

# Is Self-Reported Improvement in Osteoarthritis Pain and Disability Reflected in Objective Measures?

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**ABSTRACT.** *Objective.* To determine if self-reported improvements in pain and function correlate with improvement in objective measures of disease in osteoarthritis (OA).

*Methods.* Individuals with disabling hip/knee OA were assessed 7 years apart by questionnaire [sociodemographics, body mass index, and Western Ontario and McMaster University Osteoarthritis Index (WOMAC) scores] and physical [range of motion (ROM), disease activity based on joint stress pain, erythema, warmth, effusion] and radiographic examination of the hips and knees (Kellgren-Lawrence grade). Changes over time were expressed as improved, unchanged, or worse based on a priori criteria.

*Results.* Of 69 eligible patients, 43 (64%) with a mean age of 76.3 years participated; 77% were female. For WOMAC scores, 25% and 19% reported improved pain and function, respectively. For joint ROM, disease activity, and radiographic grade, 0% to 30% of participants were improved. However, improvements in WOMAC scores were not associated with improvements in any of the other measures ( $r < 0.24$  for all).

*Conclusion.* One-quarter of participants reported significant improvements in WOMAC pain and disability after 7 years' followup. However, these improvements were not associated with similar improvements in joint ROM, disease activity, or radiographic grade. Greater understanding of the determinants of self-reported improvements in arthritis status, in particular the role of adaptation, is warranted. (First Release Dec 1 2006; J Rheumatol 2007;34:159-64)

## Key Indexing Terms:

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Osteoarthritis (OA) ranks among the top 10 causes of disability worldwide<sup>1</sup>. Although current nonsurgical therapies may modify symptoms and disability over the short term, over the longer term, the general assumption is that the clinical course of OA is one of gradual progression, with worsening pain and physical function. Although most studies examining the disease course of OA<sup>2-8</sup> have reported progression, some individuals may self-report improvements in their symptoms and physical functioning<sup>3-8</sup>. However, prior studies have been largely performed in clinical populations using variable methods of assessment of OA disease status, particularly in the evaluation of symptoms and disability. The focus of these studies has primarily been on predictors of deterioration. There has been relatively little attention paid to the phenomenon of patient self-reported improvement. This phenomenon of "improvement" in OA warrants attention for many reasons. First and foremost, if patients are truly improved, then understanding the reasons for this improvement may lead to development and implementation of strategies to derive similar improvements in other patients. However, if this is not the case, research is warranted to elucidate the reasons for these self-reported improvements in the face of stable or worsening disease.

In an ongoing prospective community based cohort of individuals with moderate to severe hip/knee OA, we have previ-

ously reported significant variability in disease course over time<sup>9</sup>. After a followup period of 7 years, 25% of participants reported a significant improvement in their symptoms and disability using the Western Ontario-McMaster University Osteoarthritis Index (WOMAC), the Medical Outcomes Study Short Form-36 Health Survey (SF-36), and the disability subscale of the Health Assessment Questionnaire (HAQ-DI). Our aim was to evaluate the relationship between self-reported improvement in hip/knee status and objective measures of hip and knee OA (joint examination, radiographs) in order to better understand the determinants of "improvement." We hypothesized that improvements in self-reported measures would be modestly correlated with other measures of hip and knee OA status.

## MATERIALS AND METHODS

**Study population.** A previous 2-phase survey, conducted between 1996 and 1998, established a population cohort of 2411 individuals 55 years of age and older with disabling hip/knee OA<sup>10,11</sup> and assessed demographics (including highest level of education, annual household income, body mass index, and living circumstances), arthritis severity (WOMAC pain, function, and stiffness scales<sup>12,13</sup>, the SF-36<sup>14,15</sup>, the HAQ-DI<sup>16,17</sup>, use of aids and devices), and comorbidity. Because joint-related symptoms may not correlate either with radiographic changes or with clinical findings, in Phase III (1997) we examined the relationship between self-reported symptoms and disability and underlying hip/knee arthritis. Following readministration of the key arthritis "screening questions" and the WOMAC, physiotherapists used a standardized examination<sup>18</sup> to assess clinical signs of hip and knee arthritis (joint pain, swelling, reduced range of motion, and deformity) in 475 "low rate" region residents (375 with and 100 without hip/knee complaints). A random subsample of 175 of these individuals (75 with WOMAC summary scores < 39/100; 100 with scores  $\geq$  39/100) was chosen to have hip and knee radiographs at the local hospital. All radiographs, reviewed blindly by a radiologist, were graded for severity of joint space narrowing, osteophytes, subchondral sclerosis, marginal erosions, and cysts. These ratings allowed for calculation of a Kellgren and Lawrence (K-L) score for each knee and hip. Phase III interrater agreement for the therapists and radiologists was excellent (for joint stress pain, therapists' kappa = 0.94; for K-L score, radiologists' kappa = 0.92).

In 1999, the cohort participants were invited to participate in a 5-year followup study: 2103 were alive and agreed. Annual telephone followup included assessment of arthritis symptoms and disability (WOMAC and HAQ-DI, use of aids and devices) and occurrence of joint arthroplasty (yes/no), and completion of the SF-36 General Health subscale (range 5–25, higher scores indicate better health). Response rates for annual surveys, adjusted for deaths and unable to complete, were 78% or greater.

For our study, conducted during the summer of 2004, we included cohort members who: (1) completed the WOMAC and underwent joint examination and radiographs in Phase III (1997, baseline assessment); (2) had self-completed a minimum of 3 followup assessments in Phase IV; and (3) were able to provide informed, written consent to participate. Those with an inflammatory arthritis diagnosis, who had one or more proxy-completed followup assessments, who had undergone hip or knee arthroplasty during the followup period, and/or who were not well enough to attend a 2-hour hospital-based clinical assessment were excluded.

**Clinical assessments.** Participants completed a single WOMAC pain, physical function, and stiffness scale for their "hips and knee" and were asked to rate their perceived change in hip/knee arthritis severity over the past year (much improved, somewhat improved, unchanged, somewhat worse, or much worse). Participants underwent a standardized joint examination<sup>18</sup> performed by a single rheumatologist blinded to both the participant's current status

(WOMAC scores) and change scores. For each joint, the assessor examined for tenderness, stress pain, swelling, and warmth. Passive range of motion (PROM) of the hips and knees was assessed using a goniometer to the nearest degree. The intrarater reliability (intraclass correlation coefficients, ICC) for the PROM measurements demonstrated excellent reliability, with ICC values between 0.98 and 1.0.

**Radiographic assessment.** Radiographs were performed using the same protocol as at baseline. Using the K-L radiographic grading scale<sup>19</sup>, hip and knee radiographs were graded for severity of joint space narrowing, osteophyte formation, and subchondral sclerosis. Lateral and medial compartments of each knee were scored separately. A K-L score, from 0 to 4, was determined for each hip joint at baseline and followup. A baseline knee K-L score, from 0 to 4, was determined for each knee using the worst compartment score. The followup knee K-L score was determined using the same compartment used at baseline. All radiographs were reviewed, blinded to time sequence and participant details, by 2 rheumatologists (SJ and GH) and a medical student (AA). Where there was lack of agreement, radiographs were re-reviewed and a consensus rating determined.

**Statistical analysis.** For both timepoints, the arc of rotation for each hip (sum of internal and external rotation) and each knee (complete extension to full flexion) was calculated. For each knee, baseline and followup disease activity scores were created based on the presence/absence of each of stress pain, swelling, warmth, and erythema (possible score for each knee 0–4). These scores were then summed to create a total knee disease activity score from 0 to 8 at both timepoints. For each hip, disease activity scores were similarly created based on the presence/absence of stress pain on PROM and summed to create a total hip disease activity score at each timepoint from 0 to 2. Summing the scores for the hips and knees at each timepoint created composite hip and knee K-L scores, respectively. Change scores were calculated by subtracting baseline from current values. For each measure, change scores were categorized as indicating worsening, no change, or improvement based on minimal clinically important differences (MCID)<sup>20</sup>. The MCID for WOMAC pain scores is 1.6 points (out of 20) for improvement and 2.2 points for worsening. For physical function, the MCID is 5.44 points (out of 68) for improvement and 9.04 points for worsening<sup>20</sup>. As no published MCID values exist for the other measures of interest, we based threshold values for change on expert consensus (GH, JW, AD). Improvement in hip rotation was defined as an increase in PROM of  $\geq$  10°, and worsening as a loss of  $\geq$  15° of PROM. For knee PROM, improvement was defined as an increase in PROM of  $\geq$  15°, while worsening was defined as a loss of  $\geq$  20° PROM. For each of these measures (hip rotation, hip flexion, and knee flexion/extension), individuals were classified as having improved if there was improvement in both hips or both knees, worse if there was worsening in both hips or both knees, and unchanged if they were either unchanged in both hips or both knees or discordant in direction of change between the contralateral hips or knees. We defined an improvement in disease activity for each hip and knee as a reduction in the disease activity score of at least 1 point; similarly, worsening was defined as an increase in score of 1 point or more. For all joints, an increase in K-L score by at least 1 unit was defined as indicating worsening, whereas a decrease by at least 1 unit was defined as improvement.

For each measure, paired t-tests were used to evaluate differences between mean scores at baseline and followup. The correlation between change based on WOMAC scores and clinical measures, radiographic changes, and perceived change were assessed using Spearman's rho correlation coefficients for continuous scores and Kendall's tau-b correlation coefficients for scores categorized as improved, unchanged, or worsened. Sensitivity analyses were performed to examine the effect of alternative definitions for improvement and worsening for radiographic scores and joint ROM. All analyses were performed using SAS Version 8.0. Statistical significance was assessed at a 2-tailed p value of 0.003 to adjust for multiple comparisons.

The institutional ethics review board approved the study. All study participants provided written consent.

## RESULTS

**Participants.** Of the 233 Phase III participants who had radiographs performed (baseline assessment), 52 were deceased, 14 had refused further followup, and 36 were lost to followup. Of the remaining 131, 52 had undergone hip or knee replacement and/or had inflammatory arthritis, leaving 79 potential participants. Of these 79, 25 declined participation, one was deceased, 5 could not be contacted, 4 were too ill, and 44 agreed to participate (participation rate, adjusted for diseased and unable, 63.8%). Compared with the 233 Phase III participants, those who participated in the current study were similar in age, sex, and level of education, but had higher income (percentage > \$40,000, 23.4% vs 7.5%;  $p = 0.015$ ). There were no significant differences in baseline WOMAC pain, function, or stiffness scores between participants and nonparticipants. Forty-three participants were included in the analysis; one participant was excluded because of having undergone bilateral total knee arthroplasty. The mean age at followup of participants was 76.3 years; 77% were female and 93% were Caucasian (Table 1).

The number using an aid for walking was 11 at baseline and 20 at followup ( $p = 0.0005$ ). None of the participants described themselves as “much improved,” 3 (7.0%) reported being “somewhat improved,” 14 (32.6%) reported being “about the same,” 19 (44.2%) reported being “somewhat worse,” and 7 (16.3%) reported being “much worse.”

**Outcome measures.** Mean baseline, followup, and change values for all measures of interest are reported in Table 2. Compared with baseline scores, mean followup scores were unchanged for the WOMAC pain scale, and significantly higher, indicating worse disability, for the WOMAC physical

function scale. Using the MCID criteria, 11 participants (26%) experienced improvement in their WOMAC pain score, while 8 (19%) experienced improvement in their WOMAC physical function score.

With the exception of hip flexion and left knee PROM, which on average remained unchanged, mean change in all other measures of hip and knee PROM indicated significant deterioration over the study time period (Table 2).

Using our predefined criteria, between 0% (knee PROM) and 33% (right hip flexion) of participants experienced an improvement in at least one aspect of their hip or knee PROM. Ten participants (26%) had improvement in hip disease activity and 19 (45%) had improvement in knee disease activity. Mean K-L grades remained unchanged or worsened. Improvement in radiographic scores, as we defined it, was documented in up to one-quarter of participants depending on the joint examined.

**Association of changes in WOMAC scores with changes in other measures.** When expressed categorically as improved, unchanged, or worse, changes in WOMAC pain and physical function scores were not significantly associated with changes in any of hip/knee PROM, disease activity, radiograph scores, or perceived improvement (Table 3). Similar results were found when changes were expressed as continuous variables and when alternative definitions for improvement/worsening were employed (data not shown).

## DISCUSSION

Understanding the meaning of changes in various measures of OA disease status is important in health planning and patient management, and is essential to the design and interpretation of longitudinal studies. To date, most longitudinal studies in OA have focused on understanding predictors of disease progression, and have largely considered mean changes in measures over time rather than examining patterns of change within individuals. Although some of these studies have documented a subset of individuals who report improvements in their self-reported OA status after years of followup<sup>3,4,21</sup>, relatively little attention has been paid to this subgroup or to understanding what these improvements mean.

Prior work by our group documented variability in the trajectory of OA disease progression over a 7-year period, with 4 distinct patterns of change over time in individuals with disabling hip/knee OA. One pattern, found in about one-quarter of our cohort, was that of consistent improvement in WOMAC scores over time in the absence of joint replacement. We examined how these self-reported improvements relate to changes in other measures of OA, including joint examination and radiographs.

Consistent with prior studies, mean changes in both self-reported and clinical measures indicated that, as a group, participants experienced either no change or worsening of their disease status over time. However, for all measures, a subset of participants could be classified as “improved,” underscor-

Table 1. Characteristics of study sample at followup (n = 43).

Characteristic	n (%)
Female sex, n (%)	33 (77)
Education, n (%)	
No formal schooling/elementary school only	6/42 (14)
High school	20/42 (48)
University, college, or postgraduate	16/42 (38)
Caucasian, n (%)	40 (93)
Income, n (%)	
< \$20,000	14/36 (39)
\$20,001–40,000	12/36 (33)
\$40,001–60,000	7/36 (19)
> \$60,000	3/36 (8)
Living arrangement, n (%)	
Alone in house/apartment	22 (51)
With spouse/family/others	20 (47)
Residential healthcare facility	1 (2)
Mean SF-36 General Health subscale score* (/25)	15.7
Mean HAQ Disability Index score* (0–3)	1.26
Using an aid for walking, n (%)	20 (47)

\* SF-36 general health subscale and HAQ-DI were completed during the Year 5 Phase IV followup assessment.

Table 2. WOMAC scores and clinical measures at baseline and followup.

Variable	Baseline	Mean (SD) Followup	Change Score	Change by Category, n (%)		
				Improved	No Change	Worsened
WOMAC pain/20	7.58 (3.2)	8.40 (3.4)	0.81 (3.7)	11 (26)	21 (49)	11 (26)
WOMAC function/68	26.74 (12.0)	31.11 (10.6)	4.37 (10.8)	8 (19)	22 (51)	13 (30)
PROM (in degrees)						
Right hip						
Flexion	110.60 (14.4)	110.30 (13.9)	-0.73 (17.3)	14 (33)	19 (44)	10 (23)
Rotation	57.88 (21.1)	44.91 (13.9)	-12.40 (19.6)*	5 (12)	19 (44)	19 (44)
Left hip						
Flexion	111.70 (14.3)	113.5 (13.0)	1.34 (17.0)	10 (23)	28 (65)	5 (12)
Rotation	56.95 (20.5)	119.57 (29.1)	-10.85 (21.8)*	7 (16)	20 (47)	16 (37)
Right knee						
Arc of PROM	128.65 (14.0)	114.07 (25.7)	-14.58 (23.2)*	0	33 (77)	10 (23)
Left knee						
Arc of PROM	130.21 (13.7)	119.57 (29.1)	-10.64 (24.8)	0	36 (84)	7 (16)
Knee disease activity	2.04 (1.6)	1.65 (1.5)	-0.43 (2.0)	19 (45)	11 (26)	12 (29)
Hip disease activity	0.83 (0.8)	0.93 (0.8)	0.05 (1.1)	10 (26)	15 (38)	14 (36)
Hip K-L radiograph score						
Right	0.65 (0.5)	0.88 (0.5)	0.23 (0.8)	5 (12)	26 (60)	12 (28)
Left	0.86 (0.6)	0.79 (0.8)	-0.07 (0.8)	12 (28)	24 (56)	7 (16)
Knee K-L radiograph score						
Right	0.98 (1.6)	1.10 (1.2)	0.13 (0.9)	9 (21)	17 (40)	17 (40)
Left	0.79 (1.3)	1.28 (1.2)	0.48 (1.1)	5 (12)	17 (40)	21 (48)

\* Statistically significant difference using t-tests for comparison of means, p value < 0.003. Knee disease activity (bilateral): 0 = no signs/symptoms, 8 = maximum signs/symptoms. Hip disease activity (bilateral): 0 = no stress pain, 2 = stress pain bilaterally. Kellgren-Lawrence score (K-L): 0 = no radiographic changes, 4 = severe radiographic changes. PROM: passive range of motion.

Table 3. Kendall's tau-b correlation coefficients between mean WOMAC change scores (categorized as improved, unchanged, and worse) and changes in clinical outcomes (categorized as improved, unchanged, and worse).

	Change in WOMAC Pain Score <sup>†††</sup>	Change in WOMAC Physical Function Score <sup>†††</sup>
Hip		
Hip rotation*	0.06	-0.07
Hip flexion*	0.22	-0.02
Hip disease activity <sup>†</sup>	0.04	0.23
Hip radiograph score <sup>***</sup>	0.07	-0.003
Knee		
Knee arc of PROM <sup>‡</sup>	-0.09	-0.24
Knee disease activity <sup>†</sup>	0.24	0.22
Knee radiograph score <sup>***</sup>	-0.06	0.01
Perceived change <sup>**</sup>	0.13	0.06

Changes in hip rotation and hip flexion were defined as improved (increase in PROM  $\geq$  10 degrees), unchanged, or worsened (loss of  $\geq$  15°). <sup>†</sup> Changes in hip and knee disease activity were defined as improved (any decrease in disease activity score), unchanged, or worsened (any increase in Disease Activity Score). <sup>‡</sup> Changes in knee arc of ROM were defined as improved (increase in PROM  $\geq$  15°), unchanged, or worsened (loss of  $\geq$  20°). <sup>\*\*\*</sup> Changes in radiograph scores were defined as improved (any decrease in disease score), unchanged, or worsened (any increase in score). <sup>\*\*</sup> Perceived change was defined as improved, unchanged, or worsened. <sup>†††</sup> WOMAC pain and WOMAC physical function scores were defined as worse, unchanged, or improved based on previously published MCID. All p values were not statistically significant.

ing the value of examining changes over time within individuals as opposed to mean group changes.

Consistent with previous studies<sup>3,4</sup>, clinical improvement in joint PROM, disease activity, or K-L grade did not explain the observed improvements in WOMAC scores. In general,

the correlations between WOMAC change scores and each of the clinical measures assessed were low. Although our sample size was small, we had sufficient power to detect correlation coefficients of 0.4 or greater, and we would argue that correlations of less than 0.4 would be unlikely to be clinically

meaningful. Together, these studies indicate that changes in self-reported symptoms and disability relate minimally if at all to changes in so-called objective measures of OA, raising a number of important questions for both clinical researchers and clinicians regarding evaluation of OA disease status over time. Specifically, which is the correct measure or combination of measures to use to evaluate meaningful changes in OA over time, and on which changes should we base our management decisions?

Given the lack of association between improvements in self-reported pain and disability scores and improvements in objective measures of OA status, why then did a significant proportion of participants report an improvement in WOMAC scores? There are several potential explanations.

Better coping in OA has been found to be associated with reduced pain and less use of health services<sup>22-24</sup>. Greater self-efficacy has been shown to predict higher thresholds for and tolerance to pain<sup>25,26</sup> and less maladaptive coping in people with OA. Studies suggest that perceived OA pain is strongly related to mood, mediated by factors such as self-efficacy and coping strategies, and modified by social support, age, and sex. Thus, cohort members who experienced improvements in WOMAC pain or function may be those with strong social support and high self-efficacy, and who are successfully using various coping strategies.

Using qualitative methodology, Beaton, *et al* found that the concept of “being better” was highly contextualized in the experience of the individual<sup>27</sup>. That is, it reflected not only the change in the disease state, but also adjustments and adaptations made to living with the disorder, which they termed redefinition. Participants may be using strategies to manage their pain and reduce the influence of their disability in performance of daily activities, such as by pacing themselves or perhaps moving from a multistory home to a one-floor apartment. Participants may further be avoiding situations or activities that exacerbate their symptoms, or that they can no longer do, in particular leisure and recreational activities. Since we did not evaluate participants’ participation in social or recreational activities, or their physical capabilities using functional performance measures, we could not test this hypothesis<sup>28</sup>.

If these factors are the explanation for observed improvements in pain and disability over time, then this suggests that self-reported changes must be interpreted in the context of concomitant changes in level of physical activity, in particular with respect to participation in social and recreational activities<sup>28</sup>. A focus solely on pain severity or difficulty performing specific functional activities will miss such shifts. Individuals who are experiencing minimal pain or disability due to severely restricted activities may see themselves as doing well, and may not seek out appropriate healthcare, thinking that they do not require it. Further, clinicians may receive the wrong message, and not offer appropriate medical or surgical interventions to patients who may potentially benefit from them<sup>29</sup>.

Wright had previously observed, “Clinicians may all too easily spend years writing ‘doing well’ in the notes of a patient who has become progressively crippled before their eyes.”<sup>30</sup> Campbell, *et al* observed that the method in which subjective assessment is elicited and the context in which the data are recorded may affect the findings<sup>31</sup>. Finally, progressive reduction in physical activity as a measure to control symptoms may have important health sequelae including hypertension and weight gain. We encourage further research to expand our understanding of what self-reported improvements in OA really mean. We recommend that, both in clinical practice and in longitudinal studies of OA, assessment include both self-report and performance measures of impairment, activity limitation, and participation, taking into consideration the effect of adaptation.

There are several potential limitations to our study in addition to those already noted. First, in the absence of established criteria for what constitutes a significant change for hip or knee ROM, we arbitrarily based our change criteria on expert consensus opinion. However, our sensitivity analyses, which examined the effect of alternative definitions for change, gave similar results. Second, plain radiographs are known to be insensitive to structural joint changes in OA over time. Thus, it is possible that the observed improvements in K-L grade simply reflect the imprecision of the measure and may be related to changes in the position of the joint, penetration of radiographs, etc. Third, we used only 2 timepoints to categorize participants as improved or not. From our prior work<sup>9</sup> the disease course in OA is highly variable not only in outcome, but also with respect to the trajectory or pattern of change over time. Longitudinal studies are needed in which disease status is measured at multiple timepoints and within-subject changes are evaluated. The use of both qualitative and quantitative research methods (mixed methods approach) will undoubtedly improve our understanding of this issue. Finally, participants in our study represent a proportion of a population cohort (original  $n = 2411$ ) who have been followed over 8 years, who have established OA, and who have not undergone total joint replacement surgery. Since our results are based on a small sample size, our findings need to be confirmed in larger studies of individuals with varying degrees of OA.

In a small community sample with disabling hip/knee OA followed for 7 years, we documented substantial improvements in self-reported pain and function (WOMAC scores) in about one-quarter of participants. However, these improvements were not associated with similar improvements in objective clinical measures or with baseline sociodemographic characteristics. We believe the most likely explanation for the observed self-reported improvements is that these individuals have made adaptations to living with OA that have resulted in a redefinition of their concept of their OA pain and disability. While such redefinition is, in theory, a positive response to living with chronic disease, failure to evaluate changes in pain or reported disability in the context of con-

comitant changes in mobility and social/leisure participation may lead to inadequate treatment and ultimately, worse outcomes.

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