Editorial

Concerns about the taxonomy, definition and coding of fibromyalgia syndrome in ICD-11: the potential for negative consequences for patient care and research

W. Häuser[1], D.J. Clauw[2], F. Wolfe[3], P. Sarzi-Puttini[4], J.N. Ablin[5], C. Usui[6], G.O. Littlejohn[7], B. Morlion[8], E. Kosek[9,10], E.A. Fors[11], K.M. Øien Forseth[12], M.-A. Fitzcharles[13,14]

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Winfried Häuser, MD
Daniel J. Clauw, MD
Frederick Wolfe, MD
Piercarlo Sarzi-Puttini, MD
Jacob N. Ablin, MD
Chie Usui, MD
Geoffrey O. Littlejohn, MD, FRACP
Bart Morlion, MD, PhD
Eva Kosek, MD, PhD
Egil A. Fors, MD
Karin M. Øien Forseth, MD
Mary-Ann Fitzcharles, MB, ChB

Please address correspondence to:
Winfried Häuser,
Internal Medicine 1,
Klinikum Saarbrücken,
66119 Saarbrücken, Germany.
E-mail:
whaeuser@klinikum-saarbruecken.de

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International Statistical Classification of Diseases and Related Health Problems (ICD) codes of the World Health Organisation (WHO) are currently used by about 27 countries worldwide, primarily for reimbursement and resource allocation, but have become an important source of health care services research. The current ICD-10 was replaced by ICD-11 on January 1, 2022. An important change introduced in the ICD-11 is the systematic classification of clinical conditions associated with chronic pain (1), as proposed by an interdisciplinary working group of the International Association of the Study of Pain (IASP) and the WHO (2, 3). Fibromyalgia syndrome (FMS) was relocated from its legacy ICD-10 chapter location (diseases of the musculoskeletal system and connective tissue) to the new category block in the chapter "Symptoms, signs or clinical findings, not elsewhere classified", as an inclusion term under Chronic primary pain > Chronic widespread pain (CWP). This working group did not discuss the new definition and classification of FMS in the ICD-11 with the boards of other medical associations (*e.g.* rheumatology) or FMS-patient organisations. As clinicians, researchers and guideline makers occupied with FMS, we offer critical comment on taxonomy, definition and coding of FMS according to the ICD-11 and the potential for negative consequences for patient care and research.

Taxonomy

FMS is no longer identified as a condition of the musculoskeletal system, contrary to current understanding in the literature (4). Remarkably, the body structures involved in CWP as listed in the IASP proposal of June 26, 2019, namely connective tissue, skeletal and/or smooth muscle structures (5) have been eliminated in the ICD-11. The IASP working group has not published any statement to provide clarification of why the initial proposal with which we agree has not been incorporated into the definition of CWP and FMS in ICD-11. The five body quadrants identified for pain location for CWP and FM include (upper left, upper right, lower left, lower right of the body) and axial (neck, back, chest and abdomen) (1-3). With the ICD-11 requirement that 4 of 5 body regions be painful in order to meet FMS criteria, primary headache and irritable bowel syndrome (IBS) pain could be attributed to FMS. Thus, the ICD-11 definition of FMS has transformed FMS to be a multisystem pain disorder. We acknowledge that many FMS-patients meet the criteria of other chronic pain syndromes such as irritable bowel syndrome or chronic tension headache (so-called overlapping pain conditions) (6). However, this statement similarly also applies to other chronic primary pain conditions (7). The consideration of potential comorbidities is important for the management of FMS (8). However, a "lumping" approach including different chronic pain syndromes such as FMS, IBS and chronic tension headache in one category is not appropriate because – besides common general treatment principles such as education and physical activity – specific pharmacological treatment options are recommended for each of these chronic

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primary pain syndromes and may differ according to the condition.

Chronic primary headaches are cross-referenced in this section making use of the "multiple parenting" option of ICD-11, which means that chronic migraine is listed in both the headache section and the chronic pain section (2). We suggest that "multiple parenting" should also be possible for FMS in ICD-11. We believe that FMS should receive a diagnostic code in the chapter "Diseases of the musculoskeletal system or connective tissue", too.

In addition, we suggest that FMS should be integrated in the subcategory "chronic primary musculoskeletal pain" as "chronic primary widespread musculoskeletal pain" (9) in accordance with the meaning and understanding of fibromyalgia (pain in muscles and tendons) and its current use in the literature (4).

Moreover, we suggest that pain sites in the head, face, and abdomen should be excluded in the definition of FM as outlined by the 2016 criteria (10).

Definition

Chronic primary pain is defined as a pain condition when "the symptoms are not better accounted for by another diagnosis". According to the ICD-11, the diagnosis of FMS is appropriate when the pain is not directly attributable to a nociceptive process in the body regions described above and the chronic pain condition has features consistent with nociplastic pain (1-3). This definition would fail to capture a large group of individuals whose primary pain mechanism is nociceptive but develop superimposed FMS/nociplastic pain, as occurs in up to a third of individuals with nociceptive pain conditions such as autoimmune disorders or osteoarthritis (11). We suggest that the definition of FMS should allow that nociceptive processes in some body regions might contribute to the pain experience (12).

Although we welcome a biopsychosocial taxonomic framework of chronic pain, we question that "significant emotional distress or functional disability" should be defining features of chronic primary and secondary pain conditions. Most people with chronic pain in population-based studies report low pain intensity and low disability (13). Studies with people meeting FMS criteria in primary care and population-based studies have shown that "significant emotional distress and disability" does not occur for all patients (14). Remarkably, the current version of the ICD-11 webpage offers additional codes for CWP including coding "no distress" and "no pain-related interference" (1). We suggest that an acceptable modification for the definition of CWP and FMS would be the qualifier that CWP is frequently associated with significant emotional distress or functional disability.

Coding

In the ICD-11, CWP and FMS are defined as diffuse pain in at least 4 of 5 body regions, associated with significant emotional distress and/or functional disability. FMS is further qualified to be associated with sleep disorders, cognitive dysfunction and somatic symptoms (1-3). In the ICD-11 for Mortality and Morbidity Statistics version 02/2022 (https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f849253504), the diagnostic code for CWP and FMS is the same: MG 30.01. The codes in the foundation layer of the WHO Family of International Classifications are different, namely 849253504 for CWP and 236601102 for FMS (https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f236601102). However, these two codes are not visible now in the ICD-11 for Mortality and Morbidity Statistics Version 02/2022 webpage. In addition, the use of the browser and coding tool of the WHO would provide the same code for CWP and FMS, namely MG30.01. We express our concerns that the lack of a unique code for FMS has the potential for negative consequences for patient care. There remain many health care providers claiming that FMS does not exist (15). Legitimacy of FMS as a disease was previously supported when the WHO assigned a unique diagnostic code in ICD-9 and ICD-10. Thus, ICD-11 is retrogressive compared to ICD-9 and ICD-10. In addition, the lack of a unique diagnostic code for FMS can compromise patient care and research. In countries, where ICD code use is obligatory, treatment reimbursement may be challenging. Finally, health care services with data of statutory health insurance companies in countries which require ICD-codes will no longer be possible.

We suggest that a unique diagnostic code be assigned to FMS which is different from that of CWP.

We understand that the final ICD-11 classification was a compromise within the IASP/WHO working group between divergent opinions regarding the elimination or retention of a diagnostic code for FMS (R.-D. Treede, personal communication). It is unfortunate that these imminent changes in the ICD-11 were not more widely discussed in the pain or rheumatology communities nor with FMS patient representatives. The WHO offers a webpage for comments on the ICD-11: https://icd.who.int/dev11. If the reader of this paper, patient organisations and medical associations share (some of) our concerns and suggestions, we urge that commentary could be made on this webpage. We hope that sufficient comment will prompt the IASP/WHO working group to modify the taxonomy, definition and coding of FMS in ICD-11.

Affiliations

[1]Department of Psychosomatic Medicine and Psychotherapy, Technische Universität, München, Germany;
[2]Chronic Pain and Fatigue Research Center, University of Michigan Medical School, Ann Arbor, USA;
[3]National Data Bank for Rheumatic Diseases, University of Kansas School of Medicine, Wichita, USA;
[4]Università degli Studi di Milano, Luigi Sacco University Hospital, Milan, Italy;
[5]Department of Internal Medicine H, Tel Aviv Sourasky Medical Center, Tel Aviv, Israel;
[6]Department of Psychiatry, Juntendo University Faculty of Medicine, Tokyo, Japan;
[7]Department of Medicine, Monash University and Dept. of Rheumatology, Monash Health, Melbourne, Australia;
[8]Leuven Centre for Algology and Pain Management, University Hospitals Leuven, KU Leuven, Belgium;

[9]Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden;
[10]Department of Surgical Science, Uppsala University, Uppsala, Sweden;
[11]Department of Public Health and Nursing, Faculty of Medicine and Health Sciences, Norwegian University of Science and Technology, Trondheim, Norway;
[12]Department of Rheumatology, Oslo University Hospital, Oslo, Sweden;
[13]Alan Edwards Pain Management Unit, McGill University Health Centre, Montreal, Canada;
[14]Division of Rheumatology, McGill University Health Centre, Montreal, Canada.

Competing interests

W. Häuser was the head of the steering committee of the German guidelines on FMS and member of the European League Against Rheumatism task force on revised recommendations for the management of FMS. He is a member of the medical board of the European Network of Fibromyalgia Associations and of the German Fibromyalgia Association*.

D. Clauw reports grants from Aptinyx, Daiichi Sankyo, Eli Lilly, Intec Pharma, and Pfizer; personal fees from Aptinyx, Nix Patterson, Pfizer, Samumed, Theravance, Tonix, Williams & Connolly, and Zynerba; has consulted for Aptinyx, Eli Lilly, Pfizer, Samumed, and Tonix and has received research funding from Aptinyx.

J.N. Ablin has given voluntary consulting and educational activities to the Israeli association of fibromyalgia and chronic fatigue patients*. He was the head of the steering committee of the Israeli guidelines on FMS.

P. Sarzi-Puttini is a member of the medical board of the Italian Fibromyalgia Syndrome Association* and member of the steering committee of the Italian Society for Rheumatology clinical practice guidelines for the diagnosis and management of fibromyalgia.

C. Usui is vice president of Japan College of Fibromyalgia Investigation and the head of the steering committee of the Japanese guidelines on FM.

B. Morlion has received honoraria for speaker's activities from Grünenthal, Lilly, Mundipharma, Pfizer, Krka, Ache, Sandoz, Shionogi and for consultancy activities from Grünenthal, Mundipharma, TEVA, GSK, Kyowa-Kirin, Pfizer, Lilly, Boston Scientific, Reckitt&Benckiser and Shionogi.

E. Kosek has received a research grant from FOREUM.

E. Fors is a member of the medical advisory board of the Norwegian Fibromyalgia Association*.

K.M. Øien Forseth is a member of the medical board of the European Network of fibromyalgia Associations*.

M.-A. Fitzcharles was the head of the steering committee of the Canadian guideline on FMS.

*The commentary has not been mandated by the FMS self-help organisations.

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