Investigating Dimensions of Stiffness in Rheumatoid and Psoriatic Arthritis: The Australian Rheumatology Association Database Registry and OMERACT Collaboration

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ABSTRACT. Objective. It is not known how the experience of stiffness varies between diagnoses or how best to measure stiffness. The aims of our study were to (1) compare stiffness in psoriatic arthritis (PsA) and rheumatoid arthritis (RA) using patient-reported outcomes, (2) investigate how dimensions of stiffness are associated with each other and reflect the patient experience, and (3) analyze how different dimensions of stiffness are associated with physical function.

Methods. An online survey was sent to Australian Rheumatology Association Database participants (158 PsA, and 158 age- and sex-matched RA), assessing stiffness severity, duration, impact, importance, coping, and physical function [modified Health Assessment Questionnaire (mHAQ)]. Scores were compared between diagnoses and correlations among stiffness dimensions calculated. Multivariate regression was performed for stiffness severity, impact, and duration on mHAQ, adjusting for age, sex, disease duration, obesity, and pain. Cognitive debriefing was conducted through semistructured telephone interviews.

Results. Overall, 240/316 (75.9%) responded [124/158 RA (78.5%) and 116/158 PsA (73.4%)], with no significant difference in stiffness ratings between diagnoses. Scores for all stiffness dimensions were strongly correlated (r = 0.52-0.89), and severity and impact were associated with mHAQ in both diagnoses. Stiffness duration was not associated with mHAQ in RA. In cognitive debriefing, participants described stiffness severity and impact by their effect on daily activities (10/16 and 14/16 participants, respectively).

Conclusion. Stiffness ratings were similar between PsA and RA. Different dimensions of stiffness were strongly correlated. Stiffness severity and impact both independently predicted mHAQ. Stiffness was important to participants; however, measuring multiple dimensions of stiffness may have minimal additive value. (First Release August 1 2019; J Rheumatol 2019;46:1462–9; doi:10.3899/jrheum.181251)

Key Indexing Terms: RHEUMATOID ARTHRITIS PATIENT PERSPECTIVE

PSORIATIC ARTHRITIS OUTCOMES RESEARCH

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Joint stiffness is one of the key symptoms of rheumatoid arthritis (RA) and psoriatic arthritis (PsA). It is reported by up to 79% of patients with RA^{1,2}, and may be a factor contributing to patients failing to achieve remission criteria³. In the RA flare core set, stiffness has been included because it is considered by patients and healthcare providers to be an important factor defining disease flares^{4,5}. However, stiffness is not a component of the RA core domain set for randomized controlled trials (RCT), and in a 2015 review, only 8 out of 96 RCT in RA assessed stiffness as an outcome⁶. In PsA, stiffness is included in the 2016 update of the Outcome Measures in Rheumatology's (OMERACT) research agenda for a PsA core domain set^{7,8}. However, to date, stiffness of peripheral joints is not commonly assessed in PsA clinical trials^{9,10,11,12}, although severity and duration of morning stiffness in axial disease are assessed in the Bath Ankylosing Spondylitis Activity Index (BASDAI)¹³.

The optimal method for assessing stiffness is still unclear¹⁴. Attempts have been made to assess joint stiffness using a variety of methods such as arthrography or grip strength^{15,16,17,18}. However, these require specialized equipment, which limits the feasibility of their use in practice, and it is not clear whether these assessments truly represent stiffness or if they measure other factors such as hand strength or limitation of movement because of pain. Although symptoms of stiffness and pain are related, most patients can distinguish between them^{19,20}. Therefore, patient-reported outcomes (PRO) may more accurately reflect the concept of stiffness as distinct from other symptoms.

In RCT in which stiffness was assessed, duration of morning stiffness was most commonly used as an outcome⁶. However, qualitative studies in RA suggest that duration alone may not fully represent the patient experience of joint stiffness^{19,20}. Instead, patients' experiences of joint stiffness were varied, not necessarily limited to the morning, and affected their ability to participate in life activities.

It is not known how the experience of stiffness varies between RA and PsA diagnoses, and what effect it may have on physical function. At OMERACT 2016, patients in the Stiffness Special Interest Group highlighted that although stiffness is a common domain across many rheumatic diseases, the location and experience of stiffness may vary ¹⁴. The pathophysiology differs between the diagnoses, with particular involvement of the enthesis in PsA, and variable distribution of peripheral joint involvement. Therefore, it is unclear whether the same PRO measures will be meaningful

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for patients across both diagnoses. The aims of our study were to (1) compare stiffness ratings in PsA and RA using PRO measures, (2) investigate how dimensions of stiffness are associated with each other and reflect the patient experience, and (3) analyze how different dimensions of stiffness are associated with physical function.

MATERIALS AND METHODS

The Australian Rheumatology Association Database (ARAD) is a voluntary national registry established in 2003 and collects longitudinal health information from people with inflammatory arthritis, including PsA, RA, ankylosing spondylitis, and juvenile idiopathic arthritis. A detailed description of the database has been published previously²¹. Participants complete questionnaires reporting demographic data, date of diagnosis of arthritis, and arthritis medications. Participants also report comorbid medical conditions including diabetes, hypertension, and hyperlipidemia. Data are subject to quality control processes to validate entries and minimize missing data.

Ethics approval. Twenty local ethics committees and organizations have granted approval for ARAD across each state in Australia [New South Wales: Northern Sydney Local Health District (1004-125M/1006-210M), Cancer Council NSW; Victoria: Cabrini Health, Monash University, Royal Children's Hospital, St Vincent's Hospital, Cancer Council Victoria; Queensland: Queensland Government; South Australia: The South Australian Department of Health and Ageing, Women's and Children's Hospital SA Health Network; Western Australia: Department of Health WA, Fiona Stanley Hospital, Rockingham General Hospital, Royal Perth Hospital, Southern Metropolitan Health Service, Government of WA; Tasmania: Tasmania Health, University of Tasmania; the Australian Capital Territory: ACT Health and Community Care]. Approval was also granted by the Australian Institute of Health and Welfare, the Australian Government Department of Health and the Department of Defence and Veterans' Affairs, the cancer registry in each state (New South Wales, Victoria, Queensland, South Australia, Western Australia, Tasmania, Australian Capital Territory, Northern Territory), and National Cancer Statistics Clearing House. All participants provide written informed consent to participate in the parent study. Approval was obtained to send an additional survey to participants.

The online survey was sent to 158 ARAD participants with PsA and to 158 age- and sex-matched participants with RA in April 2016, with a reminder sent about 2 weeks later. Because there is currently no consensus on how to assess stiffness, we included 10 items asking about different dimensions of joint stiffness (Table 1). The items asked about stiffness severity, duration, impact, importance, and coping, using Likert, numerical rating (NRS), and visual analog scales (VAS). Items were developed in collaboration with patients, clinicians, and researchers. This rigorous process included qualitative research and item debriefing with patients, along with preliminary quantitative validation²². The VAS items were similar to those used in the BASDAI¹³. Duration of morning stiffness was also assessed as minutes from time of waking to time of maximal improvement (free text)^{1,23}.

Participants also completed a modified Health Assessment Questionnaire (mHAQ; scored 0-3, where higher scores indicate greater functional impairment)²⁴, a pain VAS (0 = no pain to 100 = pain as bad as it could be), and the patient's global assessment of disease activity (0 = none to 100 = extreme). These characteristics were extracted from ARAD: age, sex, diagnosis, date of diagnosis, ethnicity, education level, employment status, smoking status, arthritis medications, and body mass index.

Cognitive debriefing. Participants who agreed to participate in cognitive debriefing of stiffness items were selected using purposive selection to ensure a range of relevant clinical and demographic characteristics. During semistructured telephone interviews, participants were asked to think aloud when selecting responses for items asking about stiffness severity, coping, impact, and importance. They were also asked whether duration of stiffness was an important or relevant feature characterizing their stiffness, and which

Table 1. Stiffness scoring items in survey.

Dimension of Stiffness	Scoring Scale	Wording
Severity	VAS: 0 (none) to 100 (very severe)	How would you describe the overall level of morning joint stiffness you have had from the time you wake up, in the past 7 days?
	NRS: 0 (no stiffness) to 10 (extreme stiffness)	Please select the number that best describes the severity of your arthritis stiffness over the past 7 days
	Likert: none, mild, moderate, severe, very severe	In the past 7 days, how would you rate your joint stiffness, on average?
Duration	Free text (min)	Considering the past 7 days: How long does your morning joint stiffness last from the time you wake up until maximum improvement occurs?
	VAS: 0–2 h	How long does your morning joint stiffness last from the time you wake up, in the past 7 days?
	Likert: < 30 min, 30 min to < 1 h, 1 h to < 2 h, 2 h to < 4 h, 4 h or more	In the past 7 days, how long did your joint stiffness last, on average?
Impact	NRS: 0 (no effect at all) to 10 (a great deal of effect)	Please select the number that best describes the effect that arthritis stiffness has had on your life over the past 7 days
	Likert: never, rarely, sometimes, often, always	In the past 7 days, how often did your joint stiffness interfere with your activities?
Importance	NRS: 0 (not important at all) to 10 (very important)	Please select the number that best describes how important arthritis stiffness has been in your life over the past 7 days
Coping	NRS: 0 (very well) to 10 (not well at all)	Please select the number that best describes how well you have coped with your arthritis stiffness over the past 7 days

VAS: visual analog scale; NRS: numerical rating scale.

question(s) best reflected their experience of arthritis stiffness and why this was the case.

Participants were asked to identify their preferred response format (Likert, NRS, VAS, free text) and explain why they preferred this format. We also queried whether stiffness was helpful in identifying their experience of arthritis and assessing the activity and severity of their arthritis. Notes were taken by the interviewer during the phone conversation. Notes were coded by PS and then grouped into overarching themes relating to each dimension of stiffness using an inductive analytic approach²⁵. Themes were reviewed by the investigative team.

Statistical methods. Descriptive statistics were calculated and patients with RA and PsA were compared using Student t tests, chi-square tests, and Mann-Whitney U tests for variables that were not normally distributed. Pearson correlations with predetermined cutoffs were used to evaluate associations among stiffness dimensions. Correlations with an absolute value of r = 0.00-0.19 were considered very weak, 0.20-0.39 as weak, 0.40-0.59 as moderate, 0.60-0.79 as strong, and 0.80-1.00 as very strong²⁶. Multivariate regression was performed to evaluate the effect of stiffness dimensions on mHAQ by disease. Covariates included age, sex, disease duration, obesity status (yes/no), and pain VAS score. Stiffness severity (NRS), impact (NRS), and duration (VAS) were then entered into each model. P values ≤ 0.05 were considered statistically significant. Statistical analyses were performed using IBM SPSS version 24.

RESULTS

Survey respondents. Overall, 240/316 (76%) of participants responded to the survey, including 124/158 with RA (79%) and 116/158 (73%) with PsA (p = 0.3). The demographic characteristics of respondents are described in Table 2. On

average, respondents were middle aged, mostly female, and had longstanding disease, with slightly longer mean disease duration in RA than PsA. Respondents with RA were more likely to be receiving a disability pension and taking prednis(ol)one than those with PsA. Otherwise, characteristics of the 2 groups were similar.

Responses to stiffness survey items. Responses to the stiffness items by diagnosis are presented in Table 3. Responses covered a wide range of stiffness, and the distribution of responses was similar between groups for all items tested. Correlations among different dimensions of stiffness, by diagnosis, are shown in Table 4. In both diagnoses, stiffness severity was strongly to very strongly and positively correlated with impact and coping (r = 0.78-0.89, p < 0.001). Stiffness impact was also strongly to very strongly and positively correlated with importance and coping (r = 0.77-0.81, p < 0.001). Importance was strongly and positively correlated with severity and coping (r = 0.67-0.76, p < 0.001). Stiffness duration (VAS) was moderately to strongly and positively correlated with other dimensions of stiffness (r = 0.52-0.71, p < 0.001). Duration measured using Likert and free-text scales showed similar positive correlations with the other dimensions of stiffness (r = 0.53-0.66, p < 0.001).

Effect of stiffness on physical function. Table 5 shows the effect of stiffness impact, severity, and duration on mHAQ

Table 2. Characteristics of respondents to ARAD Joint Stiffness Survey.

Characteristics	Rheumatoid Arthritis, n = 124	Psoriatic Arthritis, n = 116	p*
	Mean (SD)	Mean (SD)	
Age, yrs	57.1 (10.8)	55.6 (10.7)	0.3
Disease duration, yrs	20.6 (8.2)	17.3 (9.0)	0.003
Body mass index, kg/m ²	29.0 (6.5)	29.5 (6.0)	0.5
Pain VAS score	29.7 (25.0)	30.6 (26.9)	0.8
Patient's global VAS score	28.9 (24.2)	29.6 (25.4)	0.8
mHAQ	1.4 (0.5)	1.4 (0.4)	0.5
	n (%)	n (%)	
Male	52 (41.9)	46 (39.7)	0.7
White	119 (96.0)	111 (95.7)	0.5
University- or college-level education	74 (59.7)	72 (62.1)	0.7
Work or study full time	40 (32.3)	45 (38.8)	0.3
Disability pension	25 (20.2)	9 (7.8)	0.006
Current smoker	5 (4.0)	7 (6.0)	0.5
Current bDMARD use	96 (77.4)	93 (80.2)	0.6
Current methotrexate use	74 (59.7)	68 (58.6)	0.9
Current prednis(ol)one use	46 (37.1)	11 (9.5)	< 0.00

^{*}Student t test for continuous variables and chi-squared test for categorical variables. ARAD: Australian Rheumatology Association Database; VAS: visual analog scale (0–100); mHAQ: modified Health Assessment Questionnaire; bDMARD: biologic disease-modifying antirheumatic drug.

Table 3. Descriptive statistics for dimensions of stiffness items in RA and PsA.

Dimension	Over the Past 7 Days	RA		PsA		p*
		Median (IQR)	Range	Median (IQR)	Range	
Severity	VAS: 0 (none) to 100 (very severe)	21.0 (8.25–50.0)	0.0-90.0	25.0 (7.0–51.5)	0.0-91.0	0.8
	NRS: 0 (no stiffness) to 10 (extreme stiffness)	3.0 (2.0-5.0)	0.0 - 10.0	4.0 (2.0-6.0)	0.0 - 10.0	0.6
	Likert: 1 (none) to 5 (very severe)	2.0 (2.0-3.0)	1.0-5.0	2.5 (2.0-3.0)	1.0-5.0	0.6
Duration	VAS: 0–2 h, min	31.5 (11.0-88.75)	0.0 - 120.0	28.0 (10.25-65.75)	0.0-120.0	0.3
	Free text (min)	30.0 (10.0-90.0)	0.0-300.0	30.0 (10.0-90.0)	0.0-300.0	0.3
	Likert: 1 (< 30 min) to 5 (4 h or more)	3.0 (1.0-5.0)	1.0-5.0	2.0 (1.0-5.0)	1.0-5.0	0.8
Impact	NRS: 0 (no effect at all) to 10 (a great deal of effect)	3.0 (1.0-5.0)	0.0-10.0	3.0 (1.0-5.0)	0.0-10.0	0.7
	Likert: 1 (never) to 5 (always)	3.0 (2.0-3.0)	1.0-5.0	3.0 (2.0-3.0)	1.0-5.0	0.8
Importance	NRS: 0 (not important at all) to 10 (very important)	3.0 (1.0–5.0)	0.0–10.0	3.0 (1.0–5.0)	0.0–10.0	0.7
Coping	NRS: 0 (very well) to 10 (not well at all)	2.0 (1.0-4.0)	0.0-10.0	2.0 (1.0-4.75)	0.0-9.0	0.4

^{*}Mann-Whitney U test. RA: rheumatoid arthritis; PsA: psoriatic arthritis; VAS: visual analog scale; NRS: numerical rating scale; IQR: interquartile range.

Table 4. Pearson correlations between dimensions of stiffness. Duration measured using visual analog scale (0–2 h), all other dimensions measured using numerical rating scale (0–10).

Disease	Dimension	Duration	Impact	Importance	Coping
Rheumatoid Arthritis	Severity	0.67	0.89	0.76	0.81
	Duration		0.65	0.52	0.52
	Impact			0.77	0.81
	Importance				0.73
Psoriatic Arthritis	Severity	0.69	0.89	0.74	0.78
	Duration		0.71	0.61	0.61
	Impact			0.81	0.80
	Importance				0.67

by diagnosis. Age, sex, disease duration, obesity, and pain were significant independent predictors of mHAQ in RA, but only pain was significantly associated with mHAQ in PsA. After adjusting for the covariates, stiffness severity accounted for an additional 2% of the variability in mHAQ in RA, and an additional 4% of the variability in mHAQ in PsA.

Similarly, stiffness impact was independently associated with mHAQ in RA and PA, accounting for an additional 2% and 5% of the variability in mHAQ, respectively. However, stiffness duration was no longer an independent predictor of physical function in RA after adjustment for other covariates. Cognitive debriefing. Sixteen respondents (9 women and 7 men) participated in cognitive debriefing, including 10 with RA and 6 with PsA, ranging in age from 17-77 years. Identified themes and illustrative extracts are shown in Table 6. In the cognitive debriefing, 11 subjects (63%) indicated that stiffness severity reflected their ability to perform daily activities and most (14, 88%) also indicated that they conceptualized stiffness in relation to how difficult it was to perform daily activities: "can't do something you need to, then it's more severe" (male, RA), and "depends on how you can cope with daily activities" (female, RA). Seven participants (44%) reported that the impact and importance of their stiffness were very similar in meaning. Seven others indicated that the question about the importance of stiffness was unclear or confusing: "bit of a strange question ... hard to understand" (male, RA), and "don't understand the question well" (female, RA).

Participants expressed complex views about the term "coping," reporting it reflected their ability to deal with symptoms, rather than a measure of the symptom itself: "Can be severe but 'suck it up'... more about coping mechanisms than stiffness" (male, PsA). Four participants (25%) interpreted "coping" as the emotional effect of stiffness in addition

to its effect on physical function and noted that this made it more difficult for them to provide a rating, stating, "could be a multitude of responses ... can be physical or emotional" (male, RA).

Five participants indicated that the effect on or interference of stiffness with activities best reflected their experience. Three participants preferred questions about stiffness severity and 5 did not have any preference. Although 9 participants (56%) reported that the duration of morning stiffness was relevant to their experience, for the other 7, duration was not a good indicator because their stiffness could last all day. This was particularly a problem with the BASDAI VAS stiffness item, which limits duration to up to 2 h: "I'm always stiff and it doesn't really change ... when you stop moving, you get stiff" (male, RA); "when it was bad, it lasted all day" (female, PsA); and "stiffness is not just in the morning ... duration is not as relevant" (female, RA).

Regarding the questions on duration, 9 participants (56%) preferred the Likert scale format, 3 preferred the VAS, 1 liked both equally, and 2 had no preference for question format. One participant preferred free text entry. However, 2 participants reported that the free-text style of question was particularly difficult for them to answer. For questions regarding other dimensions of stiffness, 8 (50%) preferred the Likert scale, 5 (31%) preferred the NRS, and 1 (6%) liked both equally. Although 2 people preferred the VAS, 5 reported that they disliked the VAS or found it more difficult to score than other types of items. Another theme that emerged was that variability in symptoms made it difficult to decide upon a score: "every day is different" (female, RA) and because stiffness is variable, it is "difficult to get the 'right' answer" (male, RA).

DISCUSSION

In our study, we found that PsA and RA participants reported

Table 5. The effect of different stiffness	s dimensions on physical fu	inction (regression on mHz	AO by diagnosis).

Variable	Rheumatoid Arthritis			Psoriatic Arthritis				
	β (95% CI)	Standardized β	p	Adjusted R ²	β (95% CI)	Standardized β	p	Adjusted R ²
Model 1: baseline				0.65				0.47
Age, yrs	0.01 (0.001-0.01)	0.13	0.02		0.01 (-0.001 to 0.01)	0.12	0.12	
Sex, reference male	0.14 (0.04-0.25)	0.15	0.01		0.004 (-0.12 to 0.13)	0.004	0.95	
Disease duration, yrs	0.01 (0.01-0.02)	0.19	0.001		-0.002 (-0.01 to 0.01) -0.05	0.50	
Obesity, BMI $\geq 30 \text{ kg/m}^2$	0.18 (0.07-0.29)	0.18	0.002		0.12 (-0.02 to 0.25)	0.13	80.0	
Pain, 0-100 VAS	0.01 (0.01-0.01)	0.64	< 0.001		0.01 (0.01-0.01)	0.61	< 0.001	
Model 2: baseline variables								
plus stiffness severity				0.67				0.51
Severity, 0-10 NRS	0.08 (0.03-0.12)	0.40	0.002		0.06 (0.02-0.10)	0.36	0.001	
Model 3: baseline variables								
plus stiffness impact				0.67				0.52
Impact, 0-10 NRS	0.06 (0.03-0.10)	0.36	0.001		0.06 (0.03-0.10)	0.39	0.03	
Model 4: baseline variables								
plus stiffness duration				0.65				0.53
Duration, VAS	0.001 (-0.001 to 0.002	3) 0.09	0.22		0.003 (0.002–0.01)	0.31	< 0.001	

mHAQ: modified Health Assessment Questionnaire; BMI: body mass index; VAS: visual analog scale; NRS: numerical rating scale.

Table 6. Themes and illustrative extracts from cognitive debriefing (n = 16).

Theme by Stiffness Dimension	n	RA, n = 10	PsA, n = 6	Male: female	Illustrative Extracts, Age (Yrs), Sex, Diagnosis
Severity					
Rate according to ability to perform daily activities	11	8	3	6:5	"severe means you can't get out of bed" (45, female, RA)
					"when I was severe, I couldn't get out of bed or walk" (54, female, RA) "severecan't grip toothbrush, glass" (58, male, PsA)
Rate by comparing best to worst experience	4	1	3	2:2	"go to extreme level, then work backwards" (58, male, RA)
					"go back to when it hit and could not do anything with hands" (55, female, PsA)
Limitation of joint movement	2	0	2	2:0	"how badly it is limiting movement, or pain if moving past that point" (37, male, PsA)
Impact					
Rate according to ability to perform daily activities	14	9	5	7:7	"what I am physically unable to do that I would usually do" (35, male, RA)
					"whether I can still go for walkslook at things I am able to do or not do" (55, female, PsA)
Importance					
The same or similar meaning to impact	7	4	3	5:2	"very similar to impact, impact probably better" (54, female, RA) "same as impact" (58, male, PsA)
Meaning difficult to understand	7	4	3	4:3	"didn't know what to do with that question" (37, male, PsA)
Duration					
Relevant to experience	9	6	3	5:4	"ideally want it to last a short amount of timelonger lasting implies flare" (44, male, PsA)
Not limited to the morning, can be constant	7	4	3	3:4	"How long is a piece of string? I'm always stiff and it doesn't really change" (44, male, RA)
Coping					
Ability to deal with symptoms, rather than measure of symptom itself	7	5	2	3:4	"can I push past what I feel?" (54, female, RA)
Physical and emotional	4	3	1	2:2	"not sure if it meant physical or emotional" (45, female, RA)
					"how does it get to you emotionally and physicallytwo-fold question" (44, male, PsA)
Meaning difficult to understand	3	2	1	1:2	"could be a multitude of responses" (35, male, RA) "difficult to understand" (52, female, PsA)
Cymanton youighility 1i	5	4	1	1,4	
Symptom variability makes scoring stiffness difficult	5	4	1	1:4	"large variancedifficult to get the 'right' answer" (35, male, RA)
					"variability makes it difficult to answer sometimes" (55, female, PsA)

RA: rheumatoid arthritis; PsA: psoriatic arthritis.

similar levels of stiffness and there were strong correlations among the different dimensions of stiffness we assessed. Stiffness severity and impact were independent predictors of physical function in both RA and PsA, though the additional variance explained was modest. However, duration of stiffness was associated with physical function in participants with PsA only. In cognitive debriefing, participants described stiffness severity and impact in similar terms and generally considered relating to their stiffness as how it affected their ability to perform daily tasks. Duration of morning stiffness was relevant to only some participants in both conditions.

There are few studies comparing different approaches to assessing stiffness in rheumatologic diseases. In a cross-sectional study from Norway of 1791 patients, Michelsen, *et al* reported no significant difference in morning stiffness duration (hours, 0–6) between patients with RA, PsA, and axial spondyloarthritis²⁷. Husted, *et al* also reported no

difference in duration of morning stiffness (minutes) between RA and PsA²⁸. Our results indicate that not only is duration of stiffness similar between RA and PsA, but severity and the impact of stiffness on their lives were also similar. This suggests that a common PRO may be appropriate to assess stiffness across PsA and RA and potentially other rheumatic diseases, although further research is needed.

Scores for each of the different dimensions of stiffness we assessed were strongly correlated, particularly for impact and severity. This is in contrast to findings from Rhind, *et al*²⁹, who reported poor to moderate correlations between duration of morning stiffness and severity of stiffness using a variety of rating scales in 100 patients with RA (VAS: no stiffness to very severe stiffness, NRS: 0–10 where higher scores meant more severe stiffness, and a 5-point verbal scale: no stiffness, mild, moderate, severe, and very severe stiffness). During cognitive debriefing in our survey, some participants

indicated that the impact and importance of stiffness seemed to essentially ask about the same thing. Participants reported they thought about their ability to perform daily tasks when rating both stiffness severity and impact, which may in part explain the high correlations we observed between scores. Halls, *et al* also reported that most patients tend to describe stiffness in terms of its impact, rather that severity or duration²⁰.

Duration of stiffness was of varying relevance to participants in our study with polarized opinions expressed in the cognitive debriefing. While to some, the duration of morning stiffness was an important indicator of disease activity, to others, it was not because their stiffness was constant or could occur at any time of day. Additionally, we found that the duration of stiffness was significantly associated with physical function in PsA, but not in RA. This finding is in keeping with the work of others 19,20, which suggests that although it is the most commonly used indicator of stiffness^{6,30}, duration alone is unlikely to adequately reflect the experience of some patients. Our findings also suggest that the duration of stiffness may play different roles in the patient experience in different diseases. The duration of stiffness was strongly correlated with severity and impact, suggesting that these essential aspects of stiffness are being identified by the traditional measure of duration. Nevertheless, because duration was not always a meaningful concept to patients, it may not be the best way to assess stiffness in a patient-centered approach to measurement.

Stiffness severity and impact was associated with physical function, independent of pain, age, sex, disease duration, and obesity. However, much of the variability in physical function in our model was explained by age, sex, disease duration, and pain, with a small increase in the adjusted R^2 with the addition of stiffness severity or impact. In a prospective cohort of patients with recently diagnosed RA³¹, morning stiffness was strongly and positively associated with pain and functional capacity and was a predictor of early retirement. In our survey, the participant ratings of stiffness severity and impact were strongly correlated and had similar impact on physical function in both RA and PsA. This suggests that the additive value of measuring both dimensions is probably small and may not justify the additional question burden to patients. These data will help inform the development of a stiffness measure by OMERACT researchers in the Stiffness Working Group.

Previous studies have shown good correlation between VAS, NRS, and Likert scales regarding the measurement of pain^{32,33}. We similarly found strong correlation between the different question formats for each dimension of stiffness. This suggests that because there is little distinction between the items on these grounds, the preferences of patients should guide decisions about which format may be the most appropriate.

Strengths of our study include the use of a relatively large sample size and a high response rate to the survey. We used

both qualitative and quantitative approaches to assess the performance of items measuring stiffness in both RA and PsA. There are also limitations. We did not audio-record the interviews, and instead relied on field notes. We used stiffness items from existing measures; there may be other characteristics of stiffness such as location and response to treatment that would offer additional important information. Most participants were white with a high level of education, so these findings may not be generalizable to a more diverse sample of people with RA or PsA. Additionally, participants in our study had longstanding disease, with most taking a biologic diseasemodifying agent, and it is possible that some of their reported joint stiffness and pain was due to joint damage rather than active inflammatory disease. ARAD does not record clinical data such as joint counts, dactylitis, or enthesitis, and therefore it was not possible to compare the patient-reported stiffness scores to these aspects of disease activity or phenotype.

The experience of stiffness associated with PsA and RA appears to have significant overlap. Stiffness was important to participants, and significantly affected daily activities. There were strong correlations among the dimensions of stiffness measured. Stiffness severity and impact were strongly correlated and were both independent predictors of physical function. In contrast, the duration of stiffness was not relevant to the experience of some patients, and was not associated with physical function in participants with RA. Therefore, although the duration of stiffness was strongly correlated with the other dimensions of stiffness statistically, stiffness severity and impact appeared to be relevant concepts to most participants and measuring these dimensions may be preferable in a patient-centered approach. Our findings suggest that measuring both severity and impact of stiffness may not provide independent information and that measurement of either one may be sufficient in clinical practice. Further research is needed to determine whether other aspects of stiffness should be queried to best reflect the patient experience while minimizing the question burden to patients.

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REFERENCES

 Khan NA, Yazici Y, Calvo-Alen J, Dadoniene J, Gossec L, Hansen TM, et al; QUEST-RA group. Reevaluation of the role of duration

- of morning stiffness in the assessment of rheumatoid arthritis activity. J Rheumatol 2009;36:2435-42.
- Yazici Y, Pincus T, Kautiainen H, Sokka T. Morning stiffness in patients with early rheumatoid arthritis is associated more strongly with functional disability than with joint swelling and erythrocyte sedimentation rate. J Rheumatol 2004;31:1723-6.
- Pappas DA, Holt RJ, Shan Y, Kent JD, Nguyen JT, Kremer JM, et al. The influence of patient reported morning stiffness on patient global assessment in rheumatoid arthritis patients not achieving ACR/EULAR Boolean remission in a large US registry [abstract]. Arthritis Rheumatol 2015;67 Suppl 10:3202-3.
- Bartlett SJ, Hewlett S, Bingham CO 3rd, Woodworth TG, Alten R, Pohl C, et al; OMERACT RA Flare Working Group. Identifying core domains to assess flare in rheumatoid arthritis: an OMERACT international patient and provider combined Delphi consensus. Ann Rheum Dis 2012;71:1855-60.
- Bartlett SJ, Barbic SP, Bykerk VP, Choy EH, Alten R, Christensen R, et al. Content and construct validity, reliability, and responsiveness of the rheumatoid arthritis flare questionnaire: OMERACT 2016 workshop report. J Rheumatol 2017;44:1536-43.
- Orbai AM, Bingham CO 3rd. Patient reported outcomes in rheumatoid arthritis clinical trials. Curr Rheumatol Rep 2015;17:28.
- Orbai AM, de Wit M, Mease PJ, Callis Duffin K, Elmamoun M, Tillett W, et al. Updating the psoriatic arthritis (PsA) core domain set: a report from the PsA workshop at OMERACT 2016.
 J Rheumatol 2017;44:1522-8.
- Orbai AM, de Wit M, Mease P, Shea JA, Gossec L, Leung YY, et al. International patient and physician consensus on a psoriatic arthritis core outcome set for clinical trials. Ann Rheum Dis 2017; 76:673-80.
- 9. Kalyoncu U, Ogdie A, Campbell W, Bingham CO 3rd, de Wit M, Gladman DD, et al. Systematic literature review of domains assessed in psoriatic arthritis to inform the update of the psoriatic arthritis core domain set. RMD Open 2016;2:e000217.
- 10. Mease PJ. Measures of psoriatic arthritis: Tender and Swollen Joint Assessment, Psoriasis Area and Severity Index (PASI), Nail Psoriasis Severity Index (NAPSI), Modified Nail Psoriasis Severity Index (mNAPSI), Mander/Newcastle Enthesitis Index (MEI), Leeds Enthesitis Index (LEI), Spondyloarthritis Research Consortium of Canada (SPARCC), Maastricht Ankylosing Spondylitis Enthesis Score (MASES), Leeds Dactylitis Index (LDI), Patient Global for Psoriatic Arthritis, Dermatology Life Quality Index (DLQI), Psoriatic Arthritis Quality of Life (PsAQOL), Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), Psoriatic Arthritis Response Criteria (PsARC), Psoriatic Arthritis Joint Activity Index (PsAJAI), Disease Activity in Psoriatic Arthritis (DAPSA), and Composite Psoriatic Disease Activity Index (CPDAI). Arthritis Care Res 2011;63 Suppl 11:S64-85.
- Her M, Kavanaugh A. A review of disease activity measures for psoriatic arthritis: what is the best approach? Expert Rev Clin Immunol 2014;10:1241-54.
- Orbai AM, Ogdie A. Patient-reported outcomes in psoriatic arthritis. Rheum Dis Clin North Am 2016;42:265-83.
- Garrett S, Jenkinson T, Kennedy LG, Whitelock H, Gaisford P, Calin A. A new approach to defining disease status in ankylosing spondylitis: the Bath Ankylosing Spondylitis Disease Activity Index. J Rheumatol 1994;21:2286-91.
- Halls S, Sinnathurai P, Hewlett S, Mackie SL, March L, Bartlett SJ, et al. Stiffness is the cardinal symptom of inflammatory musculoskeletal diseases, yet still variably measured: report from the OMERACT 2016 stiffness special interest group. J Rheumatol 2017;44:1904-10.
- Wright V, Johns RJ. Observations on the measurement of joint stiffness. Arthritis Rheum 1960;3:328-40.
- Hicklin JA, Wighton RJ, Robinson FJ. Measurement of finger stiffness. Rheumatology 1968;9:234-42.

- Wright V, Plunkett TG. Scientific assessment of the results of physical treatment—measurement of stiffness. Rheumatology 1966;8:280-91.
- Myers DB, Wilson K, Palmer DG. An objective measurement of change in morning stiffness. Rheumatol Int 1981;1:135-7.
- Orbai AM, Smith KC, Bartlett SJ, De Leon E, Bingham CO 3rd. "Stiffness has different meanings, i think, to everyone": examining stiffness from the perspective of people living with rheumatoid arthritis. Arthritis Care Res 2014;66:1662-72.
- Halls S, Dures E, Kirwan J, Pollock J, Baker G, Edmunds A, et al. Stiffness is more than just duration and severity: a qualitative exploration in people with rheumatoid arthritis. Rheumatology 2015;54:615-22.
- Buchbinder R, March L, Lassere M, Briggs AM, Portek I, Reid C, et al. Effect of treatment with biological agents for arthritis in Australia: the Australian Rheumatology Association Database. Intern Med J 2007;37:591-600.
- 22. Halls S, Dures E, Kirwan JR, Pollock J, Baker G, Edmunds A, et al. Development and testing of candidate items for inclusion in a new rheumatoid arthritis stiffness patient-reported outcome measure. Rheumatology 2018;57:263-72.
- van Tuyl LH, Lems WF, Boers M. Measurement of stiffness in patients with rheumatoid arthritis in low disease activity or remission: a systematic review. BMC Musculoskeletal Disorders 2014;15:28.
- 24. Maska L, Anderson J, Michaud K. Measures of functional status and quality of life in rheumatoid arthritis: Health Assessment Questionnaire Disability Index (HAQ), Modified Health Assessment Questionnaire (MHAQ), Multidimensional Health Assessment Questionnaire (MDHAQ), Health Assessment Questionnaire II (HAQ-II), Improved Health Assessment Questionnaire (Improved HAQ), and Rheumatoid Arthritis Quality of Life (RAQoL). Arthritis Care Res 2011;63 Suppl 11:S4-13.
- Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000;320:114-6.
- The BMJ Resources. 11. Correlation and regression. [Internet. Accessed June 25, 2019.] Available from: https://www.bmj.com/ about-bmj/resources-readers/publications/statistics-square-one/ 11-correlation-and-regression
- Michelsen B, Fiane R, Diamantopoulos AP, Soldal DM, Hansen IJ, Sokka T, et al. A comparison of disease burden in rheumatoid arthritis, psoriatic arthritis and axial spondyloarthritis. PLoS One 2015;10:e0123582.
- Husted JA, Gladman DD, Farewell VT, Cook RJ. Health-related quality of life of patients with psoriatic arthritis: a comparison with patients with rheumatoid arthritis. Arthritis Rheum 2001;45:151-8.
- Rhind VM, Unsworth A, Haslock I. Assessment of stiffness in rheumatology: the use of rating scales. Br J Rheumatol 1987;26:126-30.
- Kalyoncu U, Dougados M, Daurès JP, Gossec L. Reporting of patient-reported outcomes in recent trials in rheumatoid arthritis: a systematic literature review. Ann Rheum Dis 2009;68:183-90.
- Westhoff G, Buttgereit F, Gromnica-Ihle E, Zink A. Morning stiffness and its influence on early retirement in patients with recent onset rheumatoid arthritis. Rheumatology 2008;47:980-4.
- Englbrecht M, Tarner IH, van der Heijde DM, Manger B, Bombardier C, Müller-Ladner U. Measuring pain and efficacy of pain treatment in inflammatory arthritis: a systematic literature review. J Rheumatol Suppl. 2012 Sep;90:3-10.
- 33. Sendlbeck M, Araujo EG, Schett G, Englbrecht M. Psychometric properties of three single-item pain scales in patients with rheumatoid arthritis seen during routine clinical care: a comparative perspective on construct validity, reproducibility and internal responsiveness. RMD Open 2015;1:e000140.