



# ARTHRITIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

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## SELECTING OUTCOME MEASURES TO EVALUATE REHABILITATION INTERVENTIONS FOR RHEUMATOID ARTHRITIS: A Prospective Evaluation *August 1992*

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## TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
INTRODUCTION	1
METHODS	
1. Phase 1: Qualitative evaluation of established outcome measures	2
2. Phase 2: Prospective evaluation of chosen outcome measures	3
3. Analysis	3
RESULTS	
1. Phase 1: Qualitative evaluation of established outcome measures	4
2. Phase 2: Prospective evaluation of chosen outcome measures	10
DISCUSSION	11

## LIST OF TABLES

Table 1	Outcome measures qualitatively evaluated
Table 2	Evaluation performance of selected outcome measures
Table 3	Participant characteristics
Table 4	Semi-structured participant evaluation questions
Table 5	Assessment of practicality
Table 6	Baseline characteristics
Table 7	Mean percent change for all outcome measures

## EXECUTIVE SUMMARY

- Program evaluation has been an integral part of The Arthritis Society Consultation and Therapy Service (CTS) home therapy program. Two surveys of CTS clients have shown high levels of satisfaction with CTS services for physicians, therapists and clients. Evaluations of the physiotherapy intervention for ankylosing spondylitis and the occupational therapy intervention for rheumatoid arthritis have also been performed. An evaluation of the most frequently prescribed intervention (physiotherapy) for the most frequently identified disease entity (inflammatory polyarthritis) is currently being designed.
- Most arthritis-specific outcome measures have been designed for use in clinical trials of pharmacotherapy during which significant change in instrument scores is expected (usually a minimum of 30% change). The use of these same instruments to evaluate rehabilitation programs can be misleading as the same amount of expected change is not possible; improvement tends to occur slowly and steadily over time.
- This study consisted of 2 phases. The first phase was a qualitative evaluation of outcome measures to identify instruments which would measure change in the three domains identified to be the most frequently identified problems experienced by CTS clients. These three problem domains are pain, lack of disease knowledge, and impairment of activities of daily living.
- Phase 2 consisted of a prospective exploratory study to establish the stability over time, and sensitivity to change for selected outcome measures when administered to a group of patients with stable disease and a group of patients with unstable disease who participated in an ambulatory rheumatology day program. The chosen measures could then be used to evaluate the efficacy of the CTS physiotherapy intervention in a randomized controlled trial.
- This manoeuvre allowed us to identify a comprehensive set of 4 outcome measures which contained domains which were appropriate to evaluate persons with inflammatory arthritis receiving a rehabilitation intervention. The Sickness Impact Profile (SIP) is a measure of overall health status which is best representative of long-term change; the Arthritis Impact Measurement Scales 2 (AIMS2) is a disease specific measure of overall health status which again, is best representative of long term change. The Stanford Arthritis Self-Efficacy Scales (SES) and Visual Analogue Scale for Pain (VAS(P)) are representative of current health status, specifically in the areas of pain and perceived self-management.

- The change scores for the SES and VAS(P) were compared to those of other self-management rehabilitation programs who have used the same instruments to measure outcome. The percent change scores for our rehabilitation intervention group were comparable to those of other intervention studies. The control group change scores were also comparable to other controls. The results of this study suggest that the SES may be the best currently standardized measure to quantify change as a result of a short-term rehabilitation intervention.

## Selecting Outcome Measures to Evaluate Rehabilitation Interventions for Rheumatoid Arthritis: A Prospective Evaluation

### I. Introduction:

A comprehensive approach to the management of clients with rheumatoid arthritis (frequently referred to as inflammatory polyarthritis (IP)) is essential. Often a combination of counselling, physiotherapy, occupational therapy, pharmacotherapy and surgery is utilized.<sup>1-8</sup> The standard physiotherapy management includes education about the nature of the disease, the need for balancing rest and appropriate activity, and methods to protect joints from trauma and overuse. The use of physiotherapy modalities (ie ice and heat) to relieve pain and swelling, and exercise to improve joint mobility, muscle strength and endurance may result in improved function and quality of life<sup>1-17</sup>.

In 1989, the physiotherapy directors of The Arthritis Society, Ontario Division (TASOD), performed a chart review from which the ten most frequently identified client problems were selected, followed by a consensus approach to prescribe appropriate therapeutic interventions for each problem. An internal document entitled, "Inflammatory Arthritis: Management Guidelines" (IAMG)<sup>18</sup>, was created for circulation to all Consultation and Therapy Service (CTS) physiotherapists. In a review of CTS physiotherapy client charts conducted in the spring of 1992, the study team found that 96% of the client-identified problems fell within the 10 listed in the IAMG<sup>19</sup>. The most frequently recorded interventions were modalities of treatment (exercise, heat, ice, aids etc.) and education. In addition, the chart review identified pain control, limited activities of daily living, and, limited knowledge regarding disease management, as those areas most frequently identified as problems by clients.

This study consisted of 2 phases. The first phase was a qualitative evaluation of outcome measures to identify instruments which would measure change in the three domains identified to be the most frequently identified problems experienced by CTS clients.

Phase 2 consisted of a prospective exploratory study to establish the stability over time, and sensitivity to change, for selected outcome measures when administered to a group of patients:

- a) with controlled disease, who received no intervention between test 1 and test 2
- b) with variable disease activity, who participated in a Multidisciplinary Ambulatory Rheumatology Program (MARP) between test 1 and test 2.

## II. Methods:

### 1. *Phase 1: Qualitative evaluation of established outcome measures*

#### 1.1 *Identify established outcome measures.*

A variety of literature searches were conducted via MEDLINE (1961 - present) using 'outcome measures', 'questionnaires', 'musculoskeletal disease' and 'arthritis' as key MESH words to identify outcome measures already used within an arthritis population. Additional literature was identified using social science and allied health professional literature data bases. A consensus manoeuvre was conducted to compile a comprehensive list of standardized, valid and reliable outcome measures which merited further consideration. The measures collected purported to accurately measure subject status for a diversity of domains ranging from functional ability and symptom severity to psychosocial, economic and spiritual wellbeing.

#### 1.2 *Review domains tested within each measure.*

After a comprehensive review of measures deemed appropriate for the assessment of change in arthritis, several measures were selected for a comprehensive qualitative assessment if they appeared to assess any of the following domains: physical status, psychological status, social status, pain, or arthritis impact. Inclusion of comorbidity, global impact, or importance/priority rating were also criteria by which the final list of questionnaires were screened. Questionnaires and associated literature were collected and reviewed by a panel which consisted of an epidemiologist/rheumatologist, CTS program director/physiotherapist, senior arthritis research associate, and medical anthropology student. Each measure was scored on the presence/absence and weighting of variables using a multi-item checklist.

#### 1.3 *Establish feasibility and client acceptability of a battery of measures.*

Seven patients with IP who had previous clinical trial experience were asked to participate in the assessment of feasibility and acceptability of selected measures. All participants attended an office session during which they completed a battery of questionnaires, participated in a physical examination and provided feedback about their experience.

#### 1.4 *Identify gaps in coverage through client/interviewer discussion.*

During a post-manoeuvre interview, the interviewer asked the clients to identify issues that were not addressed by the questionnaires, but which were deemed important and relevant to people with a diagnosis of IP.

Using the instruments chosen in Phase 1, a prospective evaluation of the outcome measures then took place.

## **2. Phase 2: Prospective Evaluation of Chosen Outcome Measures**

### **2.1 Identify study participants**

Control Group: Five patients with controlled rheumatoid arthritis were recruited from the Hamilton practice of the study team rheumatologist.

Intervention Group: Six patients with variable rheumatoid arthritis activity were recruited from the Multidisciplinary Ambulatory Rheumatology Program (MARF), which is run at Sunnybrook Health Science Centre, Toronto.

Informed, signed consent was obtained from all participants.

### **2.2 Manoeuvre**

Control Group (n=5): Control subjects received no intervention between test 1 and test 2; mean time between assessments was 4 weeks. Four self-administered outcome measures (AIMS2, SIP, SES, VASP) were administered and a physical assessment was performed at each visit.

Intervention group (n=6): Intervention subjects participated in MARF between test 1 and test 2. MARF is staffed by a physiotherapist, occupational therapist, nurse educator, social worker, nutritionist, pharmacist and rheumatologist. Every 2 weeks, a group of 6 individuals with the same disease entity (rheumatoid arthritis or osteoarthritis) attend the MARF program for 9 consecutive half-day sessions. One half-day session is committed to team assessment of the client and goal-setting case management meetings. Each program day begins with a one hour hydrotherapy session. The remaining program hours consist of group education and exercise sessions. Several short sessions are provided to address the individual therapeutic needs of each participating client. Mean time between assessments was 10 days. Four self-administered outcome measures (AIMS2, SIP, SES, VASP) were administered at each assessment. Physical assessment data were abstracted from clinic notes. Sociodemographic and disease data were collected by the AIMS2.

*2.3 Sensitivity to change of the selected measures both within the groups and between the groups was calculated. Change scores were calculated using SPSS PC+ and converted to percent scores to allow for across measure comparisons of change.*

## **3. Analysis**

Data was managed and analyzed using SPSS PC+ Version 4.0 data entry and statistical package. Over 10% of all data entries were verified and the error rate was deemed acceptable (< 1%). Due to the nature of the analysis, missing data was minimal and, where necessary, considered in the interpretation of results.

Mean scores were compared by the Student's t-test or analysis of variance, with  $p \leq .05$  considered statistically significant. Correlations were assessed with Pearson's correlation coefficients.



### III Results:

#### 1. Phase 1: Qualitative evaluation of established outcome measures

Fourteen measures were reviewed for content, reliability, validity and feasibility (Table 1) and were then rated according using a consensus approach (Table 2).

**Table 1: Outcome Measures Qualitatively Evaluated**

AIMS1	- Arthritis Impact Measurement Scale - Version 1
AIMS2	- Arthritis Impact Measurement Scale - Version 2
BECK	- Beck Depression Inventory
CES-D	- Ctr for Epidemiologic Studies-Depression Scale
COPM	- Canadian Occupational Performance Measure
HAQ	- Health Assessment Questionnaire
MHAQ	- Modified Health Assessment Questionnaire
II	- Illness Intrusiveness Scale
MACTAR	- McMaster Toronto Arthritis Patient Preference Disability Questionnaire
NHP	- Nottingham Health Profile
OTS	- Occupational Therapy Study Questionnaire
PAIS	- Psychosocial Adjustment to Illness Scale
PET	- Problem Elicitation Technique
RASCI	- Rheumatoid Arthritis Self Care Instrument
SES	- Stanford Arthritis Self-Efficacy Scale
SF 36	- Health Status Questionnaire - SF 36
SIP	- Sickness Impact Profile
VAS(P)	- Visual Analogue Scale for Pain

The consensus manoeuvre identified six outcome measures for pilot testing. All measures have previously been tested for reliability and validity and have been used in the assessment of arthritis. The chosen measures included five self-administered questionnaires and one interviewer administered instrument.

The chosen self-administered questionnaires were the:

**Stanford Arthritis Self-Efficacy Scale (SES)**<sup>20-23</sup>: "Perceived self-efficacy" is one's **belief** that one can perform a **specific behaviour or task** in the future. As identified by Lorig et al, self-efficacy theory states that: 1) perceived self-efficacy for behaviours that affect health status will predict future health status, given that subjects believe that the outcome of the behaviour will be improved health status and that they value improved health status, 2) self-efficacy is not a static trait; it can be altered, and, 3) enhanced self-efficacy will be associated with improved health status in the areas affected by those specific behaviours. A 1991 meta-analysis of published articles on self-efficacy confirmed the relationship between self-efficacy appraisals and subsequent health related outcomes; "subject ratings of self-efficacy were found to consistently predict subsequent health related outcomes"<sup>22</sup>.

**Table 2: Evaluation Performance of Selected Outcome Measures**

Feature	AIMS1	AIMS2	BECK	CES-D	HAQ	M(HAQ)	II	MACTAR	NHP	PAIS	SES	SF 36	SIP	VAS(P)
Physical Status	yes	yes	min	min	yes	yes	no	yes	yes	min	yes	yes	yes	no
Activities of Daily Living														
Sleep														
Daytime Symptoms														
Sexual Function														
Mobility/Physical Activity														
Self Care														
Psychological Status	yes	yes	yes	yes	min	min	no	no	yes	yes	min	yes	yes	no
Cognitive Function														
Affective Symptoms														
Health Self-Perception														
Compliance														
Disease Knowledge														
Satisfaction														
Social Status	yes	yes	min	min	min	no	yes	yes	no	yes	no	min	yes	no
Sociodemographic classification														
Social integration														
Social role														
Communication														
Social interaction														
Leisure group activity														
Pain Status	yes	yes	no	no	yes	min	no	no	yes	no	yes	yes	yes	yes
Multidimensional Health Status	Arth	Arth	-	-	Arth	Arth	-	Arth	Gen	-	Arth	Gen	Gen	-
General														
Arthritis specific														
Comorbidity	yes	yes	no	no	no	no	no	no	no	no	no	yes	no	no
Global Status	yes	yes	no	no	no	yes	no	yes	no	no	no	no	no	no
Importance/Priority rating	no	yes	no	no	no	no	no	yes	yes	no	no	no	no	no
Reliability	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Validity	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Mode of Administration	SR	SR	SR	SR	Int/SR10	SR	SR	Int	SR	SR	SR	SR	Int/SR	SR
Administration Time (min)	20	20	10	10	10	10	10	10-20	10	10	10	10-45	20-30	1-2
Time period covered	1 m	1 m	1 w	1 w	1 w	today	now	2 w	now	1 m	now	multi	today	yes

The SES was developed to measure changes in self-efficacy which could be attributable to the Arthritis Self Management Program (ASMP). When administered with various other instruments, health outcomes and self-efficacy scores improved during the program, and improvements were correlated. These results persisted, albeit attenuated, for 20 months after the course, without reinforcement. The authors report that tests of construct and concurrent validity and of reliability showed that the instrument met appropriate standards. When administered to 144 new patients, coefficient alpha estimates of internal reliability were 0.87 for the other symptom self-efficacy scale and 0.76 for the pain-control self-efficacy scale. Test-retest reliability for 97 patients, with a mean interim of 9 days, was 0.90 for the other symptom domain and 0.87 for pain control.

The CTS physiotherapy intervention contains several components of the ASMP, including education to increase client knowledge of their condition, increase the frequency and practice of energy conservation and joint protection techniques, and decrease the amount of perceived pain. The CTS model of care delivery is based on contracting with clients; contracting is also the basis of the ASMP. The use of the SES to measure improvement in subject-perceived self-management is both timely and appropriate.

**Visual Analogue Scale for Pain (VAS(P))<sup>24,25</sup>:** Pain is often measured with a Visual Analogue Scale (VAS) with "no pain" anchoring the left end and "worst imaginable pain", the right end. Subjects are asked to make a mark on the 100 mm line that best indicates their average level of pain over the past week. The line is then measured from the left end to provide a score from 0 to 100. Linear analogue scale measures of pain have been found to be reliable and valid, especially when comparing subjects to themselves over time. They have good test-retest reliability and correlations with established methods of assessment of affective symptoms. VAS scales are usually more effective in measuring change over brief periods such as one week or one month than they are over 6 months or a year. These instruments are easy to use, easily comprehensible to the patient, have been shown to be sensitive to change, and to have a high test-retest reliability coefficient of  $r = 0.95$ .

**Arthritis Impact Measurement Scales 2 (AIMS 2)<sup>26</sup>:** The AIMS is an arthritis-specific, self-administered questionnaire which assesses physical, emotional and social wellbeing using 12 domain scales: mobility level, walking and bending, hand and finger function, arm function, self-care, household tasks, social activities, support from family and friends, arthritis pain, work, level of tension, and, mood. The questionnaire also collects data about the severity of disease, health perception, other significant illnesses, and sociodemographic status. The AIMS2 is a revised and expanded version of the original AIMS health status questionnaire. The comprehensiveness of the AIMS2 has been increased by the addition of items to measure satisfaction with health status, arthritis attribution, and problem prioritization. Evaluation of the scale in 299 patients with RA gave internal consistency coefficients

for the 12 scales of 0.72-0.91. Test-retest reliability was 0.78-0.94. Internal validity was significant ( $P < 0.001$ ); patient designation of a problem was significantly associated with a poorer AIMS2 scale score in that area. Reliability, factor analysis, and validity were consistent in age, sex, and education subgroups.

**Sickness Impact Profile (SIP)<sup>27-29</sup>:** The Sickness Impact Profile (SIP) is a global performance oriented instrument which provides a profile of the specific behavioral impacts of sickness using respondent self-report. It has been designed to reflect the subject's perception of performance in 14 categories of behaviour which include: social interaction, ambulation or locomotion activity, sleep and rest activity, taking nutrition, usual daily work, household management, mobility and confinement, movement of the body, communication activity, leisure pastimes and recreation, intellectual function, interaction with family members, emotions, feelings and sensations, and, personal hygiene. Each item is weighted for severity on a scale of dysfunction. The overall scores are expressed in percentages varying from 0-100%. Reliability and validity of the SIP have been demonstrated previously. The test-retest reliability and inter-rater correlations were both high at  $r = 0.88$ . Internal consistency was 0.72-0.94. The SIP discriminates among subsamples of respondents, and has positive correlations with other measures of health status such as self-assessment and physician's rating.

**Psychosocial Adjustment to Illness Scale - Self Report (PAIS-SR)<sup>30</sup>:** The PAIS-SR has been developed to measure psychosocial adjustment, including intrapsychic processes as well as interactions between the individual and other individuals, and institutions representing one's sociocultural environment. The PAIS-SR is designed to assess the quality of a client's psychosocial adjustment to a current medical illness in seven primary domains of adjustment: health care orientation, vocational environment, domestic environment, sexual relationship, extended family relationship, extended family relationship, social environment and psychological adjustment. The PAIS-SR is a structured self-report 45 item questionnaire and each item is rated on a four point scale. The PAIS has been used to examine the impact of energy conservation behaviours in clients with RA.

**The chosen interviewer administered questionnaire was the:**

**McMaster Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR)<sup>31</sup>:** The MACTAR consists of both a client preference questionnaire with which clients rank their functional activities in order of importance, and a global question about improvement in arthritis status. By assessing mobility, self-care, work and leisure, the emphasis of the MACTAR is primarily on physical and social function. Clinically important change in function has been demonstrated by serial assessment of RA clients in a controlled trial. This questionnaire can be used only by a trained interviewer. Recognized limitations of the MACTAR include its unconventional method of calculating change and a current lack of knowledge of the reliability and stability of client preference during a stable functional period.

Seven adults with a variety of rheumatic conditions, disease duration and severity, participated in the outcome measure evaluation manoeuvre (Table 3). The interviewer supervised the completion of the 5 self-administered questionnaires as well as administering one questionnaire. She kept a record of the questions asked by each participant and the number of times clarification or help was requested for each outcome measures. In a semi-structured appraisal of the manoeuvre (Table 4), subjects provided feedback which was recorded verbatim and later classified through a content analysis. All participants perceived the PAIS to be totally nonrepresentative due to its focus on negative psychosocial status. Of note, the PAIS was the only measure of all 14 reviewed to deal with sexual issues. All of the participants had used the MACTAR in a previous clinical trial and suggested that while the ability to identify preferences seems ideal, changes in disease activity and subsequent adaptive behaviours leave some preferences invalid from assessment to assessment. While this measure was chosen due to its ability to allow participants to subjectively choose outcomes of interest, it seems that the same problems arise as with irrelevant questions on self-administered questionnaires which are less costly to administer. In addition, the interviewer thought that both the MACTAR and the PAIS lacked practicality (Table 5).

**Table 3: Participant Characteristics**

Participant	#1	#2	#3	#4	#5	#6	#7
Age (years)	62	45	31	47	67	76	35
Sex	female	female	male	female	female	female	male
Disease Duration (yrs)	5	20	3	2	3	10	3
Primary Diagnosis	RA	fibromy	RA	RA	RA	RA	RA
Comorbidity Req'ing Meds	yes	yes	no	no	yes	yes	no
Grip strength mm Hg	not	not	340	254	130	146	295
Joint count	assessed	assessed	3	14	15	13	14
Morning stiffness			none	none	30 min	5 min	24 hr
Sleep disturbance			no	no	no	yes	yes
Household income	refused	< \$10 k	\$ 50-60 k	\$ 50-60 k	\$ 50-60 k	< \$10 k	\$ 20-30 k
Currently employed	no	no	yes	yes	no	no	no
Education (grade)	10-11	10-11	college	HS grad	10-11	R N	7-9
Total time to complete OM's	71 min	102 min	49 min	48 min	79 min	90 min	49 min

**Table 4: Semi-Structured Participant Evaluation Questions**

1.	Now that you have finished this process, did you find it:
a	too long
b	too short
c	just the right amount of time
2.	Was this a positive, negative or neutral experience for you?
3.	Do you think that these questionnaires covered all the areas of your life affected by your arthritis?
a	yes
b	no If no, what areas were missed or not covered fully enough?
4.	Would you do it again?
a	yes
b	no If no, why not?

**Table 5: Assessment of Practicality**

	SES	VAS(P)	AIMS2	SIP	PAIS	MACTAR
Difficulty of administering	minimal	none	minimal	minimal	high	high
Interviewer-rated difficulty for subjects (problem frequency)	minimal	none	moderate	minimal	high	moderate
Interviewer-rated comprehension by subjects (problem frequency)	moderate	minimal	moderate	minimal	high	moderate
Administration time in minutes	6	< 1	26	16	21	15

Participants identified a definite lack in ability to communicate disease knowledge and perceived wellness through any of the questionnaires. A literature review identified three knowledge questionnaires. Two self-administered questionnaires were out-of-date with regard to medication and treatment information. One interviewer administered questionnaire required the interviewer to assess physical actions by the patient. Six participants completed a combination of the two self-administered questionnaires in which out-of-date or moot questions were deleted<sup>32,33</sup>. Patients who completed this revised questionnaire felt the process was good for testing their own disease knowledge. The interviewer administered questionnaire<sup>34</sup> was deemed to be inappropriate as consensus could not be reached between study team members when evaluating the instrument on a few pilot patients. A review of literature on perceived wellness confirmed the lack of appropriate instruments for immediate administration.

As a result of the qualitative assessment, the SES, VAS(P), AIMS2 and SIP were selected for prospective evaluation.

## 2. Phase 2: Prospective Evaluation of Chosen Outcome Measures

Of the two groups used in the prospective evaluation, the MARP intervention group presented with a longer disease duration, increased frequency of daily medication for the treatment of arthritis, and an increased rate of current unemployment (Table 6).

**Table 6: Baseline characteristics**

		No Intervention n = 5	Intervention (MARP) n = 6
Gender	% female	60	83
Age	mean years (SD)	51.2 (19.7)	54.8 (7.4)
Marital Status	% married/common-law	100	50
Education	% ≥ grade 11	60	100
Household Income	% ≥ \$20,000	80	67
Employment Status	% currently employed	40	0
Disease Duration	mean years (SD)	4.2 (3.3)	11.5 (10.0)
Arthritis Medication	% taking daily meds	40	100
Other Medications	% taking daily meds	40	50

Performance of the long-term outcome measures, the AIMS<sup>2</sup> and SIP, resulted in scores which had changed minimally and which were variable in direction for both groups (Table 7); as expected, there was no clinically important change in the stable group of clients over one month in the therapy group over 10 days.

Mean change scores for the MARP group showed a tendency toward clinically important improvement for SES domains of pain control (14.3%) and symptom control (14.7%). The VAS(P) also showed a tendency toward clinically important improvement for the MARP group in both the mean change score for pain yesterday (14.3%) and pain in the last week (17.5%) suggesting that these measures may be appropriate for assessing short-term change in patients with IP receiving a comprehensive rehabilitation intervention.

**Table 7: Mean percent change for all outcome measures**

		No Intervention			Intervention (MARP)		
		n	% $\Delta$	reflects	n	% $\Delta$	reflects
SIP	Total	5	0.7	improvement	7	1.6	decline
AIMS2	Physical	5	0.03	decline	6	0.8	improvement
	Symptoms	4	1.3	improvement	6	0.8	decline
	Health Satisfaction	4	2.1	decline	4	1.1	improvement
	Impact of Arthritis	5	5.0	improvement	6	4.2	decline
SES	Pain	5	12.0	decline	6	14.3	improvement
	Other Symptoms	5	0.0	no change	6	14.7	improvement
VAS (P)	Pain yesterday	5	3.6	decline	6	14.3	improvement

#### IV. Discussion:

This process allowed us to identify a comprehensive set of 4 outcome measures which contained variables which were appropriate to evaluate persons with IP receiving a rehabilitation intervention. The SIP is a measure of overall health status which is best representative of long-term change; the AIMS2 is a disease specific measure of overall health status which again, is best representative of long term change. The SES and VAS(P) are representative of current health status, specifically in the areas of pain and perceived self management, and are therefore the best measures of short-term change.

This process also identified several areas which require further research.

*1. Content validity:* The developers of each instrument list the various dimensions of health that their measures are intended to capture. When we attempted to categorize the individual items in each questionnaire across instruments, we identified areas where a reclassification or separation of domains may result in a more consistent representation of health status. This line of inquiry is currently being pursued.

*2. Measures of wellness/wellbeing:* The lack of ability to quantify perceived wellness using the battery of chosen questionnaires resulted in an extensive review of the literature in medicine, education and the social sciences. A valid and reliable tool to measure wellness in the face of chronic disease was not found. To date, no measure has been developed or piloted. An appropriate wellness measure may be developed in the future by the ACREU team.



3. *Measures of disease knowledge:* An integral component of any therapeutic intervention for IP is education. However, a current, standardized instrument for measuring change in knowledge about the disease and its management was not available at the time of inquiry. The study team has created an appropriate instrument using focus groups of patients with IP to generate content<sup>35</sup>.

The results of this prospective study suggest that the SES and VAS(P) may be the most effective tools in the measurement of change in short-term rehabilitation programs which focus on self-management like MARP and the CTS physiotherapy intervention. The SES has a Pain Control domain in which subjects can identify perceived ability to control pain; the VAS(P) measures subjective perception of pain specifically. The SES - Other Symptom domain addresses one's perception of being able to control other symptoms of arthritis (ie "How certain are you that you can regulate your activity so as to be active without aggravating your arthritis?").

It is important to note that most outcome measures have been designed for use in clinical trials of pharmacotherapy during which significant change in instrument scores is expected (usually a minimum of 30% change). The use of these same outcomes to evaluate rehabilitation programs can be misleading as the same amount of expected change is not possible; improvement tends to occur slowly and steadily over time. The change scores for the SES and VAS(P) were compared to those of other self-management rehabilitation programs who have used the same instruments to measure outcome. The percent change scores for the MARP were comparable to those of other intervention studies. The control group change scores are also comparable. The results of this study strengthens the argument that the SES may be the best currently standardized measure to quantify change as a result of a short-term rehabilitation intervention for patients with IP.

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