





BRIEF REPORT

Codevelopment of Patient Self-Examination Methods and Joint Count Reporting for Rheumatoid Arthritis

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Objective. To determine whether training increases accuracy of self-reported joint counts in people with rheumatoid arthritis (RA) and describe the knowledge and techniques for self-examination of joints for reporting of RA disease activity.

Methods. This mixed-methods study included 10 patients with RA and four rheumatologists. A rheumatologist presented about joint inflammation and disease monitoring in RA. Patients then self-examined and reported 28-tender joint count (28-TJC) and 28-swollen joint count (28-SJC). Next, two paired rheumatologists examined patients and reported 28-TJC and 28-SJC. After watching a joint examination video for training physicians, patients discussed their training needs for self-examination, with discussion analyzed using thematic analysis. Self-examination techniques were determined by consensus. Finally, patients self-examined and reported 28-TJC and 28-SJC. Reliability between the first and second patient-reported 28-TJCs and 28-SJCs and rheumatologist pair-reported 28-TJC and 28-SJC was determined with the intraclass coefficient.

Results. The reliability for patient self-reported joint counts was higher for the 28-TJC than for the 28-SJC. Reliability improved following rheumatologist examination and training. Patients identified a preference for practical information rather than detailed information on joint anatomy and pathophysiology. Clear definitions of “swollen” and “tender” were important; patients found the concept of “tenderness” difficult. Techniques for self-examination and reporting of joint counts were agreed on and demonstrated in an instructional video.

Conclusion. Training increased reliability of patient-reported joint counts. Patients with RA identified important aspects of training for self-examination and reporting of joint counts. An 8-minute instructional video was codeveloped; the next step is the evaluation of the video’s impact on patient-reported joint counts.

INTRODUCTION

Management of rheumatoid arthritis (RA) with a treat-to-target approach requires frequent assessment of disease activity (1), with tender and swollen joint counts included in most composite disease activity measures (2). Limited health resources make frequent in-person appointments unfeasible for disease assessment given the current rheumatology workforce (3,4). Additionally, visits may be unnecessary when patients have persistent low

disease activity or are in remission. Patient self-assessment and self-report of their RA activity to their rheumatologist via telehealth systems would enable the prioritization of in-person assessments according to greatest need (5,6). This is of increased relevance in 2020 because of the widespread provision of rheumatology care by telehealth because of the 2019 novel coronavirus disease (COVID-19) pandemic (7). It remains unclear how people with RA might best perform self-examination and report their own joint counts.

Supported by an Otago Medical School collaborative grant.

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No potential conflicts of interest relevant to this article were reported.

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Submitted for publication October 4, 2020; accepted in revised form October 9, 2020.

SIGNIFICANCE & INNOVATIONS

- For the first time people with rheumatoid arthritis (RA) were involved in developing methods for self-examination and joint count reporting.
- People with RA did not require detailed medical information to perform self-examination but did require clear definitions of tenderness and swelling to confidently report tender and swollen joint counts.
- A video demonstrating the patient self-examination technique and reporting of self-joint counts was developed and can be tested as a training tool.

Previous studies suggest that self-reported joint counts from people with RA are similar to joint counts reported by rheumatologists (8-11). A systematic review comparing patient- and health care professional (HCP)-performed joint counts found a moderate to high correlation between groups for tender joint counts (TJCs) (correlation coefficients of 0.45-0.92), but low to moderate correlation for swollen joint counts (SJs) (correlation coefficients 0.16-0.67) (8). The effect of training patients in joint counts is conflicting; a study in rheumatology clinics in the United States showed that short training by a clinician emphasizing the difference between soft tissue and bony swelling improved the concordance of patient-reported TJCs and SJs with those performed by a doctor (9). In contrast, in Austrian clinics, similar short didactic training did not increase accuracy of patient-reported joint counts (10). The training in these studies was brief and not reported in sufficient detail to be reproduced. Therefore, if patients are to perform self-examination and report joint counts, there is a need for a training resource that demonstrates standardized examination techniques and how to report joint counts.

The aims of this mixed-methods study were to work in partnership with patients with RA to determine whether training increases the reliability of self-reported joint counts and identify knowledge required and practical techniques for self-examination of joints for reporting RA disease activity.

PATIENTS AND METHODS

The study was approved by the Central Health and Disability Ethics Committee (16/NTB/102). Patients provided informed consent before the workshop.

This mixed-methods study had concurrent data collection in a 1-day in-person workshop (12). Quantitative data were collected to determine whether training increased reliability of joint counts reported by patients after self-examination. The second main focus for data collection was qualitative data about knowledge and techniques of joint self-examination and reporting with data collection.

Participants. Five rheumatologists (RG, AAH, WJT, SS, and LKS) from three centers in New Zealand each purposively recruited two people with RA (patients) to participate in a workshop, aiming to include people with more than one tender and/or swollen joint and of differing age, sex, and ethnicity. Demographics (age, sex, ethnicity, and education level), disease characteristics (disease duration and medications), and functional status (modified Health Assessment Questionnaire II) were collected.

Workshop. In order to identify the key information people with RA needed to undertake self-examination and report self-joint counts, a 1-day workshop was held to develop and document techniques of joint self-examination with the purpose of standardizing reporting the 28-TJC and 28-SJC.

The workshop started with a 20-minute presentation for patients describing synovial joint structure, synovitis as the cause of joint tenderness and swelling, the purpose and features of treat-to-target management strategies, and an introduction to principles of the 28-TJC and 28-SJC.

Each patient then performed a self-examination and reported their own 28-TJC and 28-SJC (patient joint count 1) without any further instruction. Each patient was examined individually by each rheumatologist, who were grouped in two pairs (rheumatologist pair A and rheumatologist pair B), who then recorded their individual assessment of 28-TJC and 28-SJC, and following discussion between the two rheumatologists in each pair, reached a consensus on a final 28-TJC and 28-SJC for each patient. Rheumatologist pair A and rheumatologist pair B 28-TJC and 28-SJC were used for comparison with patient-reported 28-TJC and 28-SJC. Patients then watched an instructional video (originally developed for HCPs) demonstrating how to perform 28-TJC and 28-SJC (13). After a period of discussion described below (i.e., at the end of the workshop), patients performed a second self-examination and rereported 28-TJC and 28-SJC (patient joint count 2). All 28-TJCs and 28-SJCs were recorded on paper homunculi by the person undertaking the examination.

The discussion between patients with RA and rheumatologists was facilitated by the principle investigator (RG). Potential methods for self-examination for each joint in the 28-TJC and 28-SJC and patient opinions regarding their perceived knowledge and training needs were elicited. Specific topics discussed included, but were not limited to, the knowledge of anatomy and physiology required to perform self-examination and report TJCs and SJs, the information required for inclusion in an instructional video to teach joint self-examination and the reporting of joint counts, and potential barriers for RA self-examination. A rheumatologist (AAH) was videoed while demonstrating the proposed technique for joint self-examination, adjusting the technique based on feedback from patients. Discussion continued until consensus was reached on the best methods for patients to examine their own joints in

order to report TJCs and SJC. After the workshop, a professional videographer filmed and produced videos with a rheumatologist (RG) as the narrator, explaining briefly relevant RA pathophysiology, the joint count, and meaning of “swollen” and “tender.” Patients were filmed demonstrating agreed self-examination techniques and reporting 28-TJC and 28-SJC.

Data analysis. Reliability of 28-TJC and 28-SJC between patient joint count 1 and patient joint count 2 and rheumatologist pair A and rheumatologist pair B were determined by the reliability measure of intraclass correlation (ICC) (two-way random effects model for single rating and measuring absolute agreement). Values less than 0.5 are indicative of poor reliability, values between 0.5 and 0.75 indicate moderate reliability, values between 0.75 and 0.9 indicate good reliability, and values greater than 0.90 indicate excellent reliability (14). Workshop discussions were recorded, transcribed, and analyzed using thematic analysis (15).

RESULTS

Ten people with RA (nine women and one man) with median age of 49.5 years (range 29-76) attended the workshop. Seven were of New Zealand European ethnicity and one each were of Cook Island Māori, Cambodian, and Chinese ethnicities. Eight (80%) had tertiary-level education. The mean duration of RA was 14.8 years (3 months to 35 years). Nine (90%) were taking methotrexate, and four (40%) a biologic disease-modifying antirheumatic drug. Functional level was somewhat impaired, with a modified Health Assessment Questionnaire mean of 1.4 (SD 0.9). Four rheumatologists (RG, AAH, WJT, and SS) with between 12 and 24 years of postfellowship experience in rheumatology attended the workshop.

Joint count reliability. The 28-TJC and 28-SJC for patient-reported joint counts and rheumatologist pair A and pair B joint counts are shown in Table 1. Agreement between the rheumatologist pair A and rheumatologist pair B was excellent for 28-TJC (ICC 0.95) and moderate for 28-SJC (ICC 0.53).

Tender joint counts. The 28-TJC reported by patients after the explanatory presentation (patient joint count 1) showed good reliability with rheumatologist pairs' 28-TJCs (ICC with rheumatologist pair A: 0.76; ICC with rheumatologist pair B: 0.86). The second patient-reported 28-TJC (patient joint count 2) following the rheumatologists' examination, video, and discussion showed a good to excellent reliability with rheumatologist pairs' 28-TJCs (ICC with rheumatologist pair A: 0.87; ICC with rheumatologist pair B: 0.96) (Table 2).

Swollen joint counts. Reliability between patients' first 28-SJC (patient joint count 1) and rheumatologist pairs' 28-SJCs was poor (ICC with rheumatologist pair A: 0.21; ICC with rheumatologist pair B: 0.35) but improved to moderate reliability following the rheumatologists' examination and discussion (patient joint count 2; ICC with rheumatologist pair A: 0.65; ICC with rheumatologist pair B: 0.71).

Workshop discussion. Two themes were identified in the workshop discussion. First, people with RA did not perceive a need for detailed knowledge about joint anatomy or physiology to do a joint self-examination or report joint counts. They identified a preference for practical information rather than overtechnical or medicalized information, as demonstrated by the following quotes: “I think going into joint structure isn't really necessary. What you need to know is, is it swollen? And the amount of pressure you need to put on, and once you put that pressure on, does it hurt?” (female patient, 52 years old) and “I like the idea that it's [medical information] available. But it's not as important as the other stuff you said” (female patient, 35 years old). Secondly, clear definitions of the words “swollen” and “tender” were seen as important for confident reporting of joint counts. The word “tender” was difficult to understand and apply, and patients with RA felt that this may lead to under- or over-reporting of tenderness, evidenced by the following quote: “... we were talking about the word tenderness, for most of us, we will say it's sore. Or it hurts. We don't normally use the word tender” (female patient, 45 years old), “Cause tender, for a lot of people, is soft, as in a steak” (female patient, 34 years old), and “And when we say it's a little sore, because we have it all the time,

Table 1. Twenty-eight tender joint counts and 28 swollen joint counts for patient self-examination and rheumatologist pairs

Participant	28 Tender Joint Count				28 Swollen Joint Count			
	Patient joint count 1	Rheum pair A	Rheum pair B	Patient joint count 2	Patient joint count 1	Rheum pair A	Rheum pair B	Patient joint count 2
1	21	26	23	24	16	10	9	11
2	16	10	6	13	16	2	6	0
3	2	8	7	10	11	3	0	2
4	1	0	1	1	1	1	2	1
5	5	6	8	6	7	9	5	6
6	4	10	11	9	6	3	8	8
7	1	1	1	1	0	0	0	0
8	5	6	6	6	5	5	5	7
9	4	6	6	10	7	6	11	6
10	10	10	14	9	4	13	6	5

Rheum, rheumatologist.

Table 2. ICCs of 28 tender joint count and 28 swollen joint count for patient self-examination and rheumatologist pairs

ICC	28 Tender Joint Counts		28 Swollen Joint Counts	
	Patient joint count 1	Patient joint count 2	Patient joint count 1	Patient joint count 2
Self-examination compared with rheum pair A	0.76	0.87	0.21	0.65
Self-examination compared with rheum pair B	0.86	0.96	0.35	0.71
Rheum pair A compared with rheum pair B	0.95		0.53	

ICC, intraclass correlation coefficient; rheum, rheumatologist.

it is just a little sore. Whereas somebody who doesn't have it all the time would see it in a different way" (male patient, 59 years old). Additional illustrative quotes are supplied in Table 3.

Lastly, overall, people with RA expressed confidence in joint self-examination and reporting of joint counts.

Consensus was reached on practical techniques of joint self-examination that were considered most straightforward and that addressed both potential RA-related impairments and patient comfort. For example, two methods of shoulder examination were demonstrated, one of which used deep palpation with the thumb alone, whereas the other avoided this. Participants felt that using the thumb may cause unacceptable pain for some people with RA.

Videos were filmed and produced by a professional videographer and include a rheumatologist (RG) as narrator. Two patient participants volunteers from the workshop gave feedback on storyboard and script and were filmed examining their joints using the agreed techniques. The videos include a short introductory video explaining the joint count and providing a brief overview of relevant RA pathophysiology (3 minutes), videos demonstrating the self-examination technique and reporting of TJs and SJs of each of the six joint areas (proximal interphalangeal joints, metacarpophalangeal joints, wrist, elbow, shoulder, and knee; each approximately 1 minute) and a longer video (8 minutes) that

includes all of the above. The video can be viewed on request by email to corresponding author.

DISCUSSION

To our knowledge, this study is the first to involve patients with RA in developing a standardized approach to self-examination and the reporting of joint counts. We identified that people with RA did not feel that they required detailed medical information to perform self-examination but did require clear definitions of tenderness and swelling to confidently report 28-TJCs and 28-SJCs. Consistent with previous studies (8,11), patient-reported 28-TJCs showed higher reliability to rheumatologist joint counts than 28-SJCs. Reliability for both the 28-TJC and 28-SJC was higher after a rheumatologists' examination and information, suggesting that observation and training increased accuracy. In addition, the reliability for post-training self-examined joint counts was numerically similar to the reliability of joint counts performed by pairs of rheumatologists.

A key finding was identifying that people with RA need clarification of the meaning of "tender" and "swollen" to be confident in reporting joint counts. This may in part explain the improvement in reliability between patient joint counts and rheumatologist joint counts seen in this and a previous study, in which information on what defines the term "swelling" as well as instruction to ignore bony enlargement are provided (9). The difference between "pain," as experienced by patient, and "tenderness" experienced during palpation was important to explain so that patients could accurately report TJCs. Similar difficulties in understanding meanings of self-report instrument items have been identified as a potential cause of measurement error (16).

Our study has some limitations. Although people with RA were intentionally recruited with varying demographic and RA disease characteristics, their views may not be generalizable to other patient groups or health care settings in other countries. When interpreting our results, it must be noted that most of the people with RA in our study had tertiary-level education. Although our focus was on the training effect of a formal presentation of information, it is likely that some informal training occurred by observing rheumatologist examination and joint count, which cannot be replicated in a training video. Strengths of our approach include the collaborative approach of including people with RA in the development of patient self-examination techniques and the

Table 3. Additional illustrative quotes from people with RA on joint counts

Theme	Illustrative Quotes
No need for detailed knowledge	"You've got to keep it as simple as possible." (female patient, 76 years old) "I think going into joint structure isn't really necessary." (female patient, 34 years old)
Clear definitions for confidence	"And certainly, we'll have to totally understand what you as clinician's mean by tender. Because we have different concepts of it." (female patient, 35 years old) "The other thing is when it comes down to pain, is it sore or isn't it sore, but there isn't a sort of definition of how sore is it?" (female patient, 76 years old) "But it's a different- everybody has a different threshold of pain too. What I might say is a bit sore, somebody else 'oh, it really hurts.'" (female patient, 50 years old)

RA, rheumatoid arthritis.

production a standardized training video that could be replicated in other countries or languages. The process identified areas of confusion for patients, especially in terminology, which were not previously suspected by the clinicians. This standardization differs from brief didactic training by a clinician with no demonstration (9,10) or a time-consuming nurse-led, video-assisted training in a longitudinal clinical study (17), which did not have patient input into development.

Our data suggest that training people with RA in self-examination and the reporting of joint counts increases the reliability of joint counts when compared with those reported by rheumatologists. Therefore, the next step is to explore the impact of the training video on reliability of patient-reported joint counts. Although in research settings patient self-report of joint counts have been shown to lead to similar categories of RA disease activity using the Disease Activity Score 28 (18), these findings need confirmation in real-world clinical settings. This would provide confidence among clinicians that the information provided by patient self-reporting of disease activity could be used in remote or telehealth situations and by apps or websites. This is of increasing significance following the COVID-19 pandemic, when globally, there has been an unprecedented and rapid shift toward these forms of consultation, with little evidence to support their effectiveness in guiding decision-making (19). The use of patient self-assessment would enable people with RA to play a greater role in their own care and allow close disease monitoring without the need for in-person clinic visits.

ACKNOWLEDGMENTS

The authors thank the people living with rheumatoid arthritis for generously giving their time and insights.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Grainger, Stebbings, Harrison, Taylor, Stamp.

Acquisition of data. Grainger, Townsley, Stebbings, Harrison, Taylor.

Analysis and interpretation of data. Grainger, Townsley, Stebbings, Harrison, Taylor, Stamp.

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