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Pain measurement in rheumatic and musculoskeletal diseases: where to go from here?

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Short running head: Pain measurement in rheumatology

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JAS has received consultant fees from Crealta/Horizon, Fidia, UBM LLC, Medscape, WebMD, the National Institutes of Health and the American College of Rheumatology. JAS is a member of the Veterans Affairs Rheumatology Field Advisory Committee. JAS is the editor and the Director of the UAB Cochrane Musculoskeletal Group Satellite Center on Network Meta-analysis. JAS served as a member of the American College of Rheumatology's (ACR) Annual Meeting Planning Committee (AMPC) and Quality of Care Committees, the Chair of the ACR Meet-the-Professor, Workshop and Study Group Subcommittee and the co-chair of the ACR Criteria and Response Criteria subcommittee. JAS is a member of the executive of OMERACT, an organization that develops outcome measures in rheumatology and receives arms-length funding from 36 companies.

DT is the Editor-in-Chief of The Clinical Journal of Pain and serves as an industry advisor or consultant to AcelRx, GSK/Novartis, and Pfizer.

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ABSTRACT

Objective: Establishing a research agenda on standardizing pain measurement in clinical trials in rheumatic and musculoskeletal diseases (RMDs).

Methods: Discussion during a meeting at OMERACT 2018, prepared by a systematic review of existing core outcome sets and a patient online survey.

Results: Several key questions were debated: is pain a symptom or a disease? are pain core (sub)domains consistent across RMDs? how to account for pain mechanistic descriptors (e.g. central sensitization) in pain measurement?

Conclusion: Characterizing and assessing the spectrum of pain experience across RMDs in a standardized fashion is the future objective of the OMERACT pain working group.

MANUSCRIPT

Introduction

Pain is a prevailing and common symptom across rheumatic and musculoskeletal diseases (RMDs) (1). Clinically, acute and chronic pain are distinct, are managed differently and have differences in outcomes. The majority of people who experience acute pain tend to improve spontaneously or under treatment (2), but some individuals progress to a chronic pain that can cause considerable physical, emotional, and socioeconomic burdens (3). To identify preventive or effectively tailored interventions, standardized pain assessment in clinical trials is essential to making precise estimates on the effectiveness of interventions. However, heterogeneity in outcome assessment has been identified for clinical trials in patients within and between different pain conditions (4).

OMERACT 2.0 Filter (5, 6) provides guidance for harmonizing outcome assessment by developing core outcome sets (COS), consisting of domains and measurement instruments. Defining the scope of such a COS is the initial step, identifying the domains that constitute the health condition of interest. For pain conditions, several COS recommendations exist, regarding chronic pain in general (7, 8), fibromyalgia (9), low back pain (LBP) (10), or for specific treatments (11). To establish a research agenda for harmonizing pain assessment in clinical trials in RMDs, information is needed regarding:

1) the importance of chronic pain in patients with RMDs;
2) to what extent patients with chronic pain and RMDs feel different from patients with chronic pain of other origin;
3) whether the pain experience is different across RMDs;
4) the existing pain recommendations in COS for RMDs;
5) to what extent pain measurement differs across RMDs;
6) the relative contribution of different pain mechanisms (e.g. central sensitization, neuropathic pain) to the patient's experience of pain.

Methods, Results and Meeting Report

Establishing a research agenda was planned for the OMERACT Meeting in Terrigal, Australia, May 2018. In preparation, the OMERACT pain working group had multiple teleconferences, conducted an online survey in patients with RMDs and a systematic review on existing pain recommendations in COS for RMDs.

Introduction of the OMERACT 2018 SIG

PJM introduced the precursor working group that developed a COS for FM (9) and proposed a composite measure of disease activity to assess the COS (12). This group described the multidimensional nature of this chronic pain disorder by itemizing in the COS the following items: pain, fatigue, sleep disturbance, patient global, multidimensional function, and quality of life. This COS was noted to be closely correlated to the IMMPACT COS for evaluation of chronic pain conditions in clinical trials (7, 8, 13).

Following this previous work, a working group has met as a Special Interest Group (SIG) at subsequent OMERACT meetings to address the possibility of developing a COS for chronic pain across all RMDs. Nevertheless, several inherent problems exist in this standardization process. First, pain may be acute and episodic in some RMDs and in others, chronic. In the latter situation, pain may become a disease unto itself, including chronic alteration of signaling pathways in the central nervous system rather than an episodic symptom of peripheral pathophysiology of a RMD. It has been demonstrated that chronic central pain can influence RMD outcomes (14). Characterizing and assessing the spectrum of pain experience across RMDs in a standardized fashion was highlighted as the objective of this working group, comprised of academic pain researchers and patient research partners.

Importance and experience of chronic pain in RMDs

An online survey (one round between April and May 2018) was held to explore nature and relevance of chronic pain in patients with RMDs. The questionnaire was developed by one SIG members (UK) and revised by others (BH, MG, MdW, MC, EC, LSS, PJM, AC) with Survey monkey, and data were analyzed with frequencies of responses and qualitatively. The majority (84%) of patients reported experiencing a RMD AND chronic pain, 86% expressed that chronic pain is relevant for patients with various RMDs (Table 1). The majority of the patients (47%) reported that chronic pain is a common, inseparable aspect of RMDs.

In a previous survey (13), individuals experiencing chronic pain (n>800) identified 19 (sub)domains to be related to and impacted by chronic pain. Similar results were provided by patients with RMDs (Table 2, Figure 1). The most important domains (i.e. staying asleep, enjoyment of life, , and fatigue, mean ≥8/10, rating between 0 'not important at all', 10 'of highest importance') also scored among the highest in the previous survey. The most substantial distinction between respondents with RMDs and chronic pain was found for "weakness" and "difficulties concentrating" (Table 2); such difference may be explained by the fact that only a minority of patients presented with a RMD in the previous survey (i.e. 5% rheumatoid arthritis, 19% osteoarthritis) (13). Patients also felt that a specific treatment of chronic pain in RMDs would be necessary (Median = 7/10). The majority of patients (72%) expected treatment of chronic pain to have different aims than other treatments for RMDs.

Core Outcome Sets for RMDs

Our aim was to identify any COS for research or practice targeting any RMD. An ad-hoc multifaceted search strategy to retrieve COS in MEDLINE and SCOPUS [developed by the Core Outcome Measures in Effectiveness Trials (COMET) initiative (15)] was run on March 6, 2018; results were screened to

identify eligible COS. Additionally, the COMET database was searched with the keyword 'pain'. Two independent reviewers (AC, UK) performed the screening. The methodological quality of a subset of 14 retrieved COS was assessed by two reviewers (EG, JK) with the Core Outcome Set-STAndards for Development (COS-STAD) recommendations (16). One reviewer (AC) extracted data on the targeted RMDs and/or intervention(s), on the frequency of pain recommendation, and on the specific pain (sub)domains recommended.

Fifty-one COS were retrieved, targeting 37 different RMDs. Seven (14%) focused on a specific intervention. None of the 14 COS assessed with COS-STAD met all the minimum quality standards (median = 6/11; interquartile range = 5-8). Thirty-seven COS (73%) proposed pain as a core outcome domain; in 25 COS it was just labelled 'pain', in 10 'pain intensity' was recommended, in 3 'pain frequency/temporal aspects of pain', and in other 3 'pain interference'.

Pain intensity measurement

AC reported results of an external group, published elsewhere (17, 18), regarding pain intensity measurement for LBP, as an example of issues to consider when deciding about measurement instruments for pain domains. This initiative recommended 'pain intensity' as a core outcome domain, comprising perspective from clinicians, researchers and patients (10). The three most common and frequently recommended measures [i.e. visual analogue scale (VAS), numeric rating scale (NRS), and pain severity subscale of the Brief Pain Inventory (BPI-PS)] were assessed in a systematic review (18). High-quality evidence was found only for the NRS measurement error, while the evidence on all other measurement properties was lower quality (17). In a subsequent Delphi, consensus (75%) was found on endorsing the NRS as a core outcome measure for pain intensity in LBP trials, with the emphasis (96%) on average intensity over the last week (18).

Discussion, Conclusion and Next Steps

Although it is clear that chronic pain is felt by patients as a considerable concern and a separate aspect of RMDs, a consensus on whether pain is understood as a symptom or a disease cannot be easily achieved in the rheumatology field (19). According to the ICD-11 classification, chronic pain is considered a separate health condition when meeting specific criteria (20). The pain academic community has already acknowledged pain as a symptom but also chronic pain as a complex condition with multiple components affecting all aspects of functioning. Hence, the experience of chronic pain in RMDs seems to be close to those of chronic pain from other origins, but more evidence on patients' view is still needed.

The existing number of COS recommendations in RMDs hampers the original idea of harmonizing chronic pain assessment by OMERACT. It rather seems to be helpful to consider existing work and support future advancements of existing initiatives. An important field of research is identified in the investigation of the measurement properties of existent pain scales. Two important questions arise from previous discussions about pain measures: 1) the validity of the pain construct; 2) the lacking evidence on measurement properties of commonly applied scales. The validity of the pain construct has been questioned in other fields, regarding aspects like pain (sub)domains and pain stages (worst, average etc.). This may explain why measurement properties lack sufficient evidence base.

During preparatory work and the last two OMERACT meetings, the pain working group has identified various subjects for research, three of which may represent the future work of the group:

1) Following the surveys' results, beyond pain domains, are there other items (e.g. fatigue, sleep) to be measured consistently in RMDs?
2) For pain intensity measurement in RMDs, the NRS may be a simple measure to assess and standardize across RMDs, however, more work on other pain (sub)domains is needed to better capture the construct multidimensionality.

3) The pain experience may (pathophysiologically) range from peripheral to central mechanisms, therefore, pain assessment must take this variability into account and address these individual patient differences.

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Tables and Figures

Table 1: Characteristics and results of an online survey in patients with RMDs

Table 2: Importance (Median, 0 not important, 10 of highest importance) of subdomains regarding the experience of chronic pain in patients with RMDs and patients from a previous IMMPACT online survey

Figure 1: Importance of subdomains regarding the experience of chronic pain in patients with RMDs and patients from a previous IMMPAT online survey

Table 1: Characteristics and results of an online survey in patients with RMDs

Total N=72	%	n
Whom or whose interests do you represent here?		
OMERACT SIG chronic pain	8.33	6
OMERACT other SIG	1.39	1
OMERACT patient research partner	31.94	23
Dragon Claw	13.89	10
UK self support groups	5.56	4
other	38.89	28
~~Other (please specify)~~	~~19,44~~	~~14~~
How long do have you been engaged in active patient participation?		
less than 1 year	16.67	12
1.5-3 years	23.61	17
3.5-5 years	9.72	7
5.5-7 years	11.11	8
7.5-9 years	13.89	10
more than 9 years	25.00	18
How long do have you been suffering from RMDs?		
less than 1 year	1.39	1
1.5-3 years	11.11	8
3.5-5 years	4.17	3
5.5-7 years	4.17	3
7.5-9 years	9.72	7
more than 9 years	69.44	50
How long do have you been suffering from chronic pain?		
less than 1 year	8.33	6
1.5-3 years	9.72	7
3.5-5 years	13.89	10
5.5-7 years	2.78	2
7.5-9 years	6.94	5
more than 9 years	58.33	42
As a patient. does chronic pain play a major role in your daily life?		
yes	84.06	58
no	14.49	10
I do not know	1.45	1
Is chronic pain a separate aspect of RMDs?		
yes	22.81	13
no	47.37	27
I do not know	29.82	17

Table 2: Importance (*0 not important, 10 of highest importance*) of subdomains regarding the experience of chronic pain in patients with RMDs and patients from a previous IMMPACT online survey

Domains of importance	**OMERACT PRPs**		**IMMPACT**	
Total number n		**72**		**959**
	Mean	SD	Mean	SD
falling asleep	7.3	2.79	7.8	2.78
staying asleep	8.0	2.41	8.3	2.45
sex life	6.5	2.75	6.6	3.49
taking care of children	7.2	2.81	7.1	3.36
relations with family…	7.7	2.29	7.7	2.75
relations with friends	7.3	2.10	7.2	2.76
Employment	7.4	2.72	7.6	3.25
household activities	7.2	2.19	7.9	2.36
planning activities	7.7	2.22	7.0	2.87
participating in family activities	7.5	2.12	7.7	2.67
participating in recreational and social activities	8.0	1.69	7.7	2.61
physical activities	7.9	1.97	8.4	2.33
hobbies	7.1	2.14	7.1	2.86
Enjoyment of life	8.1	2.10	8.8	2.05
emotional wellbeing	7.4	2.76	8.6	2.27
fatigue. feeling tired	8.3	2.15	8.8	2.01
weakness	6.6	2.70	8.3	2.42
difficulties concentrating	6.6	2.90	8.0	2.62
difficulties remembering things	5.7	3.30	7.6	3.06

Figure 1: Scores of importance (from 0 to 10) of subdomains regarding the experience of chronic pain in patients with RMDs and patients from a previous IMMPACT online survey.