Abstract

This paper describes a proposal for the new diagnosis of chronic primary pain (CPP) in ICD-11. CPP is chosen when pain has persisted for more than 3 months and is associated with significant emotional distress and/or functional disability, and the pain is not better accounted for by another condition. As with all pain, the paper assumes a biopsychosocial framework for understanding CPP, which means all subtypes of the diagnosis are considered to be multifactorial in nature, with biological, psychological and social factors contributing to each. Unlike the perspectives found in DSM-5 and ICD-10, the diagnosis of CPP is considered to be appropriate independently of identified biological or psychological contributors, unless another diagnosis would better account for the presenting symptoms. Such other diagnoses are called ‘chronic secondary pain’ where pain may at least initially be conceived as a symptom secondary to an underlying disease. The goal here is to create a classification that is useful in both primary care and specialized pain management settings for the development of individualized management plans, and to assist both clinicians and researchers by providing a more accurate description of each diagnostic category.

Keywords: ICD-11; Classification; Chronic Pain; Chronic Primary Pain; CRPS; CWP; Fibromyalgia; Headache; Orofacial Pain; Visceral Pain; Musculoskeletal Pain; Idiopathic Pain; Functional Pain

1. Background on chronic primary pain

There are two main diagnostic classification systems used internationally for chronic pain, apart from headaches: the *Diagnostic and Statistical Manual* (DSM) published by the *American Psychiatric Association* (APA), and the *International Classification of Diseases* (ICD) published by the *World Health Organization* (WHO). However, both have been found wanting in their accounts of chronic pain conditions. In particular, neither system reflects the developments in pain research over the last two decades, and they do not have clear treatment or management implications.10,15,16,38,61 To illustrate, ICD-10 refers to pain attributable exclusively to an underlying pathophysiological mechanism.19 In the absence of a clear (pathophysiological) etiology, and when both biological, psychological and social factors appear to be contributing to a chronic pain presentation,15 ICD-10 offers only the option of ‘somatoform pain disorder’. However, this classification cannot be used when pathophysiological factors are also considered to be contributing to the pain problem.39

These distinctions have important treatment implications. As Taylor and colleagues pointed out, if we accept that chronic pain is a disease or a long-term condition, ‘*then the philosophy of care may change from a biomedical model that views chronic pain as a symptom to that of a biopsychosocial one that views chronic pain as a disease or long-term condition ‘* (p. 1948).53 In an attempt to address the problems with the representation of chronic pain in ICD, the German adaptation of ICD-10 (ICD-10 GM) introduced the concept of ‘*chronic pain disorder with somatic and psychological factors*’.18 It was an important step to acknowledge equal contributions of somatic and psychological factors and the concept seems well accepted. However, not only is this diagnosis limited to German-language countries, it still rests in the psychiatric section of the classification. Conceptually and clinically, it appears overly broad: it can be applied to most chronic pain conditions and fails to recognize subtypes. In this paper, the suggested concept of chronic primary pain overcomes these limitations by providing a clear definition unencumbered by inappropriate classification within psychiatric disorders, and it allows for subtypes. The challenge to conceptualize chronic pain as a long-term condition has been accentuated by advances in the understanding of psychological, social, and central nervous system mechanisms that may account for many hitherto inexplicable pain phenomena.60,61 These developments have meant that attempts to classify chronic pain presentations need to acknowledge the likelihood of multiple interacting contributors to a chronic pain presentation. The alternative of pain being either ‘somatic’ or ‘psychogenic’ has become obsolete in several ways. Psychological factors such as learning and coping play a role in chronic pain that was previously considered ‘somatic’, e.g. chronic osteoarthritis (now classified as one of the ‘chronic secondary pain syndromes’). Vice versa, biological changes are closely linked to psychological processes; this is most obvious in neurophysiological brain reactions contributing to changes in pain perception. As will become apparent, these developments are acknowledged by the new diagnostic entity of chronic primary pain. The new entity will also provide a framework to unite conditions that have hitherto been scattered throughout the ICD and help to focus on their commonalities and differences.

2. The need for a classification

To overcome the shortcomings identified in previous and current versions of both DSM and ICD, this paper proposes for ICD-11 the new diagnosis of *chronic primary pain* that would be appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms. The goal was to create a classification that would be useful in both primary care and in specialized pain management settings. It is also proposed that as much as possible the classification of pain conditions should be cast in ‘positive’ terms, using ’observable‘ concepts, and that diagnosis ‘by exclusion‘ should be avoided.56

3. The IASP task force ICD initiative

In order to remedy the lack of accurate classification of chronic pain in general and chronic pain where disease-oriented pain diagnoses are not appropriate, the *International Association for the Study of Pain* (IASP) established a Task Force that worked in close co-operation with WHO representatives in generating a systematic and improved classification of chronic pain.56 The classification is dedicated exclusively to chronic pain syndromes and excludes acute pain. The task force subchapter on chronic primary pain was steered by the first two authors.

Chronic pain was defined as pain that lasts or recurs for longer than three months.55 This definition was chosen because it provides a clear operationalization that is in line with widely used criteria in other fields of medicine. A code for the severity of the chronic pain syndrome was added, which records the intensity of the pain, the emotional distress and the interference in daily activities due to pain. To assist with the specification of the severity of the pain, the use of numerical rating scales categorizing its 3 dimensions is recommended.55 Each dimension can be rated on a 0-10 scale (where 0 = nil and 10 = extreme) which can then be categorized to yield a code (0-3)for each dimension (where 0 = absent; 1-3/10 = 1 or mild; 4-6/10 = 2 or moderate; and 7-10/10 = 3 or severe). This will allow a case to be given a code of 0-3 for each dimension. The use of these codes is illustrated in the case vignettes accompanying the text. ICD-11 will be coordinated with the International Code of Functioning (ICF) that will provide additional features of activities and participation.32

The classification presented here is integrated with the ‘frozen version’ of ICD-11, published by WHO on June 18, 2018. A previous version had undergone field testing by WHO for line coding and case coding in 2017, via the IASP website.

4. Classification of chronic primary pain

Many chronic pain conditions have an obscure etiology and pathophysiology, but they are characterized by a complex interplay of biological, psychological and social factors.15 Currently, these conditions are covered by labels such as chronic widespread pain, fibromyalgia, Complex Regional Pain Syndrome, type I (CRPS1), Temporomandibular Disorder (TMD), irritable bowel syndrome (IBS), and most back pain and neck pain conditions, which invariably include vague and ambiguous terms such as ‘non-specific’, ‘somatoform’, or ‘functional’. The term ‘chronic primary pain’ was chosen after extensive consultation with the ICD-11 revision committee and is expected to have widespread acceptability, especially from a non-specialist perspective.

The definition of the new diagnosis of chronic primary pain is intended to be agnostic with regard to etiology; in particular, it aims to avoid the obsolete dichotomy of ‘physical’ versus ‘psychological’,28 as well as exclusionary terms that define something by what is absent, such as ‘non-specific’. The meaning of ‘functional’ is also ambiguous. Some take it to mean ‘all in the mind’ and others as a ‘disorder of function’.54

The introduction of ‘Chronic Primary Pain’ eliminates this ambiguity. Chronic primary pain is defined as pain in one or more anatomic regions that

* persists or recurs for longer than 3 months
* is associated with significant emotional distress (e.g. anxiety, anger, frustration, or depressed mood) and/or significant functional disability (interference in activities of daily life and participation in social roles),
* and the symptoms are not better accounted for by another diagnosis.

In other words, the experience of chronic pain should be sufficiently concerning for the person to seek help for it. As in all conditions, before a diagnosis is made, it has to be ascertained whether another diagnosis better accounts for the chronic pain presentation, in which case, the diagnoses are the chronic “secondary” pain syndromes described in the companion papers: chronic cancer pain,4 chronic postsurgical or posttraumatic pain,45 chronic neuropathic pain,44 chronic secondary headache or orofacial pain,5 chronic secondary visceral pain2 and chronic secondary musculoskeletal pain.35

4.1 The general structure of the classification of chronic primary pain

Chronic primary pain can occur in any body system(e.g. nervous, musculoskeletal, gastro-intestinal systems), and in any body site(face, low back, neck, upper limb, thorax, abdominal, pelvis, urogenital region), or in a combination of body sites (e.g. widespread pain). This is mirrored by the general structure of the classification. Sub-types of chronic primary pain and their codes are listed in Figure 1. A complete overview of all chronic primary pain conditions as implemented in the ICD-11 foundation layer is provided in the supplementary material accompanying this paper.

In the ‘frozen linearization’ of ICD-11, chronic primary pain has the diagnostic code MG30.0. If it is clear that the patient had primary pain, but not which subtype, s/he will receive the code for “Chronic primary pain unspecified” (MG30.0Z). We expect that the subtypes are more informative and will often be identified easily.

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Insert Figure 1 about here

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4.2. The diagnostic codes in the classification of chronic primary pain

All codes share the characteristics of chronic primary pain explained above. Specifically, it is chronic pain in one or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional distress and/or significant functional disability. The emotional distress can take many forms, such as demoralization, depressed mood, anxiety, anger or frustration. Functional disability also covers a wide range of interference in daily life, such as difficulties working, sleeping, or taking part in social activities. In addition to these common features, the individual types of chronic primary pain have unique characteristics that distinguish one particular diagnosis from another

4.2.1 Chronic widespread pain (CWP)

Chronic widespread pain is diffuse musculoskeletal pain in at least 4 of 5 body regions and in at least 3 or more body quadrants (as defined by upper-lower/left-right side of the body) and axial skeleton (neck, back, chest and abdomen).9 CWP is characterized by the core features of chronic primary pain, such as pain persisting for at least 3 months, and associated with significant emotional distress or functional disability. The diagnosis is appropriate if the pain is not directly attributable to a nociceptive process in these regions, and if there are features consistent with nociplastic pain,26 such as spontaneous or evoked pain in the affected regions, accompanied by allodynia and/or hyperalgesia and identified psychological and social contributors. CWP is often associated with increased medical comorbidity, including sleep disturbances, obesity, hypertension, and diabetes.31

4.2.1.1 Fibromyalgia syndrome (FMS)

Fibromyalgia syndrome (FMS) is a form of chronic widespread pain, which is defined as pain in at least 4 of 5 body regions (in at least 3 or 4 body quadrants), and is associated with sleep disorders, cognitive dysfunction and somatic symptoms. The symptoms have been present at a similar level for at least 3 months, and are not better accounted for by another diagnosis. Definitions of FMS have been repeatedly revised since it was first recognized as a rheumatic disease by WHO in 1992. Some authorities prefer to reserve the term FMS for the more severe presentations of the spectrum encompassed in CWP/FMS, but this approach reflects a quantitative rather than a qualitative distinction that depends on criteria that have yet to be validated.20,42 For a case vignette featuring a patient with FMS see Box 1.

4.2.2 Complex regional pain syndrome (CRPS)

Complex regional pain syndrome is a type of chronic primary pain characterized by pain in a regional distribution, that usually starts distally in an extremity after trauma and that is disproportionate in magnitude or duration to the typical course (of pain) after similar tissue trauma.6,8,23 The pain is spontaneous, but can typically also be evoked. CRPS is further characterized by signs indicating autonomic and inflammatory changes in the affected body region that may vary between patients and over time.6 Patients can present with hyperalgesia, allodynia, skin color and temperature changes, sweating, edema, altered hair and nail growth, dystrophic skin, reduced strength, tremors and dystonia in the affected limb, and focal osteoporosis.21 Some of these changes may be related to nociplastic mechanisms,26 and they may change over time. At a late stage, some patients present with muscle atrophy, and joint and tendon retraction. (See Box 2 for a case vignette.) Two subtypes of CRPS have been delineated: type 1 and type 2. Both can occur after trauma, but in CRPS type 1 there is no peripheral nerve injury, while evidence of peripheral nerve injury is required for CRPS type 2.49 While neuropathic mechanisms are commonly thought to be associated with CRPS type 2,45 and nociplastic mechanisms are thought to be associated with CRPS type 1,26 recent studies have cast doubt on the degree of difference between the two types of CRPS once established.33 The definition of CRPS is part of the ICD-11 chapter on Disorders of the autonomic nervous system and crosslinked to chronic primary pain.

4.2.3 Chronic primary headache or orofacial pain

Chronic primary headache or orofacial pain is defined as headache or orofacial pain that occurs on at least 15 days per month for longer than three months. The duration of pain per day is at least 4 hours5 (untreated) or several shorter attacks per day may occur.34,43 Other chronic headache or orofacial pain diagnoses to be considered are listed under chronic secondary headache and orofacial pain. For most purposes, patients receive a diagnosis according to the phenotypes of headache or orofacial pain with which they currently present or with which they have presented within the last year. Each distinct type, subtype or subform of headache or orofacial pain within one patient must be separately diagnosed and coded. When a patient receives more than one diagnosis, these should be listed in the order of importance to the patient.17,22,46 There are several subtypes of chronic primary headache or orofacial pain.

4.2.3.1 Chronic temporomandibular disorder (TMD)

Chronic temporomandibular disorder (TMD) pain is one of the most common chronic facial pain syndromes, and includes pain affecting the temporomandibular joints (TMJ) and masticatory muscles and associated tissues. TMD is defined as chronic orofacial pain that occurs for at least 2 hours per day on at least 50% of the days over at least three months. There are at least two distinct phenotypes: pain in the masticatory muscles termed myofascial TMD pain, and pain in the temporomandibular joint or associated tissues termed TMJ arthralgia. (See Box 3 for a case vignette.) There are also forms of chronic secondary TMD.5

4.2.3.2 Chronic migraine

Chronic migraine is defined as headache occurring on 15 or more days/month for more than 3 months, which, on at least 8 days/month, has the features of migraine headache. Migraine is a recurrent headache disorder manifesting in attacks lasting 4-72 hours. Typical characteristics of the headache are unilateral location, pulsating quality, moderate or severe intensity, aggravation by routine physical activity and an association with nausea and/or photophobia and phonophobia. 17,22,46

4.2.3.3 Chronic tension-type headache

Chronic tension-type headache is a frequent episodic headache, which occurs for at least 2 hours per day on 15 or more days per month for more than 3 months. Typically, they are bilateral, pressing or tightening in quality and of mild to moderate intensity, lasting hours to days, but can be unremitting. The pain does not worsen with routine physical activity, but may be associated with mild nausea, photophobia or phonophobia.17,22,46

4.2.3.4 Trigeminal autonomic cephalalgias (TACs)

Trigeminal autonomic cephalalgias (TACs) share the clinical features of unilateral headache and, usually, prominent cranial parasympathetic autonomic features (e.g. lacrimation, rhinorrhoea, nasal congestion, and eyelid oedema), which are ipsilateral to the headache. Diagnostic labels commonly used for TACs include cluster headache, paroxysmal hemicrania, short-lasting unilateral neuralgiform headache attacks, and hemicrania continua. These are considered Chronic TACs if the TAC attacks persist for one year or longer without remission, or with remission periods lasting less than 3 months.17,22,46

4.2.3.5 Chronic burning mouth pain

Chronic burning mouth pain is chronic orofacial pain characterized by intraoral burning or dysaesthetic sensation that recurs for more than two hours per day on 50 % of the days over more than three months, without evident causative lesions on clinical investigation and examination. Chronic primary burning mouth pain should be distinguished from secondary burning mouth syndrome attributed to diagnoses such as candidiasis or vitamin B12 deficiency. Two separate phenotypes have been described: with and without somatosensory disturbances.17,22,46

4.2.4 Chronic primary visceral pain

Chronic primary visceral pain is chronic primary pain localized in the head or neck, thoracic, abdominal or pelvic region. Of note, it represents one of the major categories of internal medicine. The respective anatomical location is compatible with typical referral pain patterns from specific internal organs. Chronic primary visceral pain includes pain in the head/neck viscera of the digestive system (e.g. burning mouth syndrome); in the thoracic region (e.g., non-cardiac chest pain, reflux hypersensitivity); in the abdominal region arising from viscera of the digestive system (e.g., epigastric pain syndrome, irritable bowel syndrome, centrally mediated abdominal pain syndrome, biliary dyskinesia) and in the pelvic region due to involvement of the viscera of the digestive, urinary and genital systems (e.g., bladder pain syndrome, anal spasm, chronic pelvic pain, chronic testicular pain).3,13,24,25,27,50,58 Several diagnoses that prior to this new classification were termed ’functional‘ are to be subsumed under chronic primary visceral pain and have been renamed.54 There are several subtypes of chronic primary visceral pain. These are described next.

4.2.4.1 Irritable bowel syndrome (IBS)

Irritable bowel syndrome (IBS) is one of the most frequent chronic primary abdominal pain conditions. IBS is a bowel disorder in which recurrent abdominal pain occurs on average for at least 1 day / week in the last 3 months and is associated with two or more of the following: i) related to defecation; ii) associated with change in frequency of stool; iii) associated with a change in form (appearance) of stool. Criteria should be fulfilled for the last 3 months with symptom onset 6 months before diagnosis. IBS subtypes may include IBS with predominant constipation or diarrhea; IBS with mixed bowel habits; and IBS unspecified.29

4.2.4.2 Chronic primary chest pain syndrome

Chronic primary chest pain syndrome is recurrent primary retrosternal pain. Its anatomical location is compatible with typical referral pain patterns from esophageal origin. The pain must be present for 3 months with a symptom onset at least 6 months before the diagnosis with a frequency of at least once a week. Other esophageal symptoms such as heart burn and dysphagia must be absent. The symptoms are not better explained by reflux disease, other mucosal (e.g. eosinophilia esophagitis) or motor processes (e.g. achalasia, Jack Hammer esophagus, diffuse esophageal spasm), cardiac causes, heartburn, dysphagia or a diagnosis of chronic secondary visceral pain.1 The pain is perceived in the somatic tissues of the chest wall (skin, subcutis, muscle) in areas that receive the same sensory innervation as the esophagus (referred visceral pain) and can sometimes radiate to the arm and jaw much like angina. In these areas, secondary hyperalgesia (increased sensitivity to noxious stimuli in areas other than the primary site of the nociceptive input) may occur.41,59 The term ‘non-cardiac’ chest pain has been used to explain the symptoms,14 but this is inappropriate as it is describing the pain by an absence. In these areas, secondary hyperalgesia (increased sensitivity to noxious stimuli in areas other than the primary site of the nociceptive input) often occurs.41,59 (See Box 4 for a case vignette illustrating the diagnosis.)

4.2.4.3 Chronic primary epigastric pain syndrome

Chronic primary epigastric pain syndromeis chronic primary pain localized in the epigastric region. The distinct anatomical location is compatible with typical referral pain patterns from specific internal organs. Consistent with the ROME IV criteria, it is characterized by epigastric pain or burning that does not occur exclusively after meals, but can occur even during fasting, or even be improved after a meal. It may overlap with postprandial distress syndrome (PDS), which is associated with meal-induced dyspeptic symptoms.48 Bothersome epigastric pain and/or burning that is severe enough to impact on usual activities must be present for at least 1 day per week over the last 3 months with symptom onset at least 6 months before diagnosis. The pain may be perceived in the somatic tissues of the abdominal wall (skin, subcutis, muscle) in areas that receive the same sensory innervation as the small or large bowel (referred visceral pain). As with other chronic primary pain diagnoses, the diagnosis of Chronic primary epigastric pain syndrome should be used unless another diagnosis would better account for the presenting symptoms and findings from investigations such as upper gastrointestinal endoscopy.11,48 Postprandial epigastric bloating, belching, and nausea can also be present, but pain from biliary causes should be excluded. Presence of persistent vomiting should prompt the search for another disorder. Other digestive symptoms such as from gastro esophageal reflux disease and irritable bowel syndrome may coexist with chronic primary epigastric pain.

4.2.4.4 Chronic primary abdominal pain syndrome

Chronic primary abdominal pain is chronic primary pain localized in the abdominal region and associated with significant emotional distress and/or functional disability. The pain is usually continuous with no or only occasional associations with physiological events (e.g. eating, defecation, or menses). Its anatomical location is compatible with typical referral pain patterns from specific internal organs but the symptoms are not better explained by a diagnosis of chronic secondary abdominal pain. Chronic primary abdominal pain disorders may be associated with pathologies that have arisen secondary to changes in the control mechanisms of an organ or system and may be associated with neurobiological, physiological and sometimes anatomical changes in the central nervous system.2,7,11,30,48

4.2.4.5 Chronic primary bladder pain syndrome

Chronic primary bladder pain syndrome is chronic primary pain perceived in the region of the urinary bladder that is also associated with at least one other symptom, such as worsening of the pain upon bladder filling and urinary frequency during day-time and/or night time. The symptoms are not better explained by infection or any diagnosis of chronic secondary visceral pain. The presence of sexual dysfunction or dysfunction of the lower urinary tract should be considered.12,23 Specific types of inflammation may be present in subsets of patients, and need to be excluded. Other terms previously used include ‘interstitial cystitis’, ‘painful bladder syndrome’, and ‘PBS/IC’ or ‘BPS/IC’, but these are no longer recommended.12,23

4.2.4.6 Chronic primary pelvic pain syndrome

Chronic primary pelvic pain syndrome is chronic primary pain localized in the pelvic region. The anatomical location is compatible with typical referral pain patterns from specific internal organs of the pelvic area. The symptoms are not better explained by one of the other possible chronic visceral pelvic pain diagnoses: chronic visceral pelvic pain from persistent inflammation, chronic visceral pelvic pain from vascular mechanisms, chronic visceral pelvic pain from mechanical factors. Chronic primary pelvic pain includes pain in the pelvic region of the digestive, and urogenital systems.3,24,36,50,58

4.2.5 Chronic primary musculoskeletal pain (other than orofacial)

Chronic primary musculoskeletal pain is chronic primary pain located in the muscles, bones, joints or tendons. A typical example is chronic primary low back pain. (See Box 5 for a case vignette.) Chronic primary musculoskeletal pain syndromes are distinguished according to location: upper *(Chronic primary cervical pain),* middle *(Chronic primary thoracic pain)*, lower back (*Chronic primary low back pain*), and limbs (*Chronic primary limb pain)*. Patients may present with spontaneous or evoked pain in the affected region, accompanied by allodynia and/or hyperalgesia. Here the conditions that were formerly named ‘non-specific’ musculoskeletal pain are classified.

5. Discussion

Chronic primary pain is a new diagnosis in the ICD-11 classification for chronic pain that is intended to embrace a number of poorly understood conditions while avoiding obscure and potentially pejorative terms such as ‘somatoform’, ‘non-specific’ or ‘functional’. Chronic primary pain syndromes can be conceived as health conditions in their own right, while in the other six groups of chronic pain conditions (chronic secondary pain syndromes) pain may be considered a symptom of some other underlying diseases.55 The distinction between ‘primary’ and ‘secondary’ has been transferred from the headache classification. It avoids designating the basis of the pain as ‘psychological’ or ‘organic’ since chronic pain necessarily includes psychological and social dimensions in addition to the physiological components.60

Recently, in addition to nociceptive and neuropathic mechanisms, the concept of ‘nociplastic’ was introduced as a third neurophysiological mechanism underpinning some chronic pain conditions.26 It has been suggested that it may be particularly applicable to chronic primary pain. However, at this stage the relationship of nociplastic pain mechanisms and chronic primary or secondary pain syndromes cannot be determined. Further research is needed to define and understand what is meant with this new descriptor. However, it should be noted that it does require clinical and psychophysical findings suggestive of altered nociceptive function and that it does not apply to patients reporting pain without hypersensitivity.

Like the other diagnoses proposed for ICD-11, chronic primary pain can be combined with optional specifiers, such as the presence of psychological and social factors and pain severity (combined ratings for pain intensity, distress and disability). The severity ratings can be coded, and it is hoped that their dimensional nature will facilitate not only clinical communication but also interpretation of research findings. By means of these specifiers, clinicians and researchers will be able to determine whether their samples are similar to those participating in other studies that use these codes. For example, instead of describing a sample of patients as having low back pain, researchers using ICD-11 will also be able to distinguish levels of severity (mild, moderate, severe) that help guide treatment (or no treatment). These codes also provide clinicians in both primary care and more specialized facilities with a simple means for evaluating changes over time in their chronic pain patients.

Naturally, the new classification of chronic pain will have to be shown to be reliable and clinically useful. The next step in the development of ICD-11 will be to encourage field trials in order to establish the psychometric properties of these codes and their utility. A pilot field trial in four countries yielded chronic primary pain and chronic secondary musculoskeletal pain as the two most frequent diagnostic group, which were clearly distinguishable by both pain specialists and primary care physicians.47 Since the categories are more descriptive than former distinctions between ‘psychological and somatic’ pain conditions, we expect that future evaluations will confirm higher retest reliability and inter-rater reliability compared to the previous approaches of classification.

The proposal in this paper is that all chronic pain diagnoses should be presented in ICD-11 as a coherent category of diagnoses and not be divided up artificially as is the case in ICD-10. This confers a number of advantages, including when the categories are used for the worldwide collection of data for health statistics. For these statistics, different levels of granularity can be chosen. Chronic pain may be divided into primary vs six subtypes of secondary pain syndromes (level 1 in Figure 1), or any of these top level chronic pain diagnoses is subdivided into one of their level 2 diagnoses (Figure 1 here and in companion papers). WHO plans for member states to report their health statistic from 2022 onwards using level 1 and 2. We expect that this will be a useful level of aggregation in that it provides a category for pain conditions that have hitherto been counted in less useful ways by being dispersed throughout the ICD. This represents chronic pain in health statistics, which influence health policies and allocation of resources for prevention, treatment and rehabilitation as well as research.

The new ICD-11 chronic primary pain classification is also expected to enhance pain management outcomes, in that it allows inferences about unknown aspects of an individual who has been assigned a specific pain category.40 Multimodal pain management is regarded as the most helpful for chronic pain. How many ‘variants’ of multimodal pain management will be needed in the future is an important research issue. It applies to both primary and secondary pain syndromes. It is expected that the diagnoses of the new classification may be helpful in carrying out this research program by offering a more helpful grouping of the diagnoses. Indeed, given a pain (sub)category, clinicians and researchers can infer likely causes of symptoms, predict most likely consequences, estimate a timeline, the most likely future developments, and optimize treatment plans for that individual. In the case of CPP in particular, the identification of physiological, psychological, and social contributors to pain is specifically encouraged and this opens the way for multimodal interventions that can address these factors and potentially enhance treatment outcomes. The German experience with the national variant code F45.41 (pain with somatic and psychological factors) suggests that few big chronic pain diagnoses are more useful to guide treatment and its funding than the numerous more specific ones scattered throughout ICD-10.39

6. Summary and conclusion

By including a distinct chronic primary pain syndrome classification within the ICD-11 it is hoped to avoid the problems associated with previous classifications of chronic pain when the etiology is unclear but the emotional distress and functional disability associated with such pain are very evident, as the Global Burden of Disease project has reported.57 The availability of six classes of chronic secondary pain syndromes in the same classification will facilitate the distinction of pain as a disease or long-term condition from pain as a symptom,53 as already demonstrated in a pilot field trial. This classification has clear treatment and management implications: a multimodal approach that addresses the contributing psychological, social and biological contributors is expected to lead to better outcomes for patients with chronic primary pain diagnoses of at least moderate severity, relative to unimodal interventions alone. In chronic secondary pain syndromes, there will be additional disease-specific treatment options to be considered as well. In addition, the representation of chronic primary pain in health statistics is expected to advance public policy and research.

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Figure Legends

Figure 1. The general structure of the classification of primary pain

Level 1 and 2 are part of the 2018 frozen version of ICD-11; level 3 has been entered into the foundation layer. According to the new concept of multiple parenting in ICD-11, an entity may belong to more than one group of diagnoses.

Boxes: Case vignettes

Box 1: Fibromyalgia

A 35-year old woman reports persisting pain in multiple sites, including her shoulders, lower back, upper and lower limbs. The pain developed gradually about 2 years ago without any obvious causal event. Her hands sometimes feel tight, but she hasn't noticed any swelling. The pain is present most of the time but varies in severity and some days are worse than others, especially after a day at work. She reports having trouble concentrating and this, combined with feeling generally fatigued, is affecting the quality of her work. Due to her pain she has not been able to perform her duties at work as a hair dresser and fears losing her job. Her sleep is often interrupted by her pain and she usually wakes up unrefreshed. She also reports sweating at night, and occasionally feels a tingling sensation in her limbs. At times she feels dizzy, and she wonders whether this could be caused her low blood pressure that is being treated by her doctor. She has no rashes, weight loss, nor cough. She feels that she lacks the energy to do the simplest task at home, and when she pushes herself to do things her pain usually gets worse that evening and into the next day, to which she responds by resting more. She feels depressed most days, and wishes that she could sleep all the time. She reports she is struggling to care for her two small children, and she feels guilty about this. She is also more reliant on her husband to help with the chores at home. Her severity code is 333, with pain intensity estimated at 7/10 (code = 3, severe); pain-related distress at 8/10 (code = 3, severe); and pain-related disability at 7/10 (code = 3, severe).

Box 2: CRPS type I

Petra is a 45-year-old married woman who reports persisting pain in her lower right leg and foot since an an ankle sprain 6 years ago. Examination by an orthopaedic surgeon indicated that surgery was not required and a conservative rehabilitation approach was recommended instead. She started to use crutches and avoided touching the ground with her right foot when walking. She also noticed swelling in her foot and reported it often felt hot and sweaty. When sitting, she usually places her leg horizontally to prevent edema. A combination of severe pain, inability to wear socks/shoes on the affected foot due to heightened sensitivity to pressure, and difficulties in walking and standing, made it impossible to keep her job in a grocery store. She has been unable to work for over 5 years. Three years ago, she spontaneously developed unpleasant sensations in her (non-dominant) left arm and these have persisted on and off ever since. Petra relates these to her use of the crutches, and her physical therapist recommended she use a brace and avoid heavy lifting with that arm. Since then, she has used a wheelchair for longer distances outside her home. Over the years, Petra has used a range of medications for her pain, TENS, as well as nerve blocks and intravenous medication. None of these have helped so far and her pain and other symptoms persist. She is very concerned about her future, but feels hopeful that the pain clinic could help. Her severity code is 323, with pain intensity estimated at 7/10 (code = 3, severe); pain-related distress at 6/10 (code = 2, moderate); and pain-related disability at 8/10 (code = 3, severe).

Box 3: Chronic temporomandibular disorder

This 24 year old male reports a history of over 2 years of persisting bilateral jaw pain, often associated with the sound of clicking in the jaws when eating, and restricted ability to fully open his mouth. The pain varies in intensity, and is usually aggravated by chewing when he describes it as a sharp pain. As a result, he has become socially withdrawn in order to avoid aggravating his pain when out at restaurants with friends. He is increasingly concerned about the pain and its impact on his life. He still works in an office full-time, but says the pain can affect his concentration at times. He describes the pain as like a deep ache and locates it in the general area of the masseter muscles and extending towards the temporalis muscles on both sides. Palpation of the jaw muscles aggravates his pain. Dental examination reveals no major problems but there is evidence of poor oral health due to restricted ability to clean his teeth (due to the limitations in mouth opening). His dentist has tried to get him to use an oral splint at night but he finds this uncomfortable and not helpful. A combination of ibuprofen and benzodiazepine has also been tried, but with limited effect and the patient is concerned about their long-term use. A trial with a tricyclic antidepressant (25mg) helped his sleep, but the side effect of a dry mouth was uncomfortable and he ceased this agent as a result. His severity code is 222 with pain intensity estimated at 5/10 (code = 2, moderate); pain-related distress at 6/10 (code = 2, moderate); and pain-related disability at 3/10 (code = 1,mild ).

Box 4: Chronic primary chest pain syndrome

This 38-year-old man, working as a carpenter, is referred by his cardiologist for non-cardiac chest pain. The patient has a high BMI and reports that over the past 7 months, he has experienced a combination of chest pain and pressure while at rest several times per week. His chest pain is associated with shortness of breath. He reports that severe pain often wakes him at night, and he reports feeling very anxious and even on the verge of panic at these times, making it hard to return to sleep. As a result of increased fatigue and anxiety, he has been on sick leave for the last 3 months, but the rest doesn’t seem to be helping. Over the past 2 years he has reported experiencing occasional heartburn and regurgitation, usually after eating a large meal. During one severe episode of chest pain, the patient presented to the emergency department at his local hospital worrying that he was having a heart attack. Investigations at the hospital, including ECG and an exercise test revealed no abnormalities. The patient was started on (PPI) medication twice per day for 3 months to reduce the amount of acid in his stomach. After a few days, his chest pain and heartburn largely resolved. He also undertook a supervised exercise program, a change of diet and a general activity upgrading program. His weight is coming down gradually and he was able to cease the PPI without recurrence of chest pain. His severity code was 232, with pain intensity estimated at 6/10 (code = 2, moderate); pain-related distress at 8/10 (code = 3, severe); and pain-related disability at 6/10 (code = 2, moderate).

Box 5: Chronic primary low back pain

A 26-year old woman reported persisting low back pain since a fall from a short ladder at work 9 months ago. Initial radiography showed no abnormalities, though a CT scan subsequently revealed moderate posterior disc bulging at L4/5, but no apparent compression of neural structures. Neurological examination failed to show any neurological abnormality. Heat treatment and manipulation over several months, and a combination of compound analgesics and anti-inflammatory medication has provided only brief relief of the pain. The pain is almost constantly present, pinching in nature, fluctuating in severity. The pain is aggravated by physical activitiy and reduced by resting. She has been off work since her accident and is unable to perform most normal household chores. Her mood is depressed and associated with feelings of uselessness and frustration. The pain disturbs her sleep at night. The patient walks with her shoulders stooped and she is unable to touch her toes. She reports tenderness in her lumbar spine (L3/4). All back movements, rotation, flexion/extension appear reduced and are accompanied by grimaces and reports of increased pain. There is no evidence of muscle wasting and no sensory loss is detected. Her severity code is 333, with pain intensity estimated at 7/10 (code = 3, severe); pain-related distress at 8/10 (code = 3, severe); and pain-related disability at 7/10 (code = 3, severe).