. ⁷⁷ Although this information is not all specific to hand therapy, it is a reasonable assumption these factors may also have an effect on patient adherence in hand therapy. In addition, low socioeconomic status may place patients in the position of having to choose between competing priorities, as patients may shift limited available resources to meet the demands of other family members, such as children and older parents in their care. ⁴



Table 2.1 Overview of Variables Associated With Non-adherence and Adherence to Therapeutic Exercise Programs in Typical Adult Occupational Therapy Patients Using the World Health Organization Multidimensional Adherence Model.

MAM Dimension	Variable	Associated with	Associated with
		non-adherence	adherence
Social and economic	Ethnicity	Rejeski et al	
	Being unmarried	Stenstrom et al	
	Being employed	Oliver & Cronan	
	Education level, high		Oliver & Cronan
	school & lower		a:1 : 0 a1
	Smokers	Dairelai et al	Silverio & Cheung
	Restricted social or family support for activities	Rejeski et al Oliver & Cronan	
	support for activities	Minor & Brown	
		Fekete et al	
	Patients pursuing	Kolt & McEvoy	
	compensation	J	
Health-care team and	Follow-up length	No studies examined	this variable
System-related	Patient-provider		Sluijs et al
	relationship		Feinberg
G 177 1 1	II . 1	17	O'Brien & Presnell
Condition-related	Having a diagnosis of joint pathology	Kenny	
	First time injury	Milne et al	
		Alexandre et al	
Comorbidities:	High levels of depression	Shaw et al	
		Oliver & Cronan	
	No change or worse	Minor & Brown	
	depression than at baseline) (' 0 P	
	Anxiety/stress at baseline	Minor & Brown	T 1 . 1
	Pain	Rejeski et al	Lyngcoln et al
	Experience activity		Minor & Brown
	Functional activity Poor range of motion	Groth et al	Lyngcoln et al
	outcomes	Grotti et ar	
Therapy-related	Exercise proficiency		Codori et al
1 3	In-treatment exercise		Schoo et al
	adherence to predict		Lyngcoln et al
	future Attendance to		
	therapy appointments		T 1 . 1
	SIRAS* scores		Lyngcoln et al
	Complexity Interference with activities	Alexandre et al	
	of daily living/ work	Sluijs et al	
	www.j	O'Brien & Presnell	
	Worsening of pain during	Minor & Brown	
	exercise		
	Longer treatment duration	Alexandre et al	
Patient-related			
D 1 1 1. C	High perceived self-		Chen et al
Psychological factors:	efficacy		C4
			Stenstrom et al



T 11 A 1	<i>.</i>	1
Table 2.1 (CONTINII	en I
I abic 2.1	COMUNIC	cu,

			Oliver & Cronan
	High internal locus of control	Chen et al	
	High degree of helplessness	Castaneda et al Sluijs et al	
	Low extroversion scores	Castaneda et al	
	Low quality of well-being score	Castaneda et al	
Physical factors:	Low level of baseline physical activity	Schoo et al	
		Stenstrom et al	
		Minor & Brown	
Cognitive factors:		No studies	
		examined these	
		variables	

Socioeconomic Interventions to Maximize Patient Exercise Adherence in Hand Therapy.

When faced with economically disadvantaged patients, therapists can inquire of other follow-up services closer to home, involve other support agencies, and reduce follow-up services to the minimum safely required. Clinicians can work with surgeons to establish pre-operative education and motivation to patients. In the past, providing patient education leaflets and classes with multiple members of the health care team has shown success. When possible and appropriate, provide rehabilitation with other patients, or group treatment to encourage social contact, support, motivation and encouragement for exercise, and role models that may be important. Actively involving the patient's partner in the rehabilitation process may benefit some patients by the motivation and encouragement received. See Table 2.2 for a list of interventions that may improve patient adherence.



Health-care Team and Systems Interventions

Comparatively, minimal research has been conducted in the healthcare team and systems dimension. There are multiple factors within this dimension that can play a negative role on adherence. These include short consultations, poor medication distribution systems, inability to provide community support, overworked healthcare providers, lack of incentives and feedback on performance, and poorly developed health services with inadequate or non-existent re-imbursement by health insurance plans and. In contrast, it is known a good patient-provider relationship may improve adherence. It is important to be cognizant that the reason for a patient's non-adherence may not lie with the patient but rather with the clinician. In the hand therapy literature, a qualitative study

Table 2.2 Interventions That May Improve Patient Adherence

Type of intervention	Example	Intervention
Socioeconomic- related	Socially isolated patient	Provide social contact with other patients ¹ Encourage involvement of significant others in care
	Economically disadvantaged	Involve other support agencies Inquire on available follow-up services closer to home Decrease follow-up services to the minimum safely required ²
Health-care Team and System-related	Busy clinic, patient unable to share concerns or ask questions	Ensure patients are given enough individualized time each treatment session
	Patient's views not included in the treatment plan	Elicit the patient's perspective, expectation, wants, needs early to include in an individualized plan of care ³
	Inconsistent messages from the physician and the clinicians	Ensure everyone on the health-care team provides the same message ³



Table 2.2 (continued)

1 able 2.2 (continu	ea)	
Condition-related	Patient perceives pain will interfere with performing exercises	Elicit the patient's perspective on pain experience and beliefs ¹
	CACICISCS	Explain pain should not preclude most patients from participating in exercises ¹ Work as a liaison with the doctor to ensure the right analgesia is given ^{1,2}
	Patient displays signs and symptoms of anxiety or depression	Ensure clinicians can recognize signs and symptoms of comorbidities such as anxiety and depression ³
Therapy-related	Patient not understanding treatment intervention	Provide verbal instruction, review patient's recall, pamphlets ¹
	Lack of patient motivation	Provide positive feedback, exercise diaries, reward, written treatment contracts, counseling sessions ¹
	Patient does not follow through with prescribed program	Establish patient-therapist collaborative goals, action plans and coping plans ¹
Patient-related	Patient has unrealistic expectations for healing timeframe	Discuss healing progression timeline. Set realistic expectations ³
	Patient has low self- efficacy; does not believe can perform HEP	Pair patient with another patient for support and role model Review with the patient action plans and coping plans
Adapted from: 1 = Jack	et al., 2010; 2 = Sciber	ras et al., 2013; 3 = O'Brien 2012
		<u> </u>

found those participants who trusted their treatment provider and were provided with clear and consistent education were more likely to follow their exercise program.⁸⁵

The review of the hand therapy and musculoskeletal literature revealed that unfortunately this dimension of adherence has not been thoroughly investigated with most of the publications focusing on either physical structures or personal factors. ^{16,47}



According to O'Brien,⁸ this is a "missed opportunity" as we have many of the factors that can play a significant role to promote adherence, within our control. Another systematic review, on patient-practitioner interactions on adherence in people with arthritis, found that the patient's belief in the benefit of a particular treatment and affective tone had an influence on patient adherence.⁸⁶ Patients who believed that the crippling effects of arthritis were inevitable complied much less frequently than those who were less resigned to eventual disability.^{87,88}

Health-care Team and Health Systems Interventions to Maximize Patient Exercise Adherence in Hand Therapy

The health-care team can benefit from obtaining the patient's perspective, expectations, wants, and needs, early in the therapeutic process in order to incorporate them into the treatment plan. It is critical to provide consistent continuity of care. This can be achieved by ensuring the entire health-care team gives the same message. It is important for clinicians to be aware of emerging options available to increase the patient's likelihood of adhering to exercise programs through continued medical education. The ultimate focus should be to encourage the patient's own sense of self-efficacy by providing an *individualized* treatment program with the right challenge for patient success.

Condition-related

Condition-related factors represent the injury or illness-related demands faced by the patient. These include severity of the disease, the level of disability, co-morbidities, rate of progression, and the availability of effective treatments. Their effect depends on



how they influence the patient's risk perception, priority to adhere, and importance of following treatment.⁴

In a study of workers with a variety of injuries, participants with a joint pathology diagnosis were less likely to complete a supervised exercise program.⁸⁹ In the athletic population, those with a first time injury were less likely to adhere to treatment than those who had reported three or more injuries.⁹⁰ In another study, the presence of other medical illnesses predicted poorer exercise adherence compared to those with no comorbidities.⁹¹

Regarding comorbidities, high levels of depression predicted low attendance to exercise programs. For participants with OA/RA, after participating in a 3-month exercise class, improvements in depression from baseline predicted participation in regular exercise at 3-months, 9-months and 18-months. In this same study, higher levels of anxiety at baseline predicted poor exercise maintenance at 3-months and 6-months after participating in a 3-month exercise class.

Concerning pain, in participants with OA/RA improvements in pain following an exercise class positive predicted exercise behavior 18 months later, ⁸⁰ while greater levels of baseline pain predicted reduced time spent in aerobic exercise at 3-month follow-up in participants with knee OA. ⁷⁵ In the acute hand therapy literature a significant association was found between change in subjective pain rating and home exercise adherence. ⁶²

Relating to function, in the acute hand therapy literature, patient adherence measured by home exercise reporting, therapist reporting and attendance was able to significantly predict function in wrist extension range of motion (ROM) and simulated feeding. 62 In that study, adherence was able to predict 56% ($R^2 = 0.56$) of variance in Levine questionnaire change scores, 57% of variance in wrist extension change



measurements, and 52% of variance in change scores for the Jebsen Test of Hand Function (JTHF).⁶² In another study on mallet finger injuries, poor ROM outcomes were associated with non-adherence.⁹²

Condition-related Interventions to Maximize Patient Exercise Adherence in Hand Therapy Interventions

Therapists should aim to gain a clear understanding of the patient's pain experience and beliefs about pain, and argue against those that are maladaptive. ^{85,93}

Therapists can introduce messages that reduce anxiety and fear, such as 'pain should not prevent most patients from participating safely in therapeutic exercise', in order to help reduce symptoms, improve function and return to work. ⁴⁷ It is important to establish support for co-morbidities. Therapists should be trained to identify signs and symptoms of co-morbidities that may affect adherence such as anxiety disorders or depression, and refer them to appropriate services. ^{8,47}

Therapy-related

There are multiple therapy-related factors that affect patient adherence. These include duration of treatment, complexity, previous treatment failures, frequent changes in treatment, the immediacy of benefit, side effects, and interference with lifestyle, and the availability of medical support to deal with these factors.

In hand therapy, a study aiming to develop a clinical measure of compliance found a significant association between patient self-reporting rates of adherence and patient exercise proficiency. ⁹⁴ Lyngcoln et al. (2005) found a significant association between therapist rated adherence for items of the JHTF, ⁹⁵ lifting light cans r = 0.561, and simulated feeding, r = 0.59, p < 0.05. In this same study, attendance was significantly



and negatively associated to writing, r = -0.56. Participants who attended more frequently were more likely to experience less improvement in writing speed of the affected hand. The authors did not provide an explanation for this finding. Concerning intreatment program adherence, participants who reported adhering to their prescribed HEP in the first four weeks of the program were 20 times more likely to report adhering with exercise in the final four weeks.

In the acute hand therapy literature, the perceived complexity of treatment, and interference with completion of daily occupations were causes for non-adherence. The hand therapy literature has advocated for including meaningful occupation based activities in treatment. Nevertheless, only few studies have examined this concept. A small randomized controlled trial found meaningful occupation-based activities that mimic the function of the hand to be more effective than conventional exercises in restoring measures of ROM, strength and participants rated function.

A randomized control trial demonstrated that meaningful activities could also improve treatment adherence. In this study, participants' recorded higher numbers of repetitions when their exercise devise was connected to a computer game, compared with participants given only an exercise devise and told to use at a comfortable pace. ⁹⁹ Similarly, in another study of chronic stroke participants to determine the effectiveness of a bilateral, self-supported, upper-limb rehabilitation intervention using a movement-based game controller, they found significant improvements (p < 0.001) compared to all pre-intervention assessments. ¹⁰⁰ Also, significant results with stroke participants to regain supination have been reported. ¹⁰¹ In a different study, the occupationally embedded



exercise resulted in significantly more handle rotation (requiring more supination) than the rote exercise, t(24) = 2.28, P (one tailed) < .05, with a large effect size d = .885.

Therapy-related Interventions to Maximize Exercise Adherence in Hand Therapy

Therapists can provide explicit verbal instruction, review the patient's recall, and provide written instruction, as this may be effective at improving exercise adherence. 102

The use of motivational techniques such as exercises diaries, positive feedback, reward, written treatment contracts, and counseling sessions may aide in patient adherence. 103

Establishing collaborative patient and clinician goals, action plans and coping plans may be effective with patients who intend to participate in exercise. 104 Identifying potential barriers can aide in the development of action plans to begin an exercise program. 47 This can be accomplished by exploring the patient's level of self-efficacy. Questions such as "How confident are you of overcoming obstacles to exercise?" And in the event of relapsing for a few weeks on the HEP... "How confident might you be of returning to your exercise routine?" 105 can help identify the difficulties that may arise over time and help patients maintain their exercise program. 106

Patient-related

Patient-related factors include the expectations, knowledge, beliefs, attitudes, perceptions, and resources (psychological, physical or sensory).⁴ The MAM breaks the patient-related dimension into psychological, physical, and cognitive factors. Multiple models and theories have been used in an effort to understand patient-related adherence to health interventions, including the theory of planned behavior and self-efficacy, the health belief model, the transtheoretical model, and the theory of reasoned action, ¹⁰⁷ and recently in rehabilitation, the health action process approach (HAPA). ¹⁰⁸ Although each



has its advantages and disadvantages, questions remain about how to maximize adherence to exercise and physical activity. However, patient motivation is central to patient adherence to exercise, and is key to most theories used to study health behavior for either behavior change purposes or prediction.¹⁰⁷

Two common questionable assumptions in hand therapy is that the patient is motivated for treatment, and that educating them regarding their injury is enough for patient adherence.⁷ The evidence on motivation from the behavioral sciences indicates that patient readiness to engage in treatment can be at any of multiple stages. These "stages of change" can be explained by the "transtheoretical model of change" that can been applied in hand therapy to address patient motivation.¹⁰⁹ Nevertheless, caution must be observed, as a high quality study employing the transtheoretical model in physical therapy (PT) did not find it more effective than PT and sham intervention.¹¹⁰ Regarding the flawed assumption that an informed patient is an adherent patient, there is evidence information by itself is not enough for creating or maintaining good adherence habits.⁴

The fact that a therapist discusses a precaution with a patient does not necessarily mean the patient understands the implications, especially if the patient is overwhelmed from surgery or distracted in a busy clinic at the time the information is given.⁸ In a study of 28 cognitively unimpaired post-flexor tendon repair participants, only 42.5% recalled instructions without the need of a cue, to include "do not remove your orthosis." ¹¹¹

In a study on upper limb participants, high internal health locus of control was found as a predictor of non-adherence, indicating participants felt self-sufficient with their health and did not regard the recommendations from the health-care team as necessary to warrant follow through. Other psychological factors associated with non-



adherence include high degree of helplessness, ^{48,83} low extroversion scores and low quality of well-being scores. ⁸³ In the hand therapy literature patient's belief and attitudes about their condition and expected treatment have been shown to be important and have an effect on adherence. ^{48,85,113} Studies have found high-perceived self-efficacy to be a predictor for HEP adherence. ^{76,77,112}

Although physical factors have not been investigated in hand therapy, in the global literature older participants with knee or hip OA, who were physically active at baseline were 14 times more likely to adhere to a HEP. In participants with RA, performing regular ROM exercises prior to beginning a study predicted adherence with a one year HEP. The opposite was found in participants with OA/RA with low baseline levels of physical activity, where low aerobic capacity at baseline predicted negative exercise behavior at three months and 18 months after participating in an exercise class. 80

No studies were found addressing cognitive factors and exercise adherence. However, a study on adherence with splinting of post-brain injury patients, found lower rates of adherence (60.5%) compared to the overall mean of all other studies (85.17%). Further research is needed addressing patient cognitive factors and adherence.

Patient-related Interventions to Maximize Exercise Adherence in Hand Therapy

Therapists should ensure interventions go beyond providing advice and prescription, as education alone is a weak intervention. ^{4,8} In addition, the use of strategies such as establishing collaborative goals, setting and agreeing on realistic expectations, action planning, coping planning and positive reinforcement may help increase patient self-efficacy and adherence. ⁴⁷ Finally, therapist should seek specific skill development in behaviorally based interventions that can be incorporated into practice. ⁸



MEASURES OF EXERCISE ADHERENCE COMMONLY USED

Three systematic reviews on exercise adherence revealed the most commonly used measures of adherence are adherence with HEPs, in-clinic adherence, and attendance at appointments. There was a variety of the type of measures used. These could be grouped as continuous dichotomous/categorical, attendance and exercise accuracy.

Continuous measures were numeric values that had a level of magnitude between them, such as 10 is twice the value of 20 and 23 is before 24. Continuous values included rates and counts. Continuous measures of exercise adherence included number and duration of exercises completed, the total number of minutes spent on an activity, and for lower extremities, the number of step count over a pre-determined period of time.

Dichotomous variables, (or binary variables) included only two categories, such as yes/no or 1 or 2, or complete/incomplete. Dichotomous/ categorical variables included achievement of a predetermined number of exercise sessions or physical activity, self-rating as to whether or not participants had completed the home exercises as often as prescribed, and change in overall activity level. Categorical variables included three or more categories indicating a level of adherence. These were typically ordinal and were a selected level of exercises completed such as less than 30%, 30-75%, and 75% or more, and so on.

For adherence with HEPs, patient self-report using diaries was the most common method utilized in one review.⁴⁷ The use of exercise diaries have been demonstrated to increase patient adherence.¹¹⁵ However, patients tend to overestimate their actual adherence with treatment when using self-report. Despite this, self-report of exercise



adherence tends to identify 50% of non-adherents. Validated self-report instruments used to report HEP adherence with upper extremity include the Visual Analog Scale (VAS), 117-119 and the augmented medical adherence measure questionnaire. See Table 2.3 for a description of commonly used validated scales to measure exercise adherence, therapist-patient alliance and treatment goal collaboration, and the psychometric properties of the instruments. Self-reporting methods by themselves are useful as compliance enhancing interventions, but do not provide the unbiased behavioral baseline required for research purposes. Poor compliance with diary completion or recall accuracy may lead to questionable validity. Therefore a combination of adherence measures is recommended.

Some studies used the accuracy of exercises performed to rate adherence. This was achieved by having either the treating clinician or the researcher rate the patient's performance of exercise accuracy. High adherence rates were corroborated in a recent pilot study on sedentary women using phone diaries and pedometers. They achieved 93.8% overall adherence with pedometer use and 88.3% with the mobile phone. Although the pedometer would not be applicable for upper extremities due to the enhanced degrees of freedom, this study gives insight into the effectiveness of mobile phone use as a diary to measure adherence. One study used a piloted portable orthosis device to record time of day and number of exercises performed in flexor tendon repair participants. Another study used technology developed by the video rental industry;

Table 2.3 Commonly Used Validated Scales to Measure Exercise Adherence, Therapist-patient Alliance and Treatment Goal Collaboration.

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Type of instrument	Scale	Measures	Format	Reliability	Validity	Response
a) Patient- rated adherence	Augmented Medical Adherence Measure (MAM)	Patient's understanding of clinician's instructions, patient's perception of their adherence behaviors for each regimen, and the difficulties encountered following through with	Comprehensive semi-structured interview that has four general modules to assess adherence with medication, diet, exercise, and clinic attendance, as well as illness-specific modules. given weekly. Each measure is scored individually.	Not rated	Adequate convergent validity for medication portion, the percent of missed doses identified on the MAM was significantly correlated with the missed doses tracked by electronic technology, r = 0.40, p = 0.04, (Zelkovsky et al., 2008).	Not rated
	Visual Analog Scales (VAS)	Consistency with prescribed exercise.	10-cm line in a variety of formats; requires careful instruction; score is 0-100% on compliance, initially used for pain but has been revalidated for other constructs.	Can vary but, high test-retest has been demonstrated between vertical and horizontal scales, r = .99, P < .001 (Dixon & Bird, 1981), (Scott & Huskisson, 1979).	High correlation between VAS and numeric pain-rating scale .62 (Downie & Leatham 1978); finger dynamometer .38 to .46; p < .05 and verbal description of pain, .77 to .89; p < .001 (Wilkie et al., 1990).	For pain, able to detect 21 levels of just noticeable differences (Langley & Sheppeard, 1985).

Type of instrument	Scale	Measures	Format	Reliability	Validity	Response
b) Therapist- rated adherence	Sports Injury Adherence Scale (SIRAS)	Patient's adherence to in clinic rehabilitation.	3-item measure in which clinicians' rate patients' intensity of completion of rehabilitation exercises, the frequency in which they follow the clinician's instructions, and their receptivity to changes in the rehabilitation program. All 3 items measured on a 5-point Likert scale.	Test-retest reliability .77, Internal consistency .82 (Brewer et al., 2004).	Criterion validity established positively correlated in two samples (Brewer et al., 2000).	Not rated
c) Therapist- patient alliance (Patient-rated)	Outcome Rating Scale (ORS)	To assess change in patients following psychological intervention.	The ORS is a 4-item (overall, individually, interpersonally, socially) visual analogue scale developed as a brief alternative to the Outcome Questionnaire-45 (OQ-45). It takes approximately 1 min to complete.	Test-retest reliability .66, internal consistency .93 (Miller et al., 2003).	Concurrent validity, moderately strong correlations between ORS items and OQ-45 subscales and total scores, an overall correlation of59 between the ORS and OQ-45 total scores.	Not rated
(Patient-rated)	Session Rating Scale (SRS)	To encourage patients to identify any alliance problems with their therapist so that the clinician may change to better-fit patient expectations.	The SRS is a four-item (relationship, goals and topics, approach and method, overall) visual analogue scale designed specifically for everyday clinical use. It is a brief alternative to the Revise Helping Alliance Questionnaire (HAQ-II) and the Working Alliance Inventory (WAI).	Test-retest reliability .64, internal consistency .88, it is positively correlated to the ORS (.29, p<.01), indicating that the SRS functions in much the same way as other alliance measures (Duncan et al., 2003).	Concurrent validity, .48 between SRS and HAQ- II, all correlations between the SRS and HAQ-II items were between .39 and .44 (Duncan et al., 2003).	Not rated



Table 2.3 (continued)

Table 2.3 (continued)

Type of instrument	Scale	Measures	Format	Reliability	Validity	Response
d) Therapist- patient goal collaboration (Therapist & patient rated)	Canadian Occupational Performance Measure (COPM)	To assesses an individual's perceived occupational performance in the areas of self-care, productivity, and leisure.	The assessment involves a 5-step process nested within a semi-structured interview, typically conducted by an Occupational Therapist. Interview focuses on identifying activities within each performance domain that the client wants, needs, or is expected to perform. Following Step 3, the patient and therapist create goals for therapeutic interventions. Takes 10-20 min to administer (Law et al, 1990).	Test-retest reliability .87 performance .88 satisfaction (Cup et al, 2003; 2 to 6 months post onset, Acute Stroke).	Convergent validity, Significant positive correlations between the COPM scores and the Sickness Impact Profile (SIP68), Disability and Impact Profile (DIP), and Impact on Participation and Autonomy (IPA) scores (Eyssen et al., 2011; Dutch version; n=138; mean age=51 (13),	A change of 2 or more points is clinically significant, changes in scores from assessment to reassessment s tend to be significant (Law et al., 2004).
(Patient-rated)	Patient Specific Functional Scale (PSFS)	To assess functional change, primarily in patients presenting with musculoskeletal disorders.	Patients are asked to identify up to five important activities they are unable to perform or are having difficulty with as a result of their problem. In addition to identifying the activities, patients are asked to rate, on an 11-point scale, the current level of difficulty associated with each activity."	Test-retest reliability ranging from .55 to .92 on multiple conditions, (Horn et al., 2012).	Concurrent validity, of the PSFS and the Neck Disability Index (NDI) at .82. (Horn et al., 2012).	the minimal clinical important difference MCID has been found between 2 to 3 points (Horn et al., 2012).



participants' PreP videocassettes contained a hidden electronic counter that recorded each instance in which the videocassettes were played. 123

The most common measure of in-clinic adherence was the therapist-rated Sport Injury Rehabilitation Adherence Scale (SIRAS), which has been proven valid and reliable.⁷¹ However, clinicians and patients may disagree on the level of patient adherence,¹²⁴ and this variation between ratings from the therapist and the patient on the patient's adherence leaves room for considerable inaccuracy.¹⁴ It is recommended to use therapist-rated adherence measures in conjunction with patient-rated exercise diaries to corroborate patient self-reports.⁴⁷

Attendance at appointments was standardized for studies looking at individual participants as a ratio of sessions attended to sessions scheduled. Nevertheless, one drawback from attendance is it does not provide any information regarding the patient's behavior or attitude towards rehabilitation.¹⁴ This highlights even more the need to combine adherence measures.

THE IMPACT OF EXERCISE ADHERENCE IN HAND THERAPY AND OCCUPATIONAL THERAPY

The concept of a multidimensional perspective on adherence goes hand-in-hand with the holistic patient view of the occupational therapy and hand therapy professions. In spite of this, there is evidence most hand therapy clinics do not utilize client-centered interventions. ¹²⁵ Employing a client-centered approach in hand therapy such as the Canadian Occupational Performance Measure (COPM)¹²⁶ or the Patient Specific Functional Scale (PSFS)¹²⁷ can help elicit the patient's perspective and therefore maximize outcomes (see Table 2.4). A systematic review examining the effectiveness of



goal planning in rehabilitation found strong evidence (a 20% improvement on baseline testing, p < 0.05 in 4 studies) that a prescribed specific, difficult goal versus instructions to 'do your best' can improve immediate patient performance in some specific clinical contexts, and some limited evidence was identified that goal planning can influence patient adherence to treatment programs.⁵⁵

EXAMINING OCCUPATIONS DESCRIBED IN THE QDASH

The Quick Disabilities of the Arm Shoulder and Hand outcome questionnaire (ODASH), a short form of the 30-item DASH, allows patients to rate their functional activity level and symptoms of impairment in rehabilitation. The QDASH uses 11 items scored on a 1-5 Likert scale to measure physical function and symptoms in persons with multiple musculoskeletal disorders of the upper limb. The ODASH has been found to be valid and reliable, ¹²⁸ and is recommended as one of the patient reported outcome instruments of choice for distal radius conditions.⁵⁷ Some authors have identified a need to return to focus on occupation-based interventions in hand therapy while viewing the patient holistically. 125 The DASH incorporates functional activities that fall within occupation-based activities. Examples of occupations that are included in the DASH are cooking (Open a tight or new jar and Use a knife to cut food), bathing (Wash your back), and weight-training/bodybuilding (Do heavy household chores (e.g., wash walls, floors), Carry a shopping bag or briefcase, and Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.). There has been work in hand therapy utilizing the DASH and the COPM to measure patient centered goals with multiple conditions. However, what has not been done is to address one specific condition, such as distal radius fracture using the COPM to establish



client-centered goals, and measuring the effectiveness of the intervention through the patient's functional performance on their occupations on the QDASH.

CONCLUSION

In this review we identified the common terms used to describe adherence, factors associated with exercise adherence using the WHO MAM, hand therapy interventions, and methods of exercise adherence used in research. There is strong evidence of barriers to exercise adherence for poor social support, greater perceived number of barriers to exercise, low self-efficacy, anxiety, depression and helplessness, low levels of physical activity at baseline. Clinicians should elicit from patients their expectations, beliefs and concerns and incorporate these into collaborative goals.

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CHAPTER 3: SPECIFICITY OF THE MINIMAL CLINICAL IMPORTANT DIFFERENCE OF THE QUICK DISABILITIES OF THE ARM SHOULDER AND HAND (QDASH) FOR DISTAL UPPER EXTREMITY CONDITIONS

INTRODUCTION

The Minimal Clinical Important Difference (MCID) represents a change in score on a standardized assessment that is perceived to be beneficial or harmful by the patient. The MCID may be calculated for patients with upper extremity (UE) deficits using two common UE assessments, the quick Disabilities of the Arm, Shoulder and Hand (QDASH)²⁶ and The Global Rating of Change (GROC). The MCID can be clinically used to interpret patient change scores to guide clinical decision-making.

The QDASH, a region specific outcome measure, is a shortened version of the Disabilities of the Arm Shoulder and Hand (DASH). ¹²⁹ Both instruments are widely used in rehabilitation. ^{130,131} The GROC, a generic global change scale, allow patients to decide how much they have changed during recovery. The QDASH's MCID has been determined using the GROC to identify those patients who have improved and comparing them to those who have not improved with UE diagnoses. ⁴² However, the results of these studies have generated a wide range of MCID (8-20), ^{42-45,132} which represents 10-20% of the 100-point scale and suggests the instrument may have poor responsiveness. One potential explanation for this variance may be because a single diagnosis was not used in most of the previous studies. ⁴² The MCID may differ among diagnoses, and this may help explain the varying results in the literature. ¹³³ This is the primary rationale for examining MCID among separate diagnoses.

The QDASH's psychometric and clinimetric properties have been investigated.

Rasch analysis¹³⁴ and classical theory^{41,135,136} have been used to investigate the strength



and weaknesses of the QDASH measures. A recent systematic review found the QDASH English version tool to perform well with strong positive evidence for reliability and validity (hypothesis testing) and moderate positive evidence for structural validity testing. Strong negative evidence was found for responsiveness due to lower correlations with global estimates of change.¹³⁷

Multiple approaches have been used to calculate the responsiveness of these measures. The MCID current and previous values become critical in assisting providers in making clinical decisions. Several authors have suggested clinicians and researchers work with a range of MCID values instead of a fixed value, ^{138,139} another has questioned the validity of a single overall MCID. ⁴⁴ Distribution-based and anchor-based methods have been the two general approaches used to determine changes. The strategy for distribution-based approaches lies in identifying the Minimal Detectable Change (MDC), which is the smallest change in score that can be distinguished beyond random error. ⁶⁵ Distribution-based approaches do not give a good representation of the importance of the observed change as perceived by the patient and therefore cannot provide the MCID. ¹³⁸ In contrast, with anchor-based methods the choice of the anchor, to include other concepts will determine the precision of the MCID.

Recent studies advocate for the MCID be based primarily on anchor-based procedures, ¹⁴⁰ should be higher than the MDC values (the typical boundary of stable patients, that represents a value beyond measurement error), ^{65,140} and not be based on a single study. ⁴⁰ Nevertheless, there are limited studies calculating the MCID through anchor-based approaches for the QDASH. ⁴²⁻⁴⁵ Furthermore, it seems the best option to determine MCID is to select a small range of threshold estimates from the same sample



and compare and interpret multiple reference standards. ^{40,140,141} This approach has been applied in a few studies on the DASH and QDASH. ^{41,132} Some of the approaches to calculate the MCID utilized in the literature are: 0.2 x standard deviation at baseline, 0.5 x standard deviation at baseline, and one standard error of measurement (test-retest), among many others. ⁴¹

The main aim of this study was to use both anchor-based and distribution methods to triangulate on MCID values for the QDASH. We used a retrospective large sample of patients with UE musculoskeletal disorders who had undergone hand therapy. The objective was to determine condition specific thresholds for the MCID in order to enhance confidence in interpreting patient change scores for clinical decision-making.

METHODS

Subjects

This retrospective study population consisted of patients in a clinical database seen at an outpatient UE orthopedic condition rehabilitation multi-center, over the last 4 years. There were approximately 5,000 patients in the existing database treated for multiple orthopedic conditions. All data in the database was de-identified and transferred to a data sheet for study purposes and then provided to the primary investigator (PI) for use by the database manager. The University of Kentucky's Institutional Review Boards approved this exempt category study prior to data analysis.

Inclusion and Exclusion Criteria

Subjects age 18-89, were included if they were not missing QDASH scores at initial visit and visit 4, not missing last visit score determined per diagnoses at either visit 8 or visit 12, and not missing associated GROC scores for the QDASH. Diagnoses not



totaling at least 100 records, based on the above criterion were excluded. Surgical distal radius fracture, non-surgical lateral epicondylitis, and carpal tunnel release were included as the three most common conditions treated by hand therapists at these facilities.

Assessment

The QDASH uses 11 items to measure the level of function and symptoms in multiple physical activities of the shoulder, arm, or hand problem. It utilizes a 5-point Likert skale for seven functional items and three symptom items. Ten of the 11 items need to be completed for the scores to be valid. The score is calculated on a 0-to-100 point scale. A higher score reflects greater disability. The 2 optional scales of the QDASH (work and sport/music) are not collected in this clinical practice and therefore were not part of this study.

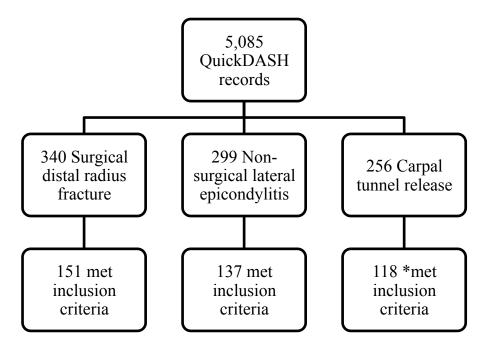
In contrast, the GROC scale 142 asks that a person assess his or her current health status in relation to when they start their treatment and rate their level of change on a 15-point scale (-7 = a very great deal worse, 0 = same, +7 = a very great deal better). Both instruments have been reported to be valid and reliable. 26,30,31

Procedure

The database was reviewed to identify the most commonly treated diagnoses. It is known from review of the database that the typical number of visits for all diagnoses ranged from 8 to 12 visits. A screening process was used to identify that adequate scores were present at the time point of interest at initial, 4th, 8th, and 12th visit (Figure 3.1). In addition, the range of days treated was explored to determine a cutoff point for the last visit.



Figure 3.1 Flow of charts meeting inclusion criteria



Inclusion criteria: have values for QDASH initial, visits 4,8 and 12, and GROC visit 12. *= last visit for QDASH and GROC is visit 8 instead of 12.

Statistical Analysis

Descriptive statistics

All statistical analyses were performed using Stata/ IC Version 13.1 (StataCorp LP, College Station, TX). Baseline characteristics per diagnoses between improved and not improved patients were determined for patient demographics of age, initial QDASH, and length of days in care using a *t*-test for parametric data and a Wilcoxon Mann-Whitney test for nonparametric data. A Chi-square test was used to calculate baseline gender differences (Table 1).⁴⁵ Patients were sub-divided per diagnoses into two groups each, stable and improved, in order to analyze baseline characteristics. Stable patients were categorized from GROC scores that ranged -2 to +3. Improved patients were



determined as reported scores on the GROC of $(\ge +4)$, 45 at visit 12 or visit eight for carpal tunnel release.

Validity and Reliability

- 1) We examined *Convergent Validity* to determine the correlation between the QDASH and the GROC using Pearson correlation coefficient (r). This was performed because the GROC was the reference standard, or external criteria by which we judged that a real patient improvement had occurred. We expected an at least a fair association (r > 0.30) between their final QDASH score (visit eight or twelve), and their final GROC score (visit eight or twelve).
- 2) *Test-retest reliability* was calculated for the QDASH using an ANOVA (ICC2,2,1) using a group of stable patients on GROC (-2 to +2).⁴⁵ In order to assess reliability, the fourth visit of the QDASH was compared to the initial visit scores, as they were the earliest available repeated QDASH scores.

Responsiveness

Responsiveness was determined by distribution-based and anchor-based methods.

a) Distribution-based methods determine the ability to detect change in general, and are based on the statistical characteristics of the sample. We calculated the Standard Error of Measurement (SEM), which links the reliability of a measurement tool to the standard deviation of the population. This was obtained from an ANOVA using the entire population for the diagnosis. We calculated the Minimal Detectable Change (MDC), which represents the smallest change in score likely to reflect a true change, free from measurement error, (MDC = SEM * z-value* $\sqrt{2}$.) We established a 90% confidence level (MDC₉₀) corresponding to a z-value of 1.65. Meaning: If the patient has a change score



greater or equal to the MDC₉₀ threshold it is possible to state with 90% confidence that this change is real and not due to measurement error.

- b) *Anchor-based methods* utilize an external patient criterion (an anchor) to determine if changes in outcome are clinically meaningful. Two approaches were used; the mean change and receiver-operating-characteristic (ROC) curve approaches. The GROC assessment was used as the external reference in evaluating responsiveness.
- c) *The Mean Change Approach:* Was calculated as the mean change score utilizing a visit-12 GROC anchor (visit-eight for carpal tunnel release) in the different subgroups of patients who respectively reported themselves as not improved (-7 to 0), minimally improved (+1 to +3), moderately improved (+4 to +5) and large changes (+6 to +7). We used changes in those minimally improved to triangulate the MCID values.
- d) *The ROC Curve Approach:* We determined the optimal cutoff score and the area under the curve (AUC) considering the subjects improved with a GROC of +4 or greater. A ROC curve plots sensitivity (y-axis) against 1 specificity (x-axis). Following this rationale, sensitivity was calculated as the number of patients correctly identified as improved based on the cutoff value divided by all patients identified as having had a meaningful change (GROC +4 or greater), whereas specificity refers to the number of patients who were correctly identified as not improved based on the cutoff value divided by all patients who truly did not have a meaningful change (GROC, less than +4). The balance point cutoff was chosen as the point that jointly maximized sensitivity and specificity (was associated with the least amount of misclassification).

The AUC can be interpreted as the probability that a given diagnostic tool will correctly assign a patient to the appropriate diagnostic category. In general, AUC values



between 0.7 and 0.8 are judged as acceptable, and an AUC value greater than 0.8 is considered to have good to excellent discrimination. The greater the AUC indicates a larger capacity to differentiate between patients who have made improvement from those who have not improved. In accordance with Turner et al, 44 our ROC analysis used the entire cohort, instead of only those subjects with ratings adjacent to the dichotomization point to increase accuracy and obtain more reasonable estimates of the MCID. We used the ICC test-retest from the product of our ANOVA that utilized a GROC of (-2 to +2).

To obtain CIs for the ROC-derived parameters, we drew 50 bootstrap samples and calculated both the cutoff value and the AUC in each bootstrap replication. The mean of the 50 bootstrap AUC values was taken as the best estimate, with the 95% CI calculated as 1.96. SD (as an estimate of the standard error) of the bootstrap values. This was need to be done because the AUC does not provide a CI, this provides an estimate of how acceptable are our findings (.50 not good .70 acceptable, .80 good).

The MCID was set at the best triangulation of the results coming from both anchor-based (mean change and the ROC curve) and distribution-based (the MDC₉₀ threshold) methods. This is considering that the MCID should be based primarily on anchor-based procedures¹⁴⁰ and be higher than the MDC value. Based on this understanding, the MDC should be interpreted as another piece in the puzzle toward establishing the MCID, by benchmarking it to the boundaries of error.¹³²

According to Turner et al,⁶⁵ "if the two anchor-based methods calculated on the same population yield different MCID values, then the knowledge that one value is below the MDC could aid in the decision to select the other." In addition, the ROC-curve approach was preferred as the first choice as it successfully addresses most limitations of



the mean change approach.^{40,140,144} Furthermore, our calculation of the 95% CIs gave a useful indication of the sampling variation.¹³⁸

RESULTS

Descriptive Statistics and Validity of the Measures

After excluding for missing data, 406 patients met inclusion criteria for three diagnoses; surgical distal radius fracture (n = 151), non-surgical lateral epicondylitis (n = 137), and carpal tunnel release (n = 118). Most demographical data yielded no significant differences between improved and not improved groups with exception of lower initial QDASH scores for the improved group for surgical distal radius fracture, P = .006 and gender for carpal tunnel release, P = .04, see Table 3.1. Scores for the QDASH (initial and last visit), last visit GROC, as well as cutoff treatment sessions and duration of treatment days are presented in Table 3.2. Based on a previous study consisting of multiple diagnoses, with an average duration of 10 visits /22 days, 132 a cutoff of 12 visits was chosen for surgical distal radius fracture and non-surgical lateral epicondylitis. A cutoff of 8 visits for carpal tunnel release occurred due to a shorter duration, see Table 3.2. Mean score changes for the QDASH questionnaire according to each GROC grade are shown in Table 3.3.



Table 3.1 Baseline Statistics for improved patients and the not improved (scores represent means and

standard deviations unless otherwise indicated)	iations unless	otherwise inc	licated						Ī
Descriptor	Surgical Di	Surgical Distal Radius Fracture	ture	Nonsurgical I	Nonsurgical Lateral Epicondylitis	dylitis	Carpal	Carpal Tunnel Release	
	IP (n = 114)	114) NP $(n = 37)$	d	(n = 69)	NP (n = 68)	Ь	P IP $(n = 84)$ NP $(n = 34)$	NP (n = 34)	Ь
Age	56(14.1)	52(12.6)	.16ª	47(9.2)	46(8.0)	.47°	53(12.0)	53(11.9)	.93°
Gender, (%male)	31(27%)	9(24%)	.73 ^b	35(51%)	31(46%)	.55 ^b	23(27%)	16(47%)	.04 ^b
Initial QDASH	60(19.8)	70(22.3)	°900.	39(17.8)	43(19.8)	.23°	56(23.6)	55(22.7)	.93°
Duration of treatment (days of care)	35(12.3)	35(13.4)	.73ª	41(12.6)	38(10.1)	.22ª	26(10.0)	26(10.1)	.77ª
IP: Improved Patients; NP:	ients; NP: Not-in	Not-improved Patients; P: Significance	P: Signi	ficance					

a: Wilcoxon (Mann Whitney-U); b: Chi-square tests; c: t-test

QDA

Table 3.2 Scores of the QDASH and GROC

Descriptor	Surgical Distal Radius Fracture	Nonsurgical Lateral Epicondylitis	Carpal Tunnel Release
Initial QDASH	63 ± 20.7	41 ± 18.8	56 ± 23.3
Last visit QDASH	29 ± 20.5	24 ± 15.6	30 ± 17.6
Last visit GROC	3.4 ± 2.0	3.4 ± 2.1	4.8 ± 1.7
Cutoff treatment sessions	12	12	8
Duration of treatment, d*	35 ± 13(21-97)	39 ± 11(24-92)	$25 \pm 9(14-56)$
d^* : Days of care, values are mean \pm <i>SD</i> (range).	mean \pm SD (range).		
QDASH: The Quick Disabilities of The Arm Shoulder and Hand.	lities of The Arm Sh	oulder and Hand.	
GROC: Global Rate of Change Scale.	nge Scale.		



Table 3.3 Mean score changes for the QDASH questionnaire according to each GROC scale grade

	Surgical Distal Radius Fracture	al Distal Radius Fracture	Nonsurgical Lateral Epicondylitis	nsurgical Lateral Epicondylitis	Carpal Tun	Carpal Tunnel Release
	(%)u	QDASH	(%)u	QDASH	n(%)	QDASH
0 or less	4(3%)	9.7	11(8%)	2.6	7(6%)	15.9
+1 to +3	33(22%)	25.8	57(42%)	15.3	27(23%)	18.7
+4 to +5	54(36%)	29.6	(%88)25	17.6	57(48%)	26.6
+6 to +7	(%6£)09	44.3	17(12%)	33.5	27(23%)	34.3
QDASH: The Quick Disabilities of The Arm Shoulder and Hand	Disabilities of	The Arm Shou	ılder and Hand	_:		
GROC: Global Rate of Change Scale.	of Change Scal	e.				



The correlation between GROC and the score changes of the QDASH was significant for all three diagnoses with a moderate relationship for surgical distal radius fracture (r = 0.39, P < 0.001) and for non-surgical lateral epicondylitis (r = 0.39, P < 0.001), and a weak, but significant relationship for carpal tunnel release (r = 0.22, P = 0.029.) The test-retest reliability using a group of stable patients on GROC (-2 to +2), had moderate agreement for all three diagnoses surgical distal radius fracture: ICC_{2,1} = 0.71, (95% CI: 0.51, 0.83)- non-surgical lateral epicondylitis: 0.69, (95% CI: 0.56, 0.79)- and carpal tunnel release: 0.69, (95% CI: 0.43, 0.84).

Responsiveness

Distribution-based methods

For the surgical distal radius fracture the SEM was 10.83 and the MDC₉₀ corresponded to 25.28, for the non-surgical lateral epicondylitis the SEM was 9.63, and the MDC₉₀ was 22.49; and for the carpal tunnel release the SEM was 11.84, and the MDC₉₀ was 27.63.

Anchor-based methods

The mean changes for the QDASH, per diagnoses, are reported in Table 3.3 In particular those patients who were rated as having a small improvement (GROC, +1 to +3) had a mean change improvement for surgical distal radius fracture of 25.8 points (95% CI: 14.4, 35.6) for the QDASH; for non-surgical lateral epicondylitis of 15.3 points (95% CI: 11.4, 19.1); and for carpal tunnel release of 18.7 points (95% CI: 8.5,25.2). Splitting the data according to a presence of moderate or larger improvement (≥ +4) versus the remainder of the entire cohort, the AUC for the QDASH for surgical distal

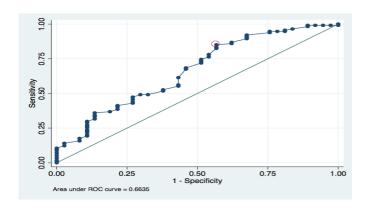


radius fracture was 0.66 (95% CI: 0.56, 0.77), (Figure 3.2); non-lateral epicondylitis was 0.64, (95% CI: 0.55, 0.73), (Figure 3:3); and for carpal tunnel release 0.66, (95% CI: 0.55, 0.77), (Figure 3:4). The ROC-curve cutoff scores that best identified meaningful improvement in clinical status (as measured by GROC values of +4 or greater) for surgical distal radius fracture 15.8 points (95% CI: -5.3, 36.9); for non-surgical lateral epicondylitis 15.8 points (95% CI: 1.0, 30.6) points; and for carpal tunnel release 13.3points (-1.7, 28.3) for the QDASH.

Surgical distal radius fracture triangulation

We took into account the following data (a) an MDC₉₀ of 25.28 points for the QDASH, (b) a mean change for small improvement of 25.8 points for the QDASH, and (c) an ROC cutoff score that best identified meaningful improvement in clinical status of 15.8 points (sensitivity 86%, specificity 37%, correctly classified 74%), for the QDASH. Analyzing the overall results we had two competing anchor-based methods, the mean change = 25.8 and the ROC = 15.8. Based on Turner et al, 65 recommendations, the MCID = 25.8, was selected since it was just right over the MDC₉₀ = 25.28 points.

Figure 3.2 QDASH Area Under The Curve (AUC) for Surgical Distal Radius Fracture

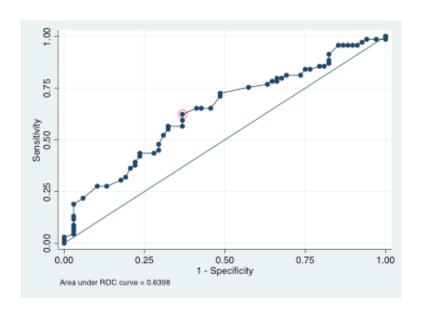




Non-surgical lateral epicondylitis triangulation

We took into account the following data (a) an MDC₉₀ = 22.49 points for the QDASH, (b) a mean change for small improvement of 15.3 points for the QDASH, and (c) an ROC cutoff score that best identified meaningful improvement in clinical status of 15.8 points (sensitivity 65%, specificity 59%, correctly classified 63%) for the QDASH. Analyzing the overall results our two anchor-based methods yielded similar results, the mean change = 15.3 and the ROC = 15.8. However, both values were lower than the MDC₉₀ of 22.49 points. Therefore, we selected a MCID = 15.8 points from the AUC since it was the closest to the MDC₉₀.

Figure 3.3 QDASH Area Under The Curve (AUC) for Nonsurgical Lateral Epicondylitis



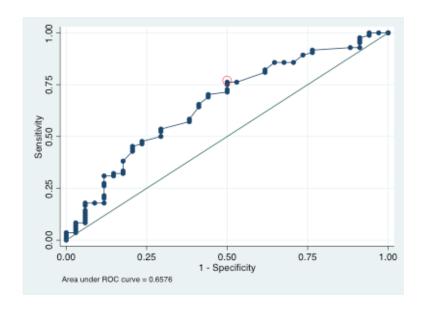
Carpal tunnel release triangulation

We took into account the following data: (a) an MDC₉₀ of 27.63 points for the QDASH, (b) a mean change for small improvement of 18.7 points for the QDASH, and



(c) an ROC cutoff score that best identified meaningful improvement in clinical status of 13.3 points (sensitivity 76%, specificity 50%, correctly classified 69%) for the QDASH. Analyzing the overall results we had competing values of mean change = 18.7, and an ROC = 13.3 points. However, again both values were lower than the MDC₉₀ of 27.63 points. Therefore, we selected a MCID = 18.7 points from the mean change approach, since it was the closest to the MDC₉₀.

Figure 3.4 QDASH Area Under The Curve (AUC) for Surgical Carpal Tunnel Syndrome



DISCUSSION

In this era of evidence-based medicine, patients, clinicians and third-party payers demand to know the effectiveness of therapeutic interventions. This study contributes to the body of knowledge on the psychometric properties of the QDASH by examining the MCID for three distal upper extremity conditions: surgical distal radius fracture, non-surgical lateral epicondylitis, and carpal tunnel release.



In order to assess reliability, the fourth visit of the QDASH was compared to the initial visit scores, as they were the earliest available repeated QDASH scores. The average time from the initial to fourth QDASH visit were 9 ± 3 days for surgical distal radius fracture, 10 ± 6 days for non-surgical lateral epicondylitis, and 11 ± 7 days for the carpal tunnel release. The test-retest reliability for all three diagnoses ranged from 0.69 to 0.71, indicating moderate agreement. Mintken et al., found a higher reliability of 0.90 examining a prospective cohort of shoulder patients. Although, in our study the average length of days between tests was 10 days, which may have contributed to recall bias. In Mintken et al's., study the average length of follow-up time was even larger at 27 days.

This study used anchor-based and distribution-based methods to triangulate and assess the MCID for the QDASH on three diagnoses: surgical distal radius fracture, non-surgical lateral epicondylitis, and carpal tunnel release. During the triangulation of our results we considered that the MCID should be based primarily on anchor-based procedures, and in the first instance on the ROC curve, ^{132,140,145} and if possible, to be higher than the MDC value. ¹⁴⁶

Regarding the distribution-based approach, in our sample the MDC₉₀ for all three diagnoses was larger than the ROC calculated values. This is not uncommon^{45,73} as distributional approaches are complicated by competing suggestions for the "beyond error" thresholds (e.g., 1, 1.96, or 2.77 SEM).^{147,148} Some authors have recommended a more reliable method to estimate the MDC is to calculate 0.5 of the SD or 1 SEM.⁶⁵ Applying this method, all our MDC₉₀'s would fall below the ROC calculated values. For the three diagnoses, the MDC₉₀ values obtained were above 20 points, and were larger than what is commonly reported in the literature. One reason may be due to the



retrospective nature of the data as higher quality control could have been provided in a prospective study design. Nevertheless, one strength of this study was that all data were collected on patients being treated in the course of normal hand therapy. The retrospective nature is a limitation, but it is more indicative of a real and typical clinical result as this is exactly what it is. Patients may or may not participate in a study due to time limitation. However, these data were collected as a standard operation procedure and were extracted after the fact. This data has strong external validity due to the manner in which it was originally collected.

The MCID measures important change because it uses a patient generated anchor for comparison. In contrast, the MDC measures statistical distribution of margins of error. 65 Following Turner et al's recommendation, the MDC90 was regarded as a benchmark to establish margins of error for the MCID, and in our sample it represented the higher bound. 65,132 Regarding the anchor-based method, the first concern about the appropriateness of the cutoff values is the selection of the anchor. We used a 15-point anchor (-7 = a very great deal worse, 0 = same, +7 = a very great deal better) and considered patients +4 to +7 as significantly improved and others as not significantly improved, to utilize the entire cohort. 144 There is no agreement in the literature on what type of GROC's to use, which groups to include in the analysis, or the level at which to dichotomize. 132,144 Furthermore, different standards have been used to determine and select the cutoff values for the QDASH. ^{26,43,45,132} In addition, it is difficult to make any direct comparisons to MCID's due to the methods employed including the choice of anchor, decision rules and types of calculation procedures. 65,132 In our sample, we found the ROC yielded values that were smaller than the mean change approach within each



category of small, moderate, and large changes, with one exception (small changes for non-surgical lateral epicondylitis) which is similar to the MCID review findings by Turner et al.⁶⁵ See Table 3:3.

We found the ROC values to fall within previously established MCID estimates for the QDASH ranging from 8 to 20 points. ¹³² In particular, two of our ROC values of 15.8 points for the surgical distal radius fracture and non-surgical lateral epicondylitis were similar to recent estimates by the Franchignoni group at 15.91 points. ¹³² However, based on the recommended methods of triangulation in the literature, the ROC value was only selected for non-surgical lateral epicondylitis. After triangulation, only one of our MCID values (post-surgical distal radius fracture, 25.8 points) fell outside the upper limit of 20 points reported in the literature. Overall, one benefit of this sample is that it is one of the largest groups of patients to examine the responsiveness of the QDASH.

In a recent review measuring clinical outcomes for distal radius fractures, pain and function were regarded as the primary domains out of seven core areas of recommendations.⁵⁷ Considering this, in our study one explanation for a larger MCID for the two post-surgical diagnoses, may be the perceived initial pain and edema restrictions from the surgical intervention. Patients can be limited by the anticipation of pain and expectations of decreased function following surgery.⁸⁵ Therefore, patients may perceive the need to regain greater ROM and decrease pain before they can report a minimal improvement in their status. This reasoning is supported by another study that examined patient satisfaction with outcomes after surgical distal radius fractures.³³ That study concluded patients need to regain greater wrist range of motion than what is necessary to perform activities of daily living, to be satisfied with treatment outcomes.³³



Limitations

Patient baseline status and patient demographics can significantly affect MCID scores. Patient baseline status and patient demographics can significantly affect MCID scores. In our study there were significant baseline QDASH differences for surgical distal radius fracture, P = .006; and gender for carpal tunnel release, P = .04. Therefore, the MCID should be interpreted with caution. It is important to note that in the case of post-surgical distal radius fracture where we selected an MCID based on a mean change for small improvement of 25.8 points for the QDASH, the ROC was 15.8 points. With this change we sacrifice sensitivity from 86% to 82% and sacrifice overall accuracy to correctly identify from 74% to 66%.

The MCID will fluctuate based on what is important to the patient, as it is not a fixed value.¹⁴⁹ It will vary based on the method chosen to determine the MCID, as well as the type of population.¹⁴⁵ For this reason, the results of this study can only be generalized to those groups of patients and individuals with similar characteristics to this sample.⁷³ In addition, the use of the GROC may have introduced recall bias and the use of a retrospective sample, without pre-existing controls, may explain the large MDC₉₀ obtained for each diagnosis as above indicated.

CONCLUSION

This study proposes the specific MCID values for the surgical distal radius fracture, non-surgical lateral epicondylitis, and carpal tunnel release diagnoses, based on a comprehensive triangulation of anchor-based and distribution-based approaches. Based on triangulation rules, 40,41,65,140 we selected MCID values of 25.8 points for surgical distal radius fracture, 15.8 points for non-surgical lateral epicondylitis, and 18.7 points for carpal tunnel release. The respective MDC₉₀ values can serve as margins of



error⁶⁵ for surgical distal radius fractu**re** (25.28), non-surgical lateral epicondylitis (22.49) and carpal tunnel release (27.63) points for the QDASH. We agree with other studies noting a need of the standardization of the MCID methodology.^{65,132,145}

Clinical Implications

Clinicians can use these MCID scores for the surgical distal radius fracture, nonsurgical lateral epicondylitis and carpal tunnel release to understand how much change
represents a meaningful change to a patient with these specific diagnoses. Previously
reported QDASH MCID values ranged from 8-20 points. 42-45,132 The results from this
study indicate a MCID range of 16 to 26 points represents the minimal clinical change
meaningful to patients presenting with three specific elbow and wrist conditions.

Specifically, post-surgical distal radius fracture patients may need to have a larger
improvement (25.8 points) than previously reported using a pool of conditions (up to 20
points). These diagnoses specific MCID's can help guide decision-making during the
course of treatment. The selected MCID's serve as a gauge on how much change a
patient may need to undergo to experience a true change during the course of treatment,
while the MDC90's serve as error margins to the MCID's.

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CHAPTER 4: ADHERENCE OF INDIVIDUALS IN UPPER EXTREMITY REHABILITATION WITH INCONGRUENCE BETWEEN THEIR QDASH AND GROC SCORES: A QUALITATIVE STUDY

INTRODUCTION

In the United States, the cost of treatment for upper extremity (UE) disorders in has been projected to be up to \$6.5 billion per year. Therefore, it is essential that acute UE rehabilitation programs be efficient and effective with patient adherence to the therapeutic program. Consistent evidence exists of the benefits of therapeutic programs; however, patient adherence is often around 50%. The term adherence implies an "active, voluntary, and collaborative involvement by the patient in a mutually acceptable course of behavior to produce a preventative or therapeutic result." He World Health Organization (WHO) undertook a major review of the adherence evidence in 2003 and noted multiple factors that affected patient adherence. These key predictors of adherence were grouped into five interdependent dimensions within the Multidimensional Adherence Model (MAM): patient-related, condition, socioeconomic, healthcare systems, and therapy-related. (Fig. 4:1). Patient adherence has been shown to be complex and multifactorial, with non-adherence to acute UE rehabilitation programs having a negative effect on outcomes and healthcare costs.

Two patient reported outcome measures typically used in acute UE rehabilitation are the quick version of the Disabilities of the Arm Shoulder and Hand (QDASH)²⁶ and the Global Rating of Change (GROC) scales.²⁷ The QDASH, a condensed version of the 30-item DASH, uses 11 items to measure physical function and symptoms in persons with disorders of the upper limb. The 15-point GROC scale asks that a person assess his



or her current progress in treatment, recall that status at a previous time-point, and then make a subjective determination between the two.²⁷ The magnitude of this difference is then scored on a numerical or visual analog scale.²⁷

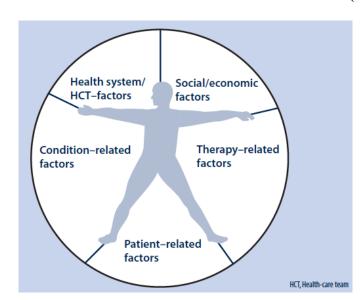


Figure 4.1 The World Health Multidimensional Adherence Model (MAM)

"Reproduced, with the permission of the publisher, from *Adherence to Long-Term Therapies: Evidence for Action*, Geneva, World Health Organization, 2003 (Fig. 3, Page 27. http://www.who.int/chp/knowledge/publications/adherence_report/en/ accessed 15 November 2014)"

While it is common to administer both the QDASH and the GROC to patients in UE rehabilitation, a perfect correlation between the two instruments would not be expected given that the GROC includes some constructs that are different from those measured by the QDASH.³² Nevertheless, it is a reasonable assumption to expect consistency between the directions of both the QDASH and GROC forms; in other words, if one instrument shows patient progress, the other instrument should as well.

Despite this expectation, a recent retrospective review of a local UE rehabilitation clinical database of over 2,500 patients with UE conditions found that 25% demonstrated



directional incongruence between the QDASH and the GROC. 150 This incongruence may be compounded by the fact that on occasion, a therapist sees improvements in a patient via objective measures (e.g. strength, range of motion, etc.), but the subjective measures of the QDASH and GROC show directional incongruence. This discrepancy may indicate a difference between therapist and patient perspectives of progress. This incongruence may affect the patient's decision to adhere to treatment recommendations provided by the therapist. Hand therapy researchers have described this discrepancy between objective and subjective outcome assessments after a variety of orthopedic interventions. These interventions include: metacarpophalangeal arthroplasty in rheumatoid arthritis,³⁷ impairment and disability after severe hand injuries with multiple phalangeal fractures.³⁴ arthroplasty for advanced osteoarthritis of the trapezio-metacarpal joint of the thumb, ³⁵ outcome assessment after distal radius fractures in aged patients, ³⁸ and injured workers undergoing carpal tunnel release. 34,35,38,39 The discrepancy between objective and subjective findings may be due to a disparity between the patient and therapist perspectives on what represents clinical meaningful improvement.

Exploring patients' incongruence between a reported level of function and perceived overall sense of improvement in hand therapy could add to the body of knowledge on the patient's decision to adhere to therapy. In this era of evidence-based medicine, patients, payers and policy makers demand to know the effectiveness of treatment interventions. Such is the new Medicare G-code regulation that requires clinicians to report patient change in function.¹⁵¹ In addition, in the US there are proposals to link patient reported outcomes to reimbursement, starting in 2015.¹⁵² Therefore, the purpose of this qualitative study was to describe the rehabilitation experiences and



expectations of patients who demonstrated incongruence between their QDASH and GROC, as well as their decisions to adhere with their treatment plan.

METHODS

A qualitative study was best suited to explore the MAM dimension of patient-related factors, which refers to the perceptions, attitudes, beliefs, expectations, resources and knowledge of the patient.⁴ Phenomenology describes the meanings people associate with their lived experiences.¹⁵³ The intent is to approach a lived experience with a sense of "newness" to gain rich and descriptive data. According to Colaizzi,¹⁵⁴ the success of the phenomenological research questions is dependent on the degree to which the questions touch lived experiences distinct from theoretical explanations. The primary investigator (PI) performed an "epoch," or bracketed his personal biases as a certified hand therapist, who previously observed the phenomena of incongruence in hand therapy practice. The institutional Review Boards of the University of Kentucky and Eastern Kentucky University approved the study.

Sampling

Our purposive sample had the inclusion criteria of (a) 18 to 89 years of age, (b) incongruence between QDASH and GROC forms (see below for procedure to determine incongruence), (c) able to communicate in English, and (d) able to provide informed consent.

Determining Incongruence

The QDASH is a region specific questionnaire that addresses physical function and symptoms in individuals with conditions involving the UE. It provides a summary score on a 100% scale, with 100 indicating the most disability. The QDASH has been



found valid, reliable and comparable to the full DASH.^{26,128} Participants completed the QDASH at initial visit and on every fourth visit. The Minimal Clinical Important Difference (MCID), which represents change over time, perceived beneficial or harmful by the patient,⁴⁰ has been reported in the literature with a range between 8-20 points. In this study, a MCID score of 11 points (beyond random error) was utilized to determine change in directionality for the QDASH.⁴³

The 15-point GROC was completed every fourth visit follow-up appointment. The scale ranges from -7 (a very great deal worse) to 0 (about the same) to +7(a very great deal better). Intermittent descriptors of worsening or improving are assigned values from -1 to -6 and +1 to +6, respectively. The GROC has also been found valid and reliable, with a MCID of 2 points on an 11-point scale. ²⁷ We chose to explore the lived-experience of individuals in UE rehabilitation that reported functional gains in their QDASH outcome measure but indicated not perceiving making any improvements in therapy with their GROC form.

Data Collection

Phenomenology strives to understand the experience of everyday living; therefore, we collected data through one-on-one semi-structured interviews. Patients in the outpatient clinic were routinely administered the QDASH upon initial evaluation, and then subsequently on every fourth visit the QDASH and the GROC forms. The outpatient clinic data for the QDASH and GROC scores were maintained in an electronic file. The administrator identified weekly potential candidates from the electronic file that met incongruence criteria and informed the therapists. The therapists contacted these patients who met inclusion criteria to volunteer for the study and informed the PI who conducted



the interviews. Research was carried out independent to treating therapists. Participants were enrolled as soon as identified in treatment. The intent was to interview patients while they experienced the phenomena as the nature of incongruity is fluid and multiple factors may cause change over time. All participants were informed before the interview how the data would be analyzed and were assured of its confidentiality. Written informed consent was obtained before the interview was conducted.

Data were collected over six months. The first author (ESF) interviewed all participants, using a semi-structured interview protocol fashioned for this study, and observational field notes were written. Interview questions elicited participants' responses based on their thoughts and beliefs regarding their treatment outcome and their desire to adhere to the treatment program. Questions were open-ended to allow for emerging-themes throughout the interview process. Sample questions included the following:

- How do you rate success with rehabilitation? Tell me more.
- <u>Do you feel as though your needs are being heard and addressed in rehabilitation?</u>

 Tell me more.
- What do/did you consider the most important component of your rehabilitation process? Tell me more.
- What do you consider as limitations/barriers in seeking and complying with upper extremity rehabilitation? Tell me more.
- *Were those expectations met? Why or why not?*



Interviews were completed in a private room in the outpatient upper extremity clinic. Interviews proceeded until no new information emerged, lasting up to one hour. Creswell recommends having at least ten interviews in order to uncover the essence of an experience and gain an understanding of the phenomenon. To promote trustworthiness this study integrated the use of an audit trail, use of the research team (PI and advisor), and member checks.

Analysis

All interviews were recorded using a digital voice recorder and transcribed verbatim for analysis by the interviewer (ESF). Once interviews were transcribed *HyperRESEACH 3.5.2* was utilized to facilitate data management and analysis. All transcriptions were checked for accuracy by the PI's advisor (DH). The research team often met to discuss the ongoing data collection and analysis and review interpretation.

Colaizzi's phenomenological method guided analysis.¹⁵⁴ Following this method, all written transcripts were read several times to gain an overall feeling for them.

Significant phrases or sentences were selected from each transcript that directly explained the lived experience of individuals experiencing incongruence. The process of horizontalization was then conducted whereby each expression was given equal weight and labeled. Repetitions were eliminated from the list. The third step was to formulate more general meanings for each significant statement, (Table 4.2). Clusters of themes were formed from the formulated meanings allowing for the emergence of themes common to all of the participants' transcripts and flow charts were utilized to obtain a graphical representation. Following this, the resulting ideas were integrated into an in depth, exhaustive description of the phenomenon, known as the essence. In the final step,



after obtaining the descriptions and themes, the researcher approached seven of the ten interviewees with the exhaustive description by e-mail and phone interviews for validation in the form of member checking. All participants agreed with the exhaustive description and there were no additional data.

RESULTS

A purposive sample of 4 men and 6 women (n=10) was recruited. Participants were from an outpatient clinic in the East South-central region of the US that primarily sees patients with acute UE conditions. Participants were predominantly white (80%) and African American (20%). Average age was 49 years, (*SD*=16.5). The average length of treatment at the time of interview was 9.1 weeks, (*SD*=4.87). Participant information is summarized in Table 4.1.

Back Into Life

The essence that emerged from the data was an overall picture of the participant's desire to move "back into life." "Back into life" represented being able to return to prior function, to physically accomplish tasks, and to return to work or sports. Participants viewed themselves as laymen and sought the knowledge of a dedicated therapist who they trusted to spend enough time with them, understood what they valued as important, treated their injury, collaboratively made goals, and explained the intervention to help them return to their regular routine, in the minimal required time. Moving "back into life" was influenced by a variety of factors that affected participant adherence to the rehabilitation process. Each of these factors is described below with direct quotations from participants as support. Table 4.3 shows a summary of the themes.



Table 4.1 Participant Demographics

u	al				ı		al l			
Occupation	Professional	Clerical	Factory	Clerical	Homemaker	Clerical	Professional	Service	Manager	Service
Total Weeks at Interview	4	4	15	8	&	9	14	9	8	18
Mechanism of Injury	Laceration	Stroke	Crush	Laceration	Fall	Fall	Ball Sport	Cumulative Trauma	Cumulative Trauma	Crush
Injury to Dominant Hand	No	oN	No	Yes	Yes	No	Yes	Yes	Yes	Yes
Age	64	09	49	21	73	99	30	41	48	43
Sex	Woman	Woman	Man	Woman	Woman	Woman	Woman	Man	Man	Man
Participant	A	В	С	D	Э	ц	Ð	Н	J	K



Table 4.2 Selected Examples of Significant Statements of Patients Experiencing Incongruence Between their QDASH and GROC and Related Formulated Meanings

Significant statement	Formulated Meaning
I know before, I started physical therapy, I had no motion, I couldn't move my wrist, there was a lot more pain, I couldn't work, at least I am back at work. So, therapy has gotten me back into life	Back into life encompasses returning to normal, being back at work, being able to regain functional ability
A little bit, is not good enough. I can do this [flexes DIP's approx 20 degrees], or a little more, it doesn't help me fix the muffler on my car. You know, so I can move it a little bit more, you know, a little bit more is not making a fist, it, it[pause]	Incremental gains of ROM do not matter unless a functional outcome to perform a task is achieved
Yeah, you put a lot of trust in a therapistand when a therapist doesn't give you a 100% of what they are suppose to do. I'm a layman. I don't know what I'm suppose to go through when I go through physical therapy for a knee, or a hand or for whatever. That's why I'm coming to a physical therapist for.	Patients view themselves as laymen and expect their therapists to have their best interest in mind.
I guess when that happens you kind of expect instant gratification. You want it to come right back, but from what I heard, I think its pretty much on track[pause] I think they said 12 weeks, and we are almost at week 8 and I feel like that's a good goal.	Patients initially anticipate a swift recovery, but often come to realize it is a slow process



Table 4.3 Themes describing the essence "back into life"

Theme	Description		
Desire to return to normal	Participants desired to return to prior level of		
	function and normal activities		
Anticipation of a brief recovery	Initial assumptions of a brief recovery were		
	challenged; collaboration with therapist eased slow		
	recovery periods		
Trust of therapist	Participants trusted therapists who they felt were		
_	dedicated to achieving successful outcomes		
Can't stop living	Participants realized it was not possible to devote		
	all time and effort to rehabilitation, because daily		
	life is ongoing		
Feelings of Ambivalence	Participants felt ambivalent about some aspects of		
	the rehabilitation process, such as the factors		
	important to their treatment success, beliefs about		
	their illness, and comparisons to others, which		
	impacted their recovery		

Desire to Return to Normal

Participants wanted to return to normal, usually comparing their injured limb to their non-involved side. They made comments about wanting to return to prior functional level for activities such as work, driving, or playing the guitar. This was evident by the following comments from participants: "to be able to use my hand like I didn't have the accident. To be back to normal." [C], and "I would like to be back the way I was, not having to wear a brace, and, not having to protect it, and think about it anymore." [F]. "Yeah, to get back to my job. To get back to some form of normalcy." [B].

Participants defined rehabilitation success in terms of their body functions returning to normal, such as recovering strength, sensation, or motions such as "making a fist", "getting rid of numbness and tingling," or "having less pain." They also described success as returning to functional activities such as "wash dishes," "have a legible signature" and "balance a check book." One woman indicated, "Typing and writing... I



couldn't write, 'cause I couldn't grip a pen, I'm just getting back to where I can do that."

[D].

Anticipation of a Brief Recovery

Participants initially assumed they would have a brief recovery. The majority of the respondents viewed healing as a slow process, "It's kind of long, it's a slow process, but anything out there is going to be a little slow. You do it overnight, (referring to the injury), but it doesn't heal overnight." [A]. They often first learned from their doctor or therapist about the lengthy recovery process. Understanding that the recovery process would be slow, led participant to seek therapist expertise. "I am used to something happening getting over it and going on. But it's going to take time. So I'm looking for a [therapist] to guide me and work with [the therapist's] expertise." [F].

Collaboration evolved as important to the participants' perspectives of anticipating a brief recovery, and they expected collaboration with their therapist to establish goals: "Well, first off, I think the goals of your therapist, plus if the therapist and the patient work together as a unit." [G]. Participants understood their role as a team member in shortening the length of their recovery process: "You have to follow through with what they want you to do." [A].

Trust of Therapist

Patients wanted to trust their therapists to get them back to regular activities.

Participants viewed themselves as laymen, expecting professional guidance from their therapists and mistrusted their therapist if therapists did not provide full concern expressed as giving "100 percent" of themselves. The issue of trust emerged when several of the participants reflected about therapists they had worked with in the past.



They were able to compare therapists, indicating: "Not all therapists/rehabs are created equal." [H]. One 66-year-old female stated:

I was trusting the therapist to know what they should have done to have gotten me back to a normal life, and in essence, that therapist...what's the word...[pause], actually denied me a full recovery, because I am still, seven years down the road, they've taken the money, and I'm still not able to do the things that [I] used to be able to do. [F].

Some respondents expressed feelings of mistrust about the therapist's abilities: "But, I'm sure they get a little self-satisfaction from being able to help somebody, and what they think they can do may be a lot more than what I think they can do." [C].

Participants described therapists as either dedicated or non-dedicated, and the level of dedication impacted their adherence. Dedicated therapists were described using positive attributes such as "intuitive," "adept," "personal," having a good "work ethic," "wanting their patient to succeed," "spending time with the patient," to "listening to patient goals," and establishing an accurate diagnosis and treatment plan. One participant explained that her current therapist:

Actually takes the time to get to know you, to get to know your goals, to get to know what you want, what you need, and takes the time to learn your body. It's not any one-size-fits-all treatment. It's tailored to you and your specific needs, and goals from the therapy and what you hope to accomplish. [G].

Non-dedicated therapists were described as impersonal and unprofessional. One participant thought a therapist took payment for therapy but did not spend time with him to ensure his success: "They instruct you to do an exercise and then they walk away.



They don't stay with you to make sure that you're staying on task. They're very impersonal." [J]. Another described unprofessional behaviors: "When the physical therapist is just there jabbering with somebody else, or they are there to just spend the day, and get a patient in and out, and they don't take the interest, I don't feel they have succeeded that patient..." [F].

Can't Stop Living

Participants valued rehabilitation, but reflected it was not possible to devote all time and effort to the process. Daily life did not stop. One participant indicated limited time to dedicate to a home program:

If I had an ideal amount of time we could go faster, but you know in reality, I can't spend all day doing these exercises, and wearing this stuff, because I have a life I have to live. [C]

Another described the challenges of engaging in work and normal activities while wearing a brace:

Still having to do things even with the brace on...whatever I can do with the brace on, that's what I do.. My biggest problem is, I have to continue working and the rehab dictates that I should not work. So, that's the biggest conflict. I have to make a living, I have to keep going and they want to shut it down. [J]

Time devoted to rehabilitation often conflicted with daily routine. One participant described the challenge of time management: "First thing catch the bus and come out here, then go back to the transfer center and catch another bus to go back to [the nursing home] where [my husband] lives." [E]. While participants wanted to engage in therapy, they could not stop living their daily life to accommodate rehabilitation.



Feelings of Ambivalence

Participants conveyed feelings of ambivalence about several aspects of the rehabilitation process, which impacted their recovery. For example, respondents expressed ambivalence about factors they considered important for treatment success, as compared to those considered by their therapist. One participant described this inconsistency: "[My therapist] is excited when I get strength, when [my therapist] measures the strength I have in my hand. Whereas, I want feelings..." [B]

Another respondent expressed some ambivalence toward incremental gains made in therapy: "A little, but, a little bit doesn't help me hold that wrench any better...They feel better about these things, they had some progress... but, in reality, that progress isn't squat, unless I can make a fist, and get back to normal." [C]

Some expressed ambivalence in their beliefs about their illness: "I think I'm screwed all the way around. I don't think it's ever going to get better, to be honest. I'm just coming here because the insurance says that I have to. I don't think it's ever going to get better...[C]. Others believed they had the wrong diagnosis: "I'm still wondering if there is anything that he missed... A sprain you get over it a couple weeks or so...this is something else." [F].

Another participant acknowledged feelings of ambivalence as he compared himself to others in a group treatment. On one hand, he gained motivation from the realization that his injury was less severe than the other patients, but felt guilty for thinking this. On the flip side, he expressed satisfaction at seeing other patients succeed at discharge, even when he was still in therapy:



It helps, anytime I think I am bad off there's always someone, that's unfortunate, but there is always someone who's worse off than me...I guess really the camaraderie, being around other people who are injured, and seeing people succeed. I call that getting paroled when people have been here so long... you know what I mean. [K]

DISCUSSION

This study aimed to describe the rehabilitation experiences and expectations of patients who demonstrated incongruence between their QDASH and GROC forms and to understand their decisions to adhere to rehabilitation. The findings address a gap in our understanding of how patients perceive this incongruence and the factors affecting their decisions to adhere to rehabilitation. Patient adherence is complex and involves multiple factors beyond the patient's decision of simply following through with treatment. The WHO MAM provides a framework for understanding how the themes that emerged in our study relate to the complexity of patient adherence to UE rehabilitation. We took each significant statement with its associated finding and attempted to match them within the five dimensions of the MAM (See Table 4.4).

Social and Economic factors

The social and economic dimension of the MAM includes factors such as poor socioeconomic status, poor social support, unemployment, lack of education, poor literacy, long distance from treatment centers, culture and lay beliefs about illness and treatment, and unstable family circumstances.⁴ In this study, socioeconomic factors had a minimal impact on adherence, which is consistent with the literature.⁴ In our results, half of the participants had private insurance while the other half had worker's compensation.



Surprisingly, participants in this sample who had worker's compensation did not show secondary gain as noted in the literature. The participant's occupations ranged from homemaker, factory work, clerical and professional. Some participants mentioned the cost of treatment as an adherence modifier because paying the bills took priority over home programs. (See Table 4.4). Clinicians can acknowledge patient financial investment, and design programs that do not compete with work schedules. Interestingly, for one participant long distance travel to therapy did not adversely affect adherence. Therefore, it is important to note, one cannot assume socioeconomic factors impact all individuals in the same manner. Clinicians can help by designing individualized programs to address social and economic factors as needed.

Healthcare System-related factors

The healthcare systems-related dimension encompasses patient provider relationships, poorly developed health services with inadequate or non-existent reimbursement by health insurance plans, poor medication distribution systems, lack of knowledge and training for health care providers on managing diseases. In our study, time spent with a therapist, communication and interpersonal style of the therapist, and the patient-provider relationship, were all adherence determinants. The aforementioned was true particularly related to the issue of trust. Consistently, others have found that patients need to perceive that their clinician listens, understands and appreciates their suffering. The clinician—patient relationship is one of the most important predictors of adherence to medical treatment, patient satisfaction, and overall treatment success. Nonetheless, the current healthcare system and reimbursement may limit the individualized time a therapist can spend with a patient. The demands for therapists to



maintain high productivity levels and incorporate insurance requirements appear to increase each year. Even with the best of intentions, often times the availability for realistic individualized treatment is decimated. Therapists can maximize their time spent with the patient by explaining the benefits of the treatment intervention and incorporating the patient's wants into their treatment plan. Affective tone and the patient's belief in the benefit of a treatment have shown to have significant influence on adherence.⁸⁶

Condition-related factors

Factors in the condition-related dimension include the availability of effective treatment, level of disability, prognosis, the rate of progression, co-morbidities, and the severity of symptoms. Although there are few studies in the acute hand therapy literature that have studied this dimension, a systematic review of adherence studies in rheumatoid arthritis found no relationship between disease severity/ level of disability and compliance. However, in this study the slow rate of progression and the participants' desired treatment emphasis helped explain the incongruence between their QDASH and GROC. For example, one participant's focus was on sensory return whereas the therapist's emphasis was on progressive motor/strength return. This finding highlights the importance of an early discussion about the focus of intervention and expectation of the rate of recovery. Early conversations on therapeutic expectations may positively impact adherence.

Therapy-related factors

The therapy-related dimension includes factors associated with the complexity of the medical regimen, the immediacy of beneficial effects, frequent changes in treatment, duration of treatment, side effects, previous treatment failures, and the availability of



medical support to deal with all these factors. In our study, the length and complexity of treatment inhibited participation in normal daily life. For instance, some participants felt orthosis wear and home exercises were cumbersome and interfered with their lifestyle, negatively affecting adherence. Likewise, in a study of patients undergoing distraction treatment for complex finger fractures, the most significant influence on adherence were perceived complexity of treatment, and interference with the completion of daily occupations: productivity, self-care, and leisure. 85 In our study, contrary to anticipated, previous treatment failures had a positive effect on adherence. The current participants' therapists used a more holistic approach to the intervention by not focusing on a particular body structure, but rather looking at the individual as a whole. This method was consistent with the biopsychosocial model by accounting for the person within the disease. ¹⁵⁸ In our study, the therapist working as a liaison for the patient among other medical specialties was viewed as a positive determinant of adherence. This result was consistent with results found by O'Brien, who found availability of support was a positive determinant of adherence. 85 Most participants experienced a longer than anticipated duration of treatment, yet it played a positive role on adherence motivating patients to seek professional help. In contrast, some participants needed to see an immediate benefit with their results, in order, to adhere to treatment. A patient's motivation to adhere to prescribed treatment is influenced by the value this person places on following the regimen and the degree of confidence in being able to follow it.⁴⁶ Therapists can set as goals, to increase the patient's perceived importance of adherence by building on his or her intrinsic motivation, and strengthening confidence by building self-management skills.4



Patient-related

The patient-related factors comprise the knowledge, resources, attitudes, beliefs, perceptions and expectations of the patient. Patients' knowledge and beliefs about their illness, motivation to manage it, confidence in their ability to engage in illness-management behaviors, expectations regarding the outcome of treatment and the consequences of poor adherence interact in ways to influence adherence behavior that are not yet fully understood.⁴ In our study, factors that negatively affected patient adherence were ambivalence and lack of understanding about their condition, as well as negative beliefs regarding the efficacy of treatment and illness. Sluijs found similar results where a bad prognosis was related to non-adherence.⁴⁸

Limitations of the Study

This study sought to understand from the patient's perspective their rationale for reporting improvement on the QDASH outcome measure while simultaneously reporting not making improvement on their GROC form. This sample represents individuals seeking UE rehabilitation from a single outpatient hand therapy clinic in the East Southcentral region of the United States over a period of six months. These findings can be applied to other hand therapy patients with like characteristics. Readers should consider if their patient population is similar in order to transfer findings.

Implications for Hand Therapy Practice

Trust in the therapist was a major determinant for patient adherence. Patients expect to have a dedicated therapist who they can trust to work collaboratively with them to establish goals and spend time with them to achieve them. This represents a challenging task for well-intentioned therapists. Today's healthcare arena with ever



increasing demands for productivity and third-party insurance requirements tend to encroach on available the quality time therapists have available to share with each patient.

The therapist and patient's perception may differ substantially on what is a clinically important change, and on what is a reasonable expectation for home regimen. Early clarification on the rate of recovery may improve patient adherence. It appears that although patient-therapist communication is occurring, the patient's views are not always included in the rehabilitation program. Having an early candid discussion, eliciting the patient's wants and needs could help clarify patient-therapist differences.

The majority of patients expected to quickly return to normal and regain full function. The treatment complexity played a role on the patient's decision to adhere to the program. Therapists can negotiate realistic goals with patients by discussing cost-benefit scenarios of adhering to the treatment program, while advising the patient of pitfalls of non-adherence. Therapists can then adjust the rate of HEP and orthosis wear to match the patient's readiness to follow through with the program. When patients' exhibit incongruence in patient reported outcomes, therapist should listen to patients with empathy in order to build trust and establish a patient-centered approach to the intervention.



Table 4.4 Findings associated with the World Health Organization's Multidimensional Adherence Model.

MAM Dimension	Related Factor	Finding associated with adherence	Participant Quote		
Social and economic	Long distance from treatment center	Can't stop living because of injury or rehabilitation	"First thing, catch the bus and come out here" [E]		
	Cost of treatment	Can't stop living because of injury or rehabilitation	"You've got to pay the bills, you got to live life. You can't stop because you got hurt." [C]		
	Social	Feelings of ambivalence of comparisons to others	"It helps, anytime I think I am bad off there's always someone who's worse off than me I guess really the camaraderie, being around other people who are injured, and seeing people succeed." [K]		
Health-care team and	Patient provider relationship	Trust of therapist impacts recovery	"Yeah, you put a lot of trust in a therapist"[F]		
system	Time spent with therapist	Non-dedicated therapist	"They instruct you to do an exercise and then they walk away. They're very impersonal" [J]		
	Communication style of therapist	Collaboration (between patient and therapist)	"Well, first off, I think the goals of your therapist, plus if the therapist and the patient work together as a unit." [G]		
	Interpersonal style of therapist	Dedicated therapist (establishes rapport)	"Having somebody that understands first of all what your goal is, and how to get you there, that is the support thing. [G]		
	Lack of knowledge & training of therapist	Non-dedicated therapist	"We have several tests and that is not a tore rotator cuff, but they are treating me for it, and [the therapist] says there is nothing we can do" [H]		
Condition- related	Prognosis	Desire to return to normal	"Yeah, regaining everythingYou want it to come right back." [D]		
	Rate of progression (incongruence between therapist and patient understanding on what is minimally important)	Feelings of ambivalence about factors important for treatment success	"[My therapist] is excited when I get strength, when [my therapist] measures the strength I have in my hand. Whereas, I want feelings" [B] "A little, but, a little bit doesn't help me hold that wrench any better" [C]		



Table 4.4 (continued)

Therapy- related	Complexity of treatment	Can't stop living because of injury or rehabilitation	"I can't spend all day doing these exercises, and wearing this stuff, because I have a life I have to live." [C]		
	Duration of treatment	Anticipation of a brief recovery	"You do it overnight, but it doesn't heal overnight." [A]		
	Interference with lifestyle/ activities of daily living/ work	Can't stop living because of injury or rehabilitation	I have to make a living, I have to keep going and they want to shut it down." [J]		
	Immediacy of benefit	Feelings of ambivalence about factors important for treatment success	"If I can't make a fist, I'm wasting my time." [C]		
	Previous treatment failures	Trust of therapist impacts recovery	[The current therapist] focuses on everything. Which has helped, just looking on the elbow, wasn't getting anything accomplished." [G]		
	Availability of medical support	Dedicated therapist (liaison)	"[The therapist] has done a lot of research and tried to get other opinions regarding what to do" [G]		
Patient- related	Psychological factors: Low motivation	Feelings of ambivalence of comparisons to others	"There is always someone who's worse off than me. It's kind of a realization; don't kick yourself in the butt because it could be worse" [K]		
	Lack of understanding of the condition	Ambivalence in their beliefs about their illness	"I'm still wondering if there is anything that he missed A sprain you get over it a couple weeks or sothis is something else. A sprain with some kind of, something else with it." [F]		
	Negative beliefs regarding the efficacy of treatment	Ambivalence in their beliefs about their illness	"I think I'm screwed all the way around." [C]		

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CHAPTER 5: PROSPECTIVE STUDY OF THE EFFECT OF THERAPIST-PATIENT COLLABORATIVE GOAL SETTING ON PATIENT ADHERENCE IN POST-SURGICAL DISTAL RADIUS FRACTURE CONDITIONS

INTRODUCTION

Adherence has been defined as an "active, voluntary, and collaborative involvement by the patient in a mutually acceptable course of behavior to produce a preventative or therapeutic result." ²⁽²⁰⁾ Adherence is increasingly recognized as an essential component for injury rehabilitation.⁴ Patient non-adherence to therapeutic treatment plan of care can negatively reduce treatment benefits, affect recovery, increase the risk of disability and bias assessment of treatment efficacy.^{5,6} Non-adherence to treatment for acute hand injuries, such as distal radius fractures (DRFs) can result in complications requiring more difficult secondary surgical procedures, and increased costs from hospitalizations and loss of productivity.⁷

Distal radius fractures are the most common fractures seen by physicians. ¹⁵⁹⁻¹⁶² In the elderly population, DRFs are the second most common fractures, only surpassed by hip fractures. ¹⁶³ In the US population over the age of 65 the annual incidence of DRFs has been reported to be between 57 to 100 per 10,000. ^{161,163,164} In 1997, 3% of the Medicare population was treated for DRF with internal fixation; by 2005 this number increased to 16%. ¹⁶⁵ In 2007, Medicare made \$170 million in DRF related payments. ¹⁶⁵ It is anticipated with the aging population, and with internal fixation becoming more widely utilized, that the burden of DRF will continue to increase. ¹⁶⁵ Adherence to DRF treatment protocols is a critical factor in improving client outcomes for this population.

In an effort to streamline Medicare costs and improve functional outcomes, the United States Centers for Medicare and Medicaid Services (CMS) now requires



outpatient therapy services to report patient functional status during the course of therapy services in the form of Medicare G-codes. This new data collection requirement is in addition to traditional patient outcome requirements. The CMS intent is to better understand patient conditions and outcomes. Is 1,166 In the past, many therapists were content with the notion of just making their patients better. However, the CMS G-code requirement provides motivation for therapists to now quantify from the patient's perspective the efficiency and effectiveness of their chosen therapeutic interventions to achieve patient functional goals. One potential way to accomplish this aim of improving function is for the therapist to focus on rehabilitation goals that are meaningful for the patient.

There is evidence that setting specific, patient-centered goals can enhance patient outcomes in rehabilitation. The effectiveness of goal planning in rehabilitation can improve immediate patient performance from both clinical context and improved components of adherence to treatment programs. Therapeutic alliance between a patient and a treatment provider is positively correlated with treatment adherence and outcome in both general medicine and psychotherapy settings. In view of all of these dynamics, a critical factor affecting patient adherence is the therapist-patient collaboration in goal setting.

Collaborative goal setting is grounded in patient-centered or (client-centered) care. Client-centered care has been defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions."⁷⁰⁽⁶⁾ One client-centered instrument often used in occupational therapy is the Canadian Occupational Performance Measure (COPM). ⁵¹



The COPM is an individualized, client-centered outcome measure designed to capture a client's self-perception of occupational performance (or function) and establish collaborative goals between the therapist and patient.⁵²

The collaborative role of goal setting in hand therapy has been minimally studied. Recently, in a study by Ydreborg et al., 2014, the COPM was utilized to assess three specific goals of range of motion, grip strength and pain level over time in patients with plate-fixation surgery for DRFs. The study concluded scores for performance and satisfaction for the most important activity in the COPM did not deteriorate to a statistically significant difference from 6 months to 24 months. 168

The aims of this study were: 1) to examine the effect of patient-therapist collaborative goal setting on improved patient adherence to treatment. We hypothesized the experimental group of patients with DRF, who were receiving the collaborative goal setting intervention using the COPM would have better adherence as measured by self-reported adherence, therapist-reported adherence, and attendance rate compared to the control group. 2) to examine the effect of patient-collaborative goal setting using the COPM on improved patient functional outcomes as measured with scores from a commonly used outcome measure, the Quick Disabilities of the Arm Shoulder and Hand (QDASH). We hypothesized the experimental group receiving the collaborative goal setting intervention would have better self-reported UE function as measured by the QDASH scores compared to the control group.

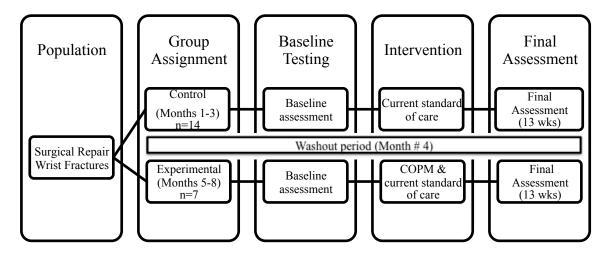
METHOD



Research Design

We used a prospective quasi-experimental, 2-cohort study with a washout period, of patients that presented with signs and symptoms consistent with post-surgical distal radius wrist fractures, see Figure 5.1.

Figure 5.1. Procedure Diagram



Note: QDASH = Quick Disabilities of the Arm, Shoulder and Hand. COPM = Canadian Occupational Performance Measure.

Primary Outcome: Adherence

Adherence was measured in both groups by four dependent variables:

1) therapist-perspective of adherence: once a week the therapist used the Sport Injury Rehabilitation Scale (SIRAS)⁷¹ to rate patient adherence during a treatment session. See Appendix A. The SIRAS is a 3-item instrument in which the clinicians rates the patients' intensity of completion of rehabilitation exercises, the frequency with which they follow the clinician's instructions and their receptivity to changes in the rehabilitation program. The three items are measured on a 5-point Likert Scale, and responses include minimum effort/maximum effort, never/always, and unreceptive/very receptive, respectively.⁷¹ The SIRAS has been found reliable for clinic-based rehabilitation settings for general



musculoskeletal conditions with test-retest reliability (0.63-0.76) and inter-rater reliability (0.76-0.89). ¹⁶⁹ In addition, the SIRAS has been positively correlated with rehabilitation attendance, indicating criterion validity. ⁷¹

- 2) patient-perspective of adherence: once a week patients rated their adherence to their home exercise program (HEP) using either a paper exercise diary or a mobile phone exercise diary. ⁶² The average number of exercises was calculated weekly. See Appendix B.
- 3) attendance rate: over the course of care the number of missed, cancelled appointments relative to scheduled appointments were calculated as an adherence rate. (i.e. 12 scheduled appointments attended 10 = 83% attendance rate), and
- 4) patient perspective of alliance with the therapist: once a week patients completed the Session Rating Scale (SRS), a brief therapist-patient alliance measurement tool (Duncan et al., 2003). To See Appendix C. The SRS is used as a comparable shortened version for the 19-item Helping Alliance Questionnaire II (HAQ-II) questionnaire that measures the strength of the therapist-client alliance (Luborsky et al., 1996). SRS consists of four 10-cm visual analog scales (relationship, goals and topics, approach and method, overall) with instructions to place a hash mark on a line with negative responses depicted on the left and positive responses indicated on the right. The SRS is scored by simply summing the marks made by the client measured to the nearest centimeter on each of the four lines. Based on a total possible score of 40, any score lower than 36 overall, or 9 on any scale, could be a source of concern and therefore prudent to invite the client to comment. The reliability for the SRS compared favorably with the HAQ-II Cronback's alpha (0.88 and 0.90, respectively). To the test-retest reliability for the SRS (0.64)

compared to (0.63) for the HAQ-II. Concurrent validity was estimated by Pearson product moment correlations averaged (0.48). Patients were informed of the confidentiality of their rated information. The exercise diaries and SRS information was blinded to the therapists, and the therapist-rated SIRAS was blinded to the patients.

Secondary Outcome: Functional Outcome

Functional outcomes were measured with the QDASH as our dependent variable. Participants completed the form at initial evaluation, every fourth visit and at discharge. The 11-items ODASH is the short form of the 30-item Disabilities of the Arm. Shoulder and Hand (DASH).²⁶ See Appendix D. The QDASH measures the degree of difficulty in performing various physical activities due to a shoulder, arm, or hand problem (six items); the severity of pain and tingling (two items); and the problem's effect on social activities, work, and sleep (three items). There are five response Likert scale, from 1 (no difficulty to perform, no symptom, or no impact) to 5 (unable to do, very severe symptom, or high impact). At least ten of the eleven items need to be completed, the responses are added to form a raw score, then converted to a 0-to-100 scale. ²⁶ The two optional scales of the QDASH (work and sport/music) are not commonly collected in this clinical practice and therefore were not part of this study. The QDASH's reliability and validity have been well established. Internal consistency and cross-sectional reliability: Cronbach's α (0.92–0.95). Test–retest reliability: intraclass correlation coefficient $(0.90-0.94)^{26,45,128}$

Independent Variable

The COPM was our independent variable, see Appendix E. The COPM has been translated to 36 languages, and its reliability and validity is well established.¹⁷² When



using the COPM, the therapist and patient together identify occupational performance problem areas and level of performance and satisfaction relative to those problem areas. The patient identifies problems and goals in personal care, functional mobility, community management, work, household management, and leisure. The patient rates his or her performance and satisfaction with performance using a 1- to 10-point scale with 1 representing "notable" or "not satisfied" and 10 representing "able to do well" and "extremely satisfied."⁵¹

Participants

Between August 2014 and April 2015 all sequential patients presenting with post-surgical DRF to two outpatient hand therapy clinics in Lexington, Kentucky and met inclusion criteria were invited to participate in the study. The University of Kentucky and Eastern Kentucky University Institutional Review Boards approved this study. All participants that agreed to be in the study provided written informed consent. Patients were invited to participate if they: a) were seeking therapeutic intervention from a therapist with a diagnosis of surgically treated DRF, b) reported unilateral or bilateral DRFs, c) were between the ages of 18 and 89, and d) demonstrated the willingness and ability to fill out the required forms. Patients were excluded if they reported one of the following issues: a) previous history of fracture of the affected hand/wrist within the last 5 years, b) history of inflammatory arthritis, c) any concurrent same upper limb fractures, c) a confounding additional musculoskeletal condition (i.e. tendonitis), central neurological disorder (i.e. Parkinson's Disease), or peripheral neurological disorder (i.e. radial nerve palsy), or f) other criteria as determined by the treating therapist.



Procedure

Following the initial examination of a patient the treating therapist made a determination if the patient was eligible for potential enrollment in the study. Patients were then asked for written consent to participate in the study. On their initial visit patients were asked to fill out the QDASH survey to evaluate their self-reported level of disability. After the potential participant had a chance to review the documents, a member of the research team reviewed the forms with the participant and answered any additional questions the participant had regarding the research project.

Patients were assigned to one of the two groups, experimental or control, based on the date they presented to the therapy facility. The control group was enrolled during the first three months of the study. At the fourth month, a washout period was instituted to allow the last control patient to complete the program. This minimized the chance of intervention bias between the two groups. See Figure 5.2. In addition, during this fourth month, the principal investigator (PI) educated the treating therapists for one hour on how to incorporate the COPM into their treatment interventions. The therapist education consisted on an overview of the COPM principles to ensure common understanding of use. Additionally, therapists were instructed on how to breakdown the biomechanical components of each patient functional goal and apply these to the COPM as demonstrated by Jack and Estes, 2010. The experimental group was enrolled starting on the fifth month of the study and followed until completion of their rehabilitation program. This design was selected for this study to allow therapists to treat the control cohort in an unbiased method before introducing the COPM for the experimental group.

During the experimental group enrollment period, the PI performed the COPM



evaluation. In order to complete this study and not over burden the treating therapist the PI, who is a certified hand therapist and licensed occupational therapist, administered the COPM and then shared these results with the treating therapist. Nine licensed therapists, eight occupational and one physical, carried out the DRF protocol. The median experience level was 12 (1-26 years). There were four certified hand therapists (CHTs) in this group and all but the one physical therapist had previous knowledge of the COPM, but none of them were using this in clinical practice.

The treating therapist, having been previously educated in how to integrate information from the COPM into the standard treatment intervention, was monitored by the PI to assure this was occurring by completing a weekly review of the patient rated Session Rating Scale (SRS). 170 Fidelity checks of comparing treatment interventions to established treatment goals were incorporated to assure the COPM was being applied. This was further confirmed by weekly randomly asking the patients if they felt their goals were addressed in therapy that week. The PI performed the COPM again with each member of the experimental group at the six-week mark, and at discharge to track progress and to modify goals as needed. Each patient's COPM mean scores across all goals were used in the analysis. Two patients out of seven who did not return for their last visit were contacted over the phone to complete the exit COPM. Patients were treated following treatment guidelines that consisted of a schedule for introducing different interventions during three-phase levels for participants in both the control and experimental group. See Appendix F. 175 All participants also received written information about the injury, exercises, and advice about using the hand in activities.



Data Analysis

All statistical analyses were performed using Stata/ IC Version 13.1 (StataCorp LP, College Station, TX). Baseline characteristics per diagnoses between the control and the experimental group were determined for patient demographics of age, initial QDASH, and length of days in care. All four of our demographic continuous dependent variables violated a parametric independent sample T-test assumption. The Shapiro-wilk test revealed two of our variables were not normally distributed. The Levene's test of equal variances demonstrated that the other two normally distributed variables violated the assumption of homogeneity of variances. We used the non-parametric Wilcoxon Mann-Whitney U test for our continuous data. A Fisher's exact test was used for our dichotomous data of gender, presently working, hand dominance and race because each variable had a cell size less than five.

The primary hypothesis investigated if the use of the COPM improved adherence compared to the standard of care in post-operative distal radius fracture patients. The adherence dependent measure was evaluated with 4 measures; self-reported adherence was measured with home exercise log and session rating scale, therapist-reported adherence was measured with SIRAS, and attendance rate was measured by percentage of schedule appointments attended. These measures were examined at both 6 weeks and at discharge. For each of the three continuous independent variables of: SIRAS scores, self-rated scores, and attendance scores, the medians and inter-quartile range of the control and experimental groups were compared with Mann-Whitney-U which is a non-parametric test similar to independent T-test.

The secondary hypothesis was to improve outcomes with collaborative goal



setting intervention. This was measured with a QDASH for both groups at 6 weeks and at discharge using a Mann-Whitney U tests.

RESULTS

Descriptive statistics

A total of 21 patients were admitted in the study from, August 2014 until March 2014, see Figure 5.2. The surgical procedures included post-surgical distal radius patients admitted with a variety of procedures to include pinning, volar and dorsal open reduction internal fixation (ORIF), DRF with distal ulna fractures, DRF with concurrent carpal tunnel release (CTR) and one dorsal distraction plating ¹⁷⁶ for comminuted DRFs, The baseline demographical characteristics were similar for both groups at baseline. See Table 5.1. For our primary outcome of adherence, there was no statistical significant difference between groups for any the adherence measures. The results are presented in Table 5.2. For our secondary outcome of functional outcomes there was no statistical significant difference between groups for the QDASH at either baseline or at the sixweek timeline. The mean change in both groups was similar at roughly 46 points; the results of the QDASH are presented in Table 5.3.



Figure 5.2 Patient Admission Flow Chart

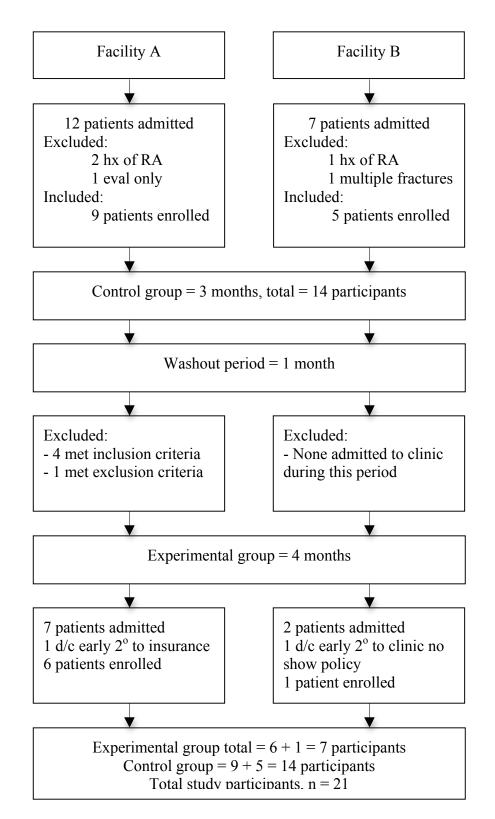


Table 5.1 Demographics and Clinical Features of the Participants

			Control	Experimental	P
			Group	Group	
n			14	7	
Age(y)(SD)			52 (14)	61 (13)	0.178^{a}
Gender	femal	e (male)	9 (5)	6(1)	0.613^{b}
Race	white	(black)	13 (1)	7 (0)	1.000^{b}
Time from surge	ery to eva	al (days)	13 (13.1)	12 (10.7)	0.969^{a}
Time of injury to	o eval	(days)	18.1 (11.7)	22.2 (14.7)	0.550^{a}
Baseline Pain le	vel	(0-10)	5.1 (2)	3.4 (2.5)	0.164^{a}
Presently working	ng	Y(N)	9 (5)	2 (5)	0.183^{b}
Hand dominance	e	R(L)	13 (1)	7 (0)	1.000^{b}

a: Wilcoxon (Mann-Whitney U); b: Fisher's Exact tests

Table 5.2 Adherence Measures for Home Diaries, Sport Injury Adherence Measures for Home Diaries, Sport Injury Rehabilitation Adherence, Attendance, and Session Rating Scale

Final	Control	Experimental	Mann-	Effect
Median	Group	Group	Whitney U	Size
Scores	MD (25-75%)	MD (25-75%)	P	d
HEP Diaries	87.5 (70-94)	96.2 (89-99)	0.100	0.66
SIRAS	14.7 (14.1-15)	14.8 (13.1-15)	0.782	0
Attendance	100 (93-100)	100 (94-100)	0.608	0.25
SRS	39.4 (37-40)	36.6 (35-39)	0.123	0.58
n	14	7		

HEP: Home Exercise Program – 100% maximum adherence

SIRAS: Sport Injury Adherence Scale 15 points maximum adherence

Attendance: % of attended scheduled appointments

SRS: Session Rating Scale - 40 points maximum agreement

Table 5.3 The Quick Disability of Arm, Shoulder, and Hand Questionnaire (QDASH)

	Control	Experimental	Mann-Whitney U
$\mathrm{QDASH}^{\mathrm{a}}$	Group	Group	(p value)
Pre-Test	73.2 (19.8)	67.7 (27.7)	0.550
Post-Test	27.3 (19.9)	21.6 (10.8)	0.793
Change	45.9	46.1	0.851
Effect Size	2.32	1.66	
n	1./	7	_

a = Scale 0–100 (Lowest scores indicate no disability; highest scores indicate high disability.)



DISCUSSION

This study contributes to the body of knowledge on the effect of therapist-patient collaborative treatment goals for post-surgical DRF on two areas: 1) patient adherence to treatment care and 2) treatment outcomes. We hypothesized the experimental group receiving the collaborative goal setting intervention using the Canadian Occupational Performance Measure (COPM) would have better adherence as measured by self-reported adherence, therapist-reported adherence, and attendance rate compared to the control group.

Our hypothesis was not supported for our primary outcome on Adherence. For our dependent variable of home exercise diaries, the control group attained a median of 87.5% and the experimental group 96.2%. Although there was a trend of 8.7% improvement favoring the experimental group, that represented a moderate effect size of d = 0.66, this improvement did not attain statistical significance. In the acute hand therapy literature, O'Brien reported splinting adherence at 75% or more with a mean at 85%. 16 These numbers are similar to a recent unpublished systematic review, in which adherence for acute UE home exercise programs was found to be 75%. 177 Lyngcoln et al., in their study on adherence of DRF patients reported a median of 70% adherence to home exercise programs. 62 Based on these numbers, it is important to note the standard treatment procedure produced by therapist prior to the introduction of collaborative goal setting was above average rate of adherence of 81% reported by the patients. To observe a statistical difference with an 11% improvement in HEP adherence based on the numbers we have generated would have required a sample of 34 patients in each group. The current study was underpowered to truly determine if there is or is not a benefit



toward home exercise program adherence by incorporating collaborative goal setting at the initial evaluation. The trend is encouraging when taken into the fact that two additional observations of less number of treatment visits and 6-week QDASH scores are slightly lower than the control group.

Our dependent variable of sports injury rehabilitation scale was 14.7 and 14.8 out of 15 possible points for both the control and experimental groups, respectively. These findings may be indicative of a ceiling effect for the SIRAS in acute hand therapy for DRFs, rendering the instrument not sensitive enough to detect change in this population on acute injuries. In chronic conditions, such as lower back pain, the SIRAS was reported with a mean of 11.6 out of 15.¹⁴ However, in acute injuries such as DRF previous research finding by Lyngcoln et al. reported SIRAS scores of 14.1 points, ⁶² which is similar to our findings. This is likely indicative of patients' high motivation level to improve in hand function following an acute fracture. This was further supported with high attendance results.

Both the control and experimental groups had high attendance rates of a median of 100%. Lyngcoln et al. reported similar findings at 100% attendance with distal radius fracture patients, 62 whereas Kolt and McEvoy reported 87.7% attendance with lower back pain. 14 In another study on lower back pain, 50% of participants were classified as non-compliant or low compliant, meaning they attended 80% or less of scheduled appointments. 15 The pathology is in part a factor, but the severe physical limitation created by a hand fracture and the intervention of splinting is likely to have a large effect on exercise adherence, attendance and perception of the therapist on patient adherence.



In our study, the SRS was blinded to the therapists and served as a means to measure the therapist-patient alliance throughout both the control and experimental group periods. The SRS yielded a median of 39.4 points for the control group and 36.6 points for the experimental group out of 40 possible points. According to Duncan et al., clients tend to score all alliance measures highly, and to have an overall score lower than 36 on the SRS should be a source of concern to invite the client to comment. We can infer from our SRS results that on average neither the control nor experimental group perceived to have a problem with their therapist's overall approach or method to achieve goals. Once again, this finding falls in line with previous findings from this study indicating the current hand therapy clinic group had a strong therapist-patient alliance prior to performing the intervention portion of this study of introducing the COPM.

The second hypothesis of improving functional outcome measured by QDASH, with collaborative goal setting, was not supported, as the change scores were not different between the two groups at 6 weeks. The effect size (ES) for both the control (2.3) and experimental group (1.7) were very large. The amount of change was equal but the level of function at 6 weeks was 21 in the experimental group compared to 27 in the control group. This was also not significant but approaches near normal functional levels of 15 which has been reported in healthy population using the full DASH. The QDASH and full DASH have a correlation of (r=0.96-0.98) for the function and total scores suggesting that these values approximate each other. The other key point was that the QDASH level of 21 points was reached in a median of four fewer visits. It is encouraging that the collaborative goal setting process may improve effectiveness of outcomes of the QDASH measure, which was not directly measured in this study.



The effect size observed in this study using the QDASH were greater than previous studies that examined multiple diagnoses, in which effect sizes ranged from 0.50^{128} to 1.26^{178} Specifically in hand therapy when multiple diagnoses were examined the typical effect size was 1.5^{49} This would suggest that the therapist-patient collaborative goal setting could have a large and meaningful effect on improving patient reported functional outcomes in an adequately powered study. Based on our results on HEP adherence and the QDASH's effect size with a group that performs above average of what is reported in the literature, we can infer the collaborative goal setting serves as a standard of excellence for treatment intervention with DRFs.

Clinical Implications

Therapists should be aware that our hypothesis on the use of collaborative goals to improve patient adherence to treatment, HEP or attendance was not supported. Nevertheless, there were trends towards significance for HEP diaries with a moderate gain ES (0.7) and small ES (0.3) for attendance. In addition, the collaborative goal intervention produced a reduced number of visits to attain established goals. At an average hand therapy visit of \$160, this could equate to \$640 in savings in treatment cost.

Therapists should be aware our hypothesis on the use of collaborative goals to improve the QDASH outcome measure was not supported. However, it appears the collaborative goal intervention may have an effect on attaining the same outcomes in a shorter period of time. The collaborative group receiving the goal setting intervention attained the same amount of change on the QDASH of 46 points, as the control group. This was achieved in spite of starting from a lower level of disability by 5.5 points and



having half the number of participants in this group, and again, with a median of four treatment visits less than the control group.

Limitations

The *a priori* power analysis revealed that 24 participants in each group was necessary and based on the results of no difference it is clear this study was underpowered. The study was limited by having to wait for patients with the particular diagnoses and were willing to participate. Unfortunately, to this time point we do not have adequate data to either support or refute the effect collaborative goal setting has on multiple measures of adherence and on outcomes. The time is limited due to the principle investigator's military service duties. However, the intent is to continue the study until he leaves to attend his next duty station and continue the study at the next location. Recall bias might have been introduced, as there was no guarantee patients filled out their HEP paper diaries in real time. We attempted to use mobile diaries to diminish the recall bias of the paper HEP diaries, however for this elderly population mobile diaries were an inconvenience.

In both the control and experimental group the average age represented patients in the 5th and 6th decade of life and the results may not generalize to younger patients. In this study, the sample represented individuals seeking UE rehabilitation for post-surgical DRFs from two outpatient clinics in the East South-central part of the United States over a period of eight months. Readers should consider if their patient population is similar in order to generalize findings. A major limitation of this study revealed was the high adherence level encountered in both of the clinics where this study was conducted. The clinics participating in this study were an elite group as evidenced by their baseline



outstanding attendance rate, in-clinic adherence and functional outcomes in place compared to what has been reported in the literature. Therefore, the gains obtained may have been smaller compared to the average hand therapy clinic.

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CHAPTER 6: SUMMARY

This series of studies about patient adherence and the multi-dimensional adherence model (MAM) had three aims. The first was to explore in a quantitative study, the MAM dimension of condition-related factors as measured by one of the most common tools used by hand therapist, the Quick Disability of Arm, Shoulder, Hand (QDASH), in order to determine how much change was meaningful. This was determined by calculating a minimal clinical important difference (MCID) score. These scores tell health care professionals when a meaningful change according to the patient has occurred. This first study investigated three common injuries that physical and occupational therapists treat: distal radial fractures, lateral epicondylitis, and carpal tunnel syndrome. The second aim was to explore in a qualitative study, the MAM dimension of personal factors to learn how individuals who expressed incongruence in directionality between their ODASH and their Global Rate of Change (GROC) scores described their perceived change in therapy. The third aim was to explore in a quasi-experimental study, the MAM dimension of therapy-related factors to examine the effect of patient-therapist collaborative goal setting on patient adherence to treatment and QDASH outcomes.

Hypothesis and findings for Specific Aim 1

We hypothesized that there would be a greater MCID score needed using the QDASH for the three specific pathologies compared to the previous literature in which multiple diagnoses were combined to calculate QDASH MCID that ranged between 8-20 point and 18 points on the QDASH website.



Finding: Our hypothesis was partially supported regarding MCID. Based on triangulation rules, we would recommend MCID values of 25.8 (26) points for surgical distal radius fracture, 15.8 (16) points for non-surgical lateral epicondylitis, and 18.7 (19) points for carpal tunnel release be used for meaningful change in patients with these diagnoses.

Hypothesis and findings for Specific Aim 2

We aimed to learn about the patient's experiences and expectations of rehabilitation.

Finding: Patients in this study expected to have a dedicated therapist who they could trust to work collaboratively with them to establish goals and spend time with them to achieve their goals. Patients identified contrasting descriptive characteristics between a dedicated therapist and non-dedicated therapist.

We aimed to learn about the patient's decisions to adhere and comply with rehabilitation guidelines.

Finding: We observed that therapist's and patient's perceptions could differ substantially on what was a clinically important change, and on what was a reasonable expectation for a home regimen. The treatment complexity played a role on the patient's decision to adhere to the program. Early clarification on the rate of recovery may improve patient adherence. Particularly, in the case of sensation loss, explaining the rate of sensory regeneration and timeline expectations can set realistic expectations.

Hypothesis and findings for Specific Aim 3

We hypothesized that_the experimental group receiving the collaborative goal setting intervention would have better adherence as measured by self-reported adherence, therapist-reported adherence, and attendance rate compared to the control group.



Finding: This hypothesis was rejected for all three measures. The median for home exercise program diary adherence was found to trend towards significance by 8.7 percent favoring the experimental group Mann-Whitney U (p < .100).

We hypothesized the experimental group receiving the collaborative goal setting intervention will have better self-reported UE function as measured by the QDASH scores compared to the control group.

Finding: This hypothesis was rejected. The experimental group receiving collaborative goal setting intervention had similar QDASH mean change scores at 45.9 ± 27.6 compared to the control group 46.1 ± 23.8 , Mann-Whitney U (p < .859).

SYNTHESIS AND APPLICATION OF RESULTS

One explanation for a larger MCID for the two post-surgical diagnoses may be the perceived initial pain and edema restrictions from the surgical intervention. Patients can be limited by the anticipation of pain and expectations of decreased function following surgery. Therefore, patients may perceive the need to regain greater ROM and decrease pain before they can report a minimal improvement in their status. Our qualitative study supports this rationale, as the patient's perception of collaborative, meaningful goals tailored to the patient's specific need was important. Furthermore, this reasoning is supported by another study that examined patient satisfaction with outcomes after surgical distal radius fractures.³³ That study concluded patients needed to regain greater wrist ROM than what was necessary to perform activities of daily living, to be satisfied with treatment outcomes. It appears that the MCID becomes larger for surgical conditions, and this is augmented by the amount of required post-surgical immobilization.



The exploration of the MAM condition-related dimension now enables clinicians to have specific QDASH thresholds per diagnoses to add to their clinical reasoning, and establish meaningful goals with their patients. We learned that a post-surgical DRF patient, compared to a non-surgical lateral epicondylitis patient, requires as a minimum 10 points more on the QDASH before they perceive meaningful gains in treatment.

Therefore, when establishing functional post-surgical distal radius goals, therapists can aim for 26 points on the QDASH as a minimum threshold of improvement. In addition, therapists can use the diagnosis-specific MCID to report attainment of functional gains to third parties (e.g. Medicare G-codes, referring providers, insurers) being confident that a QDASH MCID of 26 points represents the minimum functional gains for post-surgical distal radius fractures compared to previous global diagnoses measures of 8-20 points. The findings from this study add to the body of knowledge that MCID need to be different for different pathologies.

Examining the MAM dimension of patient-related factors gave us first-hand information on how patients perceive incongruence in therapy. Our results indicated that trust in the therapist was a major determinant for patient adherence. Patients expect to have a dedicated therapist who they can trust to work collaboratively with them to establish goals and spend time with them to achieve these goals. Specifically related to incongruence, we learned the therapist's and patient's perception might differ substantially on what is a clinically important change, and on what is a reasonable expectation for a home regimen. We also learned how to identify patients that exhibit incongruence. Indications of a possible incongruence are: inconsistencies between the directionality of improvement or worsening of objective findings, such as ROM, grip



strength, and the patient's reported functional outcome on a form such as the QDASH.

The inconsistency in directionality could be between two subjective forms such as the QDASH and the GROC forms. Identifying potential incongruence is important to ensure both therapists and patient are aiming to achieve the same goal, which leads to the patient's buy-in to the therapeutic program, which we observed in our third study.

It is important to note that the MCID is based on patient input and adds a level of patient trust in the functional measure. The understanding of this concept by therapists and the variation in diagnoses specific MCID thresholds will help decrease the perceived dissonance between the patient and the therapist views on the amount of change that is clinically important. The mutual level of understanding on the diagnoses specific MCID thresholds provide an avenue of trust between the patient and therapist as it allows for a discussion on establishing realistic, collaborative goals that are tailored specific to the patient's condition. Early clarification on the rate of recovery may improve patient adherence. Particularly, in the case of sensation loss, explaining the rate of sensory regeneration and timeline expectations can set realistic expectations. The majority of patients expected to return to normal and regain full function. The treatment complexity played a role on the patient's decision to adhere to the program.

Clinical implications

Our overarching goal was to examine the effect of therapist-patient collaboration on patient adherence and outcomes. None of the three adherence measures demonstrated a statistical significant difference between groups. For home exercise diaries, there was a trend of 8.7% favoring the experimental group, for attendance there was no difference between groups with a median of 100%, and the QDASH made similar gains in both



groups although in the experimental group had less disability by 6 points at baseline.

Clinicians may use collaborative gains with HEP diaries with the surgical DRF population to attain clinical gains although this study did not prove their effectiveness.

For our secondary outcome, the QDASH, our hypothesis was not met. Although the control group had a larger level of initial impairment by 6 points, there was no statistical significant difference for the QDASH between groups at 6-wks. What this study adds is the knowledge that therapist-patient collaborative goal setting produces a QDASH effect of 1.7, which is larger than what is reported in the literature. Although it is was not larger than the control group's ES at 2.3 points. See Table 6:1 for clinical implications.

Table 6.1 Clinical Implications

Finding	Recommendations
MCID is variable per distal upper extremity diagnosis	When establishing Long-term goals, therapists should aim to gain as a minimum 26 points for surgical DRF patients, 19 points for CTR and 16 points for lateral epicondylitis.
Dedicated therapist	To gain patient trust, therapists should actively listen to the patient, eliciting the patient's perspective, validating their concerns with empathy and establishing plans of care that incorporates the patient's wants and needs.
Early clarification on the rate of recovery may improve patient adherence	Therapists can use the clinical level system of functional return to allow for a discussion on the timeline of functional return for different activities.
	Particularly in the case of sensation loss, therapists should explain the rate of sensory regeneration timelines to set realistic expectations.
Adherence	Therapists should be aware that the use of collaborative goals to improve patient adherence was not supported. Nevertheless, there was a 9% trend towards significance for home exercise diaries and these outcomes were achieved with 4 visits less than the control group.



Table 6.1 (Continued)

Effective outcome measures	Therapist should be aware the use of collaborative goals was not supported for the QDASH outcome measure. However, therapist-patient collaborative goal setting produces a QDASH effect of 1.7, which is larger than what is reported in the literature. Although it was not larger than the control group's ES at 2.3 points.

Future Research

To repeat this piloted study as a multi-center randomized control trial with a larger sample size, with three groups: 1) an experimental group receiving COPM, 2) a control group receiving standard of care, and 3) another group receiving attention. Prior to conducting the study, one recommendation would be to rate the hand therapy clinic's current level of adherence to home exercise programs, utilizing a pool of diagnoses, in addition to testing the therapist-patient alliance using the SRS.

To this date, no gold standard measure of adherence to HEP's exists. The creation of a device for UE's, similar to a pedometer, with the ability to distinguish between multiple degrees of freedom would greatly enhance the reliability of reported HEP's,

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APPENDIX A: Therapist-rated Sport Injury Rehabilitation Adherence Scale (SIRAS)

1.	Circle the number the completed the rehab				•		•
	Minimum effort	1	2	3	4	5	Maximum effort
2.	During today's appoinstructions and adv		nt, how f	requer	ntly did t	his pat	ient follow your
	Never	1	2	3	4	5	Always
3.	How receptive was today's appointment	-	eient to cl	hanges	in the re	ehabilit	tation program during
	Very unreceptive	1	2	3	4	5	Very receptive

Brewer BW, Van Raalte JL, Petitpas AJ, Sklar JH, Pohlman MH, Kruskell RJ, et al. Preliminary psychometric evaluation of a measure of adherence to clinic-based sport injury rehabilitation. Phys Ther Sport 2000; 1:68-74.

APPENDIX B: Home Exercise Diary

For each exercise prescribed: Write the number of **sessions** of exercise completed, and number of **exercises** completed each session.

	exercise	Mon	Tues	Wed	Thu	Fri	Sat	Sun
Month /Day		/	/	/	/	/	/	/
/		/	/	/	/	/	/	/
		/	/	/	/	/	/	/
		/	/	/	/	/	/	/
		/	/	/	/	/	/	/
		/	/	/	/	/	/	/
		/	/	/	/	/	/	/
		/	/	/	/	/	/	/

APPENDIX C : Session Rating Scale (SRS V.3.0)

ID#		
Session # Date: _		
Please rate today's se description that best	ssion by placing a mark on the line near fits your experience.	est to the
	J 1	
	Relationship	
I did not feel heard, understood, and respected.	II	I felt heard, understood, and respected.
	Goals and Topics	
We did <i>not</i> work on or talk about what I wanted to work on and talk about.	II	We worked on and talked about what I wanted to work on and talk about.
The therapist's approach is not a good	Approach or Method	The therapist's approach is a good
fit for me.	II	fit for me.
	Overall	
There was something missing in the session today.	II	Overall, today's session was right forme.
Ir	nternational Center for Clinical Excellenc	e
	www.scottdmiller.com	

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APPENDIX D: QuickDASH & GROC Forms

Survey of Upper Extremity Disability (DASH)	Date:	Date of Birth:
	Name:	Therapist:

The Disability of the arm, shoulder and hand (DASH) is a questionnaire to ask you about your symptoms as well as your ability to perform certain activities. Please answer every question, based on your condition in the last week, by circling the appropriate number. If you did not have the opportunity to perform an activity in the past week, please make your best estimate on which response would be most accurate. It does not matter which hand you use to perform the activity; please answer based on your ability regardless of how you perform the task. Please rate your ability to do the following activities by circling the number:

, , ,	No Difficult	Mild Difficult	Moderate Difficulty	Severe Difficult	Unable
		y	Difficulty	y	
Open a tight jar	<u>y</u> 1	2	3	y 4	5
Do heavy household chores (e.g.,	1	2	3	4	5
wash walls, floors)	· ·	2	3	4	3
Carry a shopping bag or briefcase	1	2	3	4	5
Wash your back	1	2	3	4	5
Use a knife to cut food	1	2	3	4	5
Recreational activities which you				-	
take some force or impact					
through your arm, shoulder, or	1	2	3	4	5
hand (golf, hammering, tennis,		_		-	J
etc)					
9	Not at	Slightly	Moderatel	Quite a	Extrem
	All	0 7	y	Bit	ely
During the past week, to what					•
extent has your arm, shoulder, or					
hand problem interfered with	1	2	3	4	5
your normal social activities with	ı	2	3	4	5
family, friends, neighbors, or					
groups?					
	Not	Slightly	Moderatel	Very	Unable
	Limited	Limited	y Limited	Limited	
	at All				
During the past week, were you					
limited in your work or other					
regular daily activities, as a result	1	2	3	4	5
of your arm, shoulder, or hand					
problem?					
Please rate the severity of the	None	Mild	Moderate	Severe	Extrem
following symptoms in the last week					е
Arm, shoulder, or hand pain	1	2	3	4	5
Tingling (pins & needles) in your					
arm, shoulder, or hand.	1	2	3	4	5
	No	Mild	Moderate	Severe	So
	Difficult	Difficult	Difficulty	Difficult	Much I
	y	y		y	can't
					Sleep
During the past week, how much					
difficulty have you had sleeping	1	2	3	4	5
because of the pain in your arm,					



shoulder or hand?			
For office use only			
Percent Disability Score ()			
Sum all columns for raw score (
)			

If this is your first visit, ignore the question below.

Overall, since you started your treatment, has there been any change in your symptoms in your arm, shoulder, or hand during your daily activities? Please indicate if there has been any change by choosing one of the following options.

Worse	Same (0)	Better
Almost the same, hardly any worse		Almost the same, hardly any better
at all (-1)		at all (1)
A little worse (-2)		A little better (2)
Somewhat worse (-3)		Somewhat better (3)
Moderately worse (-4)		Moderately better (4)
A good deal worse (-5)		A good deal better (5)
A great deal worse (-6)		A great deal better (6)
A very great deal worse (-7)		A very great deal better (7)



APPENDIX E: Independent and Dependent Variables Used in the Study

Independent and Dependent Va	Dependent Vari	riables Used in the Study.	he Study.		
		Pr	Primary Outcome: Adherence		
Dependent variables	Instrument	Measures	Format	Reliability	Validity
1) Therapist-rated - once a week	The Sport Injury Rehabilitation Scale, (SIRAS) (Brewer et al., 2000).	Patient's adherence to in clinic rehabilitation.	3-item measure in which clinicians' rate patients' intensity of completion of rehabilitation exercises, the frequency in which they follow the clinician's instructions, and their receptivity to changes in the rehabilitation program. All 3 items measured on a 5-point Likert scale.	Inter-rater reliability 0.76-0.93, intra-rater reliability 0.63-0.76 (Kolt et al., 2007).	Criterion validity established positively correlated in two samples (Brewer et al., 2000).
2) Patient-rated - once a week	Home exercise diary -paper -mobile	Patient's perception of their adherence behaviors for each regimen.	7-day rating of the number of sessions and number exercises completed each session, for each prescribed exercise.	Not rated	Utilized for distal radius fracture conditions (Lyngcoln et al., 2005).
3) Attendance Rate - upon discharge	N/A	Rate of attendance.	Over the course of care rate of appointments attended over prescribed, (i.e. 12 scheduled appointments attended 10 = 83% attendance rate) (Jack et.al, 2010).	Not rated	Not rated
4) Patient-rated - once a week	Session Rating Scale (SRS), (Duncan et al., 2003).	Therapist- patient alliance.	The SRS is a four-item (relationship, goals and topics, approach and method, overall) visual analogue scale designed specifically for everyday clinical use. It is a brief alternative to the Revise Helping Alliance Questionnaire (HAQ-II) and the Working Alliance Inventory (WAI).	Test-retest reliability .64, internal consistency .88, it is positively correlated to the Outcome Rating Scale (.29, p<.01), (Duncan et al., 2003).	Concurrent validity, .48 between SRS and HAQ-II, all correlations between the SRS and HAQ-II items were between .39 and .44 (Duncan et al., 2003).

APPENDIX E (continued)

		Secondary	Secondary Outcome: Functional Gains		
Dependent variables	Instrument	Measures	Format	Reliability	Validity
U) Patient-rated Quick Disabilities of the Arm, Shoulder, and the Arm, Conduct, and Hand (QDASE) (Beaton et al., 2005)	Quick Disabilities of the Arm, Shoulder, and Hand (QDASH) (Beaton et al., 2005).	Region specific functional outcome measure	Region specific The QDASH has 11 items (3 for functional symptoms, 8 for function). All cross-sectional outcome measure items are scored on a scale of 5 (Likert) levels: 1= no difficulty/symptoms, 2 = mild al, 2005; Gummesson difficulty/symptoms, 3 = 1, 2006). Test-retest moderate difficulty/symptoms, and 5 correlation coefficient = extreme difficulty/unable to do)/symptoms. Takes 2 minutes to complete (Angst et al, 2011) 2006; Mintken et al, 2009).	α t et et ll,	Pearson's correlations of the QDASH total score to the SPADI: 0.84 (Angst et al, 2009) and to the SF-36 PCS: 0.68 (Angst et al, 2009), and to the Global rating of change: 0.45 (Mintken et al, 2009)
Independent variable for both outcomes	Instrument	Measures	Format	Reliability	Validity
1) Therapist-patient goal collaboration (Therapist & patient rated) - At initial evaluation/ enrollment in the study, at six weeks, and upon discharge	Canadian Occupational individual Performance Measure perceived (COPM) (Law et al., 1991). performar the areas care, productive perceived care, productive leisure.	Assesses an individual's perceived occupational performance in the areas of selfcare, productivity, and leisure.	Assesses an The assessment involves a 5-step individual's process nested within a semi-structured interview, typically conducted by an Occupational performance in Therapist. Interview focuses on the areas of self-identifying activities within each performance domain that the productivity, and client wants, needs, or is expected to perform. Following Step 3, the patient and therapist create goals for therapeutic interventions. Takes 10-20 min to administer (Law et al, 1990).	Test-retest reliability Significant positive S8 satisfaction (Cup et correlations between the al, 2003; 2 to 6 months COPM scores and the COPM scores and the COPM scores Impact Profile (SIP68), Disability and Impact on Participation and Autonomy (IPA) scores (Eyssen et al, 2011; Dutch version; n=138; mean age=51 (13), Mixed Population)	Convergent validity, Significant positive correlations between the COPM scores and the Sickness Impact Profile (SIP68), Disability and Impact Profile (DIP), and Impact on Participation and Autonomy (IPA) scores (Eyssen et al, 2011; Dutch version; n=138; mean age=51 (13), Mixed Population)



APPENDIX F: Clinical Level System of Functional Return

Level I	Level II	Level III
4-6 weeks	5-8 weeks	7-12 weeks
Edema control	Increase load	Overhead tasks
Scar management	Joint mobilizations grade III	Torque tasks
Orthoses	Corrective orthoses	Motion plus load
Joint mobilizations grade	Weight bearing	Pace
I-II		
Muscle balancing	Stress loading	
Goals: Independence	Goals: Independence with	Goals: Independence
with ADL tasks	IADL tasks	in Essential Job Tasks

Adapted from: Pitts, G., Willoughby, J., Morgan, R. (2013). Clinical Reasoning and Problem Solving to Prevent Pitfalls in Hand Injuries. In Fundamentals of Hand Therapy: Clinical Reasoning and Treatment Guidelines for Co Diagnoses of the Upper Extremity (2nd ed., pp. 87-102). St. Louis: Elsevier



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- **178.** Angst F, Goldhahn J, Drerup S, Flury M, Schwyzer HK, Simmen BR. How sharp is the short QuickDASH? A refined content and validity analysis of the short form of the disabilities of the shoulder, arm and hand questionnaire in the strata of symptoms and function and specific joint conditions. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation.* Oct 2009;18(8):1043-1051.



Vita

MAJ Enrique V. Smith-Forbes, MOT, OTR/L, CHT

I. General Information

Place of Birth Panama city, Republic of Panama.

Certificate or Specialty Board Licensure

Graduate Certificate in Clinical Research Skills, University of Kentucky, 7 August 2014

National Board for Certification in Occupational Therapy: #7017

Hand Therapy Board Certification: #1041100289

Texas Board of Licensure: #109386

American Occupational Therapy Association: #11427

American Society of Hand Therapists: #25954

IRB Certification, CITI: #8491286

II. Education

2012 - Present The University of Kentucky, Lexington, KY

Candidate, Doctor of Philosophy, Rehabilitation Sciences

Anticipated graduation May 9, 2015

Dissertation: "Exploration of factors associated with patient adherence in upper extremity rehabilitation: A

mixed-methods embedded design."

1997-1999 <u>Texas Woman's University</u>, Denton, TX

Master of Occupational Therapy

Professional Project: "The occupational adaptation frame of

reference tutorial."

1989-1991 Park College, Parkville, MO

Bachelor of Science in Management/ Computer Information

Systems

1989-1989 <u>Academy of Health Sciences</u>, Fort Sam Houston, TX.

Occupational Therapy Specialist Course 303-91L10

1983-1987 Universidad Tecnologica de Panama, Panama City, Panama

Technician in Engineering specialized in Computer

Programming



III. Professional experience

2010-2012	Chief occupational therapy section, General Leonard Wood Army Community Hospital.
2009-2009	Prevention team Officer In Charge (OIC) 98 th Combat Stress Control (CSC) and Staff OT at Madigan Army Medical Center
2008-2009	98 th CSC, OIC of the largest restoration/fitness behavioral health clinic in Iraq
2006-2008	98 th CSC prevention OIC, Fort Lewis, WA
2005-2006	Assistant Chief outpatient orthopedic occupational therapy section, Walter Reed Army Medical Center, Washington DC
2002-2005	Hand therapist, Reconstructive Orthopedic Therapy of Houston (former Houston Hand and Upper Extremity) Houston, TX
1999-2002	Head of occupational therapy department, Park Plaza Hospital, Houston TX
1999-1999	(August-Nov.) Occupational therapist, Herman Hospital, Houston, TX.
1999-1999	(March-June) Phase II OT student, Health-South 1960, Hand Rehab, Houston TX. Student on-the-job training – hand rehabilitation.
1999-1999	(Jan-March) Phase II OT student, U.S. Brooke Army Medical Center, FSH, TX.Student on-the-job training – neurology/orthopedics.
1992-1998	Certified Occupational Therapy Assistant, San Antonio, Dallas, & Houston, TX. Worked in long-term care facilities with the geriatric population in rehabilitation programs.
1989-1992	OTA Specialist/ COTA, US Air Force, Wilford Hall Medical Center, Lackland AFB, TX.



IV. Teaching Activity

Eastern Kentucky University – Teaching Apprenticeship, 2013 OTS 836 Occupation-Based Practice: Optimizing Occupation

University of Kentucky – Guess Lectures, 2014

PT 654 Physical Therapy Motor Control and lab

ATC 690 Athletic Training Orthopedic Evaluation of the Upper extremity
ATC 695 Athletic Training Orthopedic Evaluation of the Lower extremity

Eastern Kentucky University – Guess Lecture, 2014

OTS 884 Qualitative Inquiry

V. Scholastic and Professional Honors

"Experiences of Individuals in Upper Extremity Rehabilitation with Incongruence Between QUICKDASH and GROC Scores: A Phenomenological Study," at the 37th American Society of Hand Therapists Annual Meeting in Boston, Massachusetts, on September 18-20, 2014.

"First Time Presenter Award" for quantitative dissertation study, "Minimal Clinical Important Difference of the Quick Disabilities of the Arm Shoulder and Hand (QUICKDASH) for Post-surgical Distal Radius Fractures," at the 37th American Society of Hand Therapists Annual Meeting in Boston, Massachusetts, on September 18-20, 2014.

VI. Professional Publications

Peer-Reviewed Manuscripts

Smith-Forbes EV, Moore-Reed SD, Westgate PM, Kibler WB, Uhl TL. (In press) Descriptive analysis of common functional limitations identified by patients with shoulder pain. *Journal of Sport Rehabilitation*. Jan 22 2015.

Smith-Forbes E, Najera C, Hawkins D. Combat operational stress control in Iraq and Afghanistan: Army occupational therapy. *Military medicine*. 2014;179(3):279-284.

Smurr, L., Robinson, M., & **Smith-Forbes, E.** (2008). Treating the war casualty: Case Reports of Polytrauma. *Journal of Hand Therapy*, 21, (2) 177-188.

Manuscripts In Peer-Review

Smith-Forbes EV, Howell DM, Willoughby J, Pitts GD, Uhl TL. Specificity of the Minimal Clinical Important Difference of the Quick Disabilities of the Arm Shoulder and Hand (QDASH) for Distal Upper Extremity Conditions. *Journal of Hand Therapy*.



Manuscripts In Progress

Smith-Forbes EV, Howell DM, Morgan R, et al. Adherence of Individuals in Upper Extremity Rehabilitation With Incongruence Between Their QDASH and GROC Scores: A Phenomenological Study.

Smith-Forbes EV, Howell DM, Uhl TL. Adherence to Therapeutic Home Exercise Programs in Adults With Acute Upper Extremity Injuries: A Systematic Review.

Smith-Forbes EV, Howell DM, Myers CT, et al. Prospective Study of the Effect of Therapist-Patient Collaborative Goal Setting on Patient Adherence in Distal Radius Fracture Conditions.

Smith-Forbes EV, Howell DM, Myers CT, et al. Outcomes in Post-surgical Distal Radius Fracture Rehabilitation Using a Patient-Centered Approach to Intervention.

VII. Invited Speaking Engagement/ Presentations National – Peer – Reviewed

Smith-Forbes, E., Howell, D.M., Uhl, T. (2014, December) *Experiences of Individuals in UpperExtremity Rehabilitation with Incongruence Between their QuickDASH and GROC Scores: A Phenomenological Study*. Platform presentation at the Association of Military Surgeons of the United States (AMSUS) Meeting, in Washington, DC.

Smith-Forbes, E., Howell, D.M., Willoughby, J., Pitts, G., Uhl, T. (2014, September) *Minimal Clinical Important Difference of the Quick Disabilities of the Arm Shoulder and Hand (QuickDASH) for Post-surgical Distal Radius Fractures.* Platform presentation at the American Society of Hand Therapists 37th Annual Meeting, Boston, MA.

Smith-Forbes, E., Morgan, R., Clark, K., Hall., S. Willoughby, J., Armstrong, H., Pitts, G., Uhl, T., Howell, D.M. (2014, September) *Experiences of Individuals in Upper Extremity Rehabilitation with Incongruence Between their QuickDASH and GROC Scores: A Phenomenological Study*. Platform presentation at the American Society of Hand Therapists 37th Annual Meeting, Boston, MA.

Nitz, A., Brown, D., Gagnon, P., **Smith-Forbes, E.,** Brown, T., & Uhl, T. (2014, February). *Early changes in self reported-outcomes predict final outcome in patients with shoulder impingement.* Platform presentation at the American Physical Therapy Association Combined Sections Meeting, Las Vegas, NV.

Uhl, T., **Smith-Forbes,** E., Moore, S., & Kibler. B. (2014, February). *Descriptive analysis of functional limitations in patients with shoulder pain using G-codes*. Platform presentation at the American Physical Therapy Association Combined Sections Meeting, Las Vegas, NV.



Kibler, W., Moore S., **Smith-Forbes E.,** & Uhl T. (2013, October). Why Is The Patient In Your Office: A Descriptive Analysis Of The Functional Limitations Reported By Patients With Shoulder Pain. E-poster presented at the American Shoulder and Elbow Surgeons (ASES) Meeting, Las Vegas, NV

Smith-Forbes, E. (2013, October). *Reclaiming lost occupations: Empowering upper extremity chronic pain clients to re-enter valued participation*. Poster presentation at the Society for the Study of Occupation: USA, Lexington, KY.

Smith-Forbes, E., Hawkins, D., & Najera. C. (2011, April) *Maximizing quality of life in combat operations*. Platform presentation at the American Occupational Therapy Association Annual Conference and Exp, Philadelphia, PA.

Smith-Forbes, E., Hawkins, D., & Najera. C. (2011, April) *Maximizing quality of life in combat operations*. Poster at the American Occupational Therapy Association Annual Conference and Exp, Philadelphia, PA.

State – Peer –Reviewed

Smith-Forbes, E.V, Howell, D.M., Willoughby, S., Pitts, G., Uhl, T., (2015, March) *Minimal Clinical Important Difference of the Quick Disabilities of the Arm Shoulder and Hand (QuickDASH) for Non-surgical Lateral Epicondylitis*. Poster presentation at the University of Kentucky College of Health Sciences Research Day Meeting, Lexington, KY.

Smith-Forbes, E., Gregg, B., Reer, T., Howell, D., Shordike, A. (2014, September) *The Deployment Role of Army Occupational Therapy in Behavioral Health*. 3-hour minicourse presented at the Kentucky Occupational Therapy Association Annual conference, Lexington, KY.

Smith-Forbes, E., Morgan, R., Clark, K., Hall., S. Willoughby, J., Armstrong, H., Pitts, G., Uhl, T., Howell, D.M. (2014, March) *Experiences of Individuals in Upper Extremity Rehabilitation with Incongruence Between their QuickDASH and GROC Scores: A Phenomenological Study*. Platform presentation at the University of Kentucky College of Health Sciences Research Day Meeting, Lexington, KY.

Smith-Forbes, E. (2013, November). *Reclaiming lost occupations: Empowering upper extremity chronic pain clients to re-enter valued participation*. Poster presentation at the Eastern Kentucky University Research Day Meeting, Richmond, KY.

Smith-Forbes, E., Moore, S., Kibler. B. & Uhl, T. (2013, September). *Descriptive analysis of functional limitations in patients with shoulder pain using G-codes.* Poster presentation at the Kentucky Occupational Therapy Association Annual conference, Bowling Green, KY.



Smith-Forbes, E., Moore, S., Kibler. B. & Uhl, T. (2013, September). *Descriptive analysis of functional limitations in patients with shoulder pain using G-codes.* Poster presentation at the Kentucky Physical Therapy Association Fall Function Meeting, Lexington, KY.

Local – Invitations

Smith-Forbes, EV. Keynote Speaker for the 2014 Phi Lambda Sigma Chi Chapter Leadership Banquet. Phi Lambda Sigma, also known as the national Pharmacy Leadership Society, (21 OCT 2014).

Smith-Forbes, EV. Presenter – "*Therapeutic Management of Chronic Regional Pain Syndrome (CRPS)*," (8 JAN 2015). 2-hour training at Ireland Rehabilitation Service, Fort Knox, Kentucky.



