

11th revision of the International Classification of Diseases chronic primary pain diagnoses in children and adolescents: representation of pediatric patients in the new classification system

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Abstract

Chronic pain is common among children and adolescents; however, the diagnoses in the newly developed 11th revision of the International Classification of Diseases (ICD-11) chronic pain chapter are based on adult criteria, overlooking pediatric neurodevelopmental differences. The chronic pain diagnoses have demonstrated good clinical applicability in adults, but to date, no field study has examined these diagnoses to the most specific diagnostic level in a pediatric sample. The current study aimed to explore pediatric representation within the ICD-11, with focus on chronic primary pain. Healthcare professionals (HCPs) at a specialized pediatric pain center documented the symptoms of and assigned both ICD-10 and ICD-11 diagnoses to N = 402 patients. Using criteria-based computer algorithms, specific ICD-11 pain diagnoses were allocated for each documented pain location, with residual diagnoses (ie, “unspecified”) assigned if criteria were not (fully) met. Within the ICD-11, the algorithms assigned specific pain diagnoses to most patients (73.6%). In ICD-10, HCPs could not specify a diagnosis for 5.2% of patients; the ICD-11 algorithm allocated a residual chronic primary pain diagnosis in 51.2%. Residual categories were especially prevalent among younger children, boys, patients with headaches, and those with lower pain severity. Overall, clinical utility of the ICD-11 was high, although less effective for chronic back pain and headache diagnoses. The latter also exhibited the lowest agreement between HCPs and algorithm. The current study underscores the need for evidence-based improvements to the ICD-11 diagnostic criteria in pediatrics. Developing pediatric coding notes could improve the visibility of patients internationally and improve the likelihood of receiving reimbursement for necessary treatments through accurate coding.

Keywords: ICD-11, Pediatrics, Chronic pain, Primary pain, Clinical utility, Pain classification, Field study

1. Introduction

Chronic pain in children is a common condition. Approximately 44% of school-aged children report having experienced pain at least weekly during the last 6 months.⁹ Among them, 8% report severely disabling chronic pain.¹² Most chronic pain conditions in children and adolescents are primary, indicating that the pain is not a symptom of an underlying disease or dysfunction but rather is a distinct condition characterized by pain-related emotional distress or functional disability.^{1,21,25,26} The International

Classification of Diseases (ICD) is used by countries for various purposes, such as health statistics, treatment reimbursement, decision support, and resource allocation.^{11,31} It is thus of utmost importance that the ICD includes clinically meaningful diagnoses that accurately capture the spectrum of affected patients.

The 11th revision of the ICD (ICD-11) now includes a separate section on chronic pain developed by an International Association for the Study of Pain Task Force.²⁶ This addition is intended to increase the visibility of chronic pain, reduce stigma, and improve access to multimodal care. The chronic pain section contains one subcategory for chronic primary (CP) and 6 subcategories for chronic secondary pain.²⁶ While the new diagnostic criteria aim to be applicable across all age groups, they are based on adult data; pediatric neurodevelopmental differences were not taken into account.²⁹

The new chronic pain classification system and its diagnoses have been tested in field studies involving the adult chronic pain population. These studies have demonstrated clinical utility, diagnostic specificity, and overall improvement compared to the preceding ICD-10.^{2–4,7,10,14,34} One study has retrospectively examined CP and secondary pain diagnoses and their potential overlap in a pediatric sample.¹⁹ It did not, however, evaluate the suitability of the proposed criteria; rather, it assigned codes based on pain etiology and location. To date, no prospective field study has examined the ICD-11 chronic pain diagnoses in a pediatric sample or investigated diagnoses at the lowest (ie, most specific) diagnostic level,²⁹ which is recommended for specialized clinical settings.^{15,26}

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

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The current study aims to address these research gaps by investigating the application of the ICD-11 in a sample of pediatric patients at a tertiary care pain center, with a particular focus on chronic primary pain (CPP) diagnoses. It specifically explores (1) the mapping of ICD-10 pain diagnoses to ICD-11, (2) the identification of frequently comorbid ICD-11 pain diagnoses, (3) the characteristics of patients who fail to receive a specific CPP diagnosis (ie, receive a less specific “residual” diagnosis), (4) the agreement between diagnoses assigned by healthcare professionals (HCPs) vs those generated by criteria-based algorithms, and (5) the HCPs’ perspectives on the clinical utility of the ICD-11 CPP diagnoses and how their views evolve over the course of the study.

2. Methods

Healthcare professionals ($N_{\text{HCP}} = 10$; for HCP sample properties, see Supplementary Table S1, <http://links.lww.com/PAIN/C124>) at the German Paediatric Pain Centre successively documented the symptoms and diagnoses of all pediatric pain patients less than 18 years old during their initial outpatient visit from March 30, 2021 to October 29, 2021. The German Paediatric Pain Centre is a specialized tertiary care institution, so patients underwent thorough diagnostics prior to their initial visit. These initial visits simultaneously involve a child psychotherapist, a pediatrician, the patient, and at least one parent. After the visit, the HCPs (specifically child psychotherapists and pediatricians) documented each patient’s symptoms using a digital symptom checklist containing all symptoms derived from the ICD-11 CPP diagnoses, supplemented by criteria from Rome IV and International Classification of Headache Disorders third edition (ICHD-3) when needed (At the time of study preparation [March 2021], the criteria for certain ICD-11 diagnoses were either not yet established or inadequately defined, particularly concerning headache disorders and abdominal pain. This remains unchanged during preparation of this manuscript [May 23, 2024]. Headache and abdominal criteria are, therefore, based on the ICHD-3 and Rome IV, respectively.¹³) (Supplementary Material S2, <http://links.lww.com/PAIN/C124>). For each patient, HCPs recorded the ICD-11 diagnoses and rated the clinical utility of these diagnoses. To ensure standardized coding of the ICD-11 diagnoses, HCPs participated in 2 training workshops led by B.K. and L.R. These workshops introduced the ICD-11 system as well as its key diagnoses. In addition, HCPs received a handbook containing relevant ICD-11 diagnoses and criteria translated into German to assist with coding (Supplementary Material S3, <http://links.lww.com/PAIN/C124>). During a 2-week pilot phase, HCPs familiarized themselves further with the ICD-11 and received feedback on coding. The analyzed sample comprised $N = 402$ patients with complete checklist data (71.9% girls; $M_{\text{age}} = 13.1$ years, $SD_{\text{age}} = 3.2$ years, $\text{range}_{\text{age}} = [3-17]$ years; **Figure 1** and **Table 1**).

Healthcare professionals also recorded each patient’s ICD-10 diagnoses. In the ICD-10, among other diagnoses, severe CPP can be coded as *persistent somatoform pain disorder* (F45.40) or, in the German Modification (ICD-10-GM), as *chronic pain disorder with somatic and psychological factors* (F45.41). While both diagnoses require contributing psychological factors, the F45.41 is additionally defined by an underlying biomedical or physiological factor, whereas F45.40 should be considered if such a factor is not present.²³

2.1. Measures

Before HCP contact, all patients provided demographic information (age, sex), pain disability, as well as symptoms of

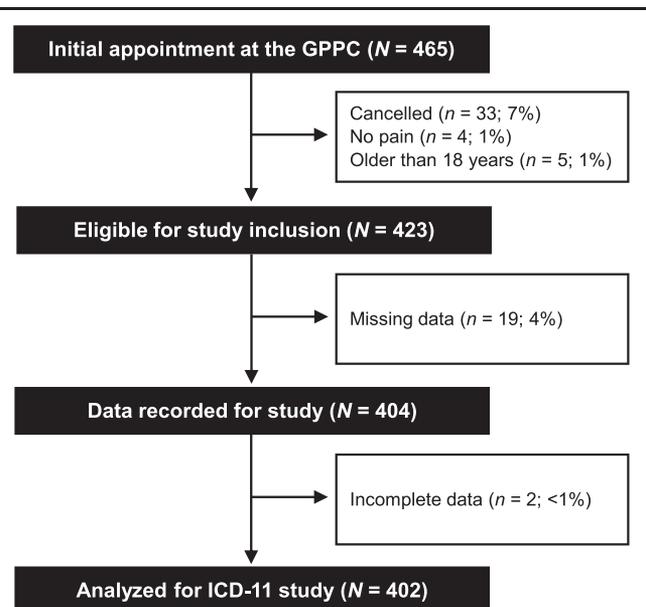


Figure 1. Flowchart of participation. GPPC, German Paediatric Pain Centre; HCP, healthcare professional; ICD-11, 11th revision of the International Classification of Diseases.

anxiety and depression. During the HCP interview, patients aged 8 years and older ($n = 378$) additionally reported their pain severity. Pain severity was assessed using 3 pain severity items developed for the ICD-11 chronic pain extension codes²⁶ and adapted for pediatric use. Missing data ($n = 47-49$) occurred when HCPs lacked sufficient time or omitted the questions accidentally ($n = 39$) or when they forwent them purposefully (eg, because of the situation being too emotionally laden; $n = 10$). Where available, missing data were imputed from patients’ written self-reports assessed prior to the interview ($n = 35-36$ imputed), resulting in a 97% completion rate ($n = 12-13$ missing). After the initial appointment, HCPs globally rated each patient’s pain on an 11-point numeric rating scale (NRS; “Please give your overall rating of the pain problem. On a scale from 0 to 10, how severe would you rate this pain problem?”). Clinical utility was evaluated using 3 items adapted from Barke et al.²: representation of patient symptoms (“How well could this child’s symptoms be represented with the ICD-11 diagnoses?”), diagnostic certainty (“How certain are you in the allocation of the ICD-11 diagnoses?”), and ease of coding (“How easy was the allocation of the ICD-11 diagnoses for you?”). Healthcare professionals rated these items once for each patient, encompassing all assigned ICD-11 diagnoses, using 11-point NRS scales ranging from 0 (“not at all”) to 10 (“completely”); see Supplementary Material S2, <http://links.lww.com/PAIN/C124>).

2.2. Algorithm diagnoses

The ICD-11 chronic pain chapter follows a hierarchical structure and encompasses several diagnostic levels. This implies that a lower-level diagnosis should contain all criteria from corresponding upper-level diagnoses along the diagnostic path (**Fig. 2**). Each diagnostic criterion was translated into a computer-based algorithm using R.²² Criteria were supplemented by criteria from Rome IV and ICHD-3 when necessary, using adult criteria unless diagnoses were explicitly labelled as pediatric. For diagnostic criteria and their corresponding algorithms, see Supplementary Material S4 (last updated from the ICD-11

Table 1
Patient characteristics.

Characteristic (dichotomous/ordinal)	n	% (N = 402)
Pain location (multiple possible)		
Head	286	71.1%
Limb	147	36.6%
Visceral	135	33.6%
Back	120	29.9%
No. of pain locations		
1	220	54.7%
2	107	26.6%
3	46	11.4%
4	29	7.2%
Pain duration*		
<3 months	11	2.7%
3-6 months	14	3.5%
6-12 months	40	10.0%
1-2 years	72	17.9%
2-3 years	50	12.4%
>3 years	215	53.5%
Chronic primary pain criteria fulfilled†		
Head‡	239	83.6%
Limb‡	91	61.9%
Visceral‡	98	72.6%
Back‡	69	57.5%
Characteristic (numeric)	Mean (SD)	Min-max
No. of ICD-10 HCP diagnoses	1.4 (0.6)	1-4
No. of ICD-11 algorithm pain diagnoses	1.6 (0.9)	1-6
Global pain severity (HCP)	6.8 (2.0)	0-10
ICD-11 pain severity ratings§		
Pain intensity (n = 366)	5.6 (2.4)	0-10
Emotional distress (n = 365)	4.8 (3.0)	0-10
Functional disability (n = 366)	5.5 (3.1)	0-10

* Refers to the pain location with the longest pain duration.
 † Chronic primary pain criteria (pain for longer than 3 months; emotional distress or functional disability present; not better accounted for by another chronic pain condition) are fulfilled for at least one pain location. In n = 7 patients, all reported chronic pain locations were better accounted for by chronic secondary pain conditions.
 ‡ Percent of n pain location. Chronic secondary pain fit the symptoms better in n = 1 head, n = 6 limb, n = 2 visceral, and n = 4 back pain locations.
 § Assessed during HCP interview in patients ≥8 year old; n = 35-36 written patient self-report; n = 12-13 missing.
 ICD, International Classification of Diseases; HCP, healthcare professional.

foundation as of January 31, 2024,³² <http://links.lww.com/PAIN/C124>). Patients received a separate diagnosis for each chronic pain location. Each diagnosis was coded to the lowest level for which the criteria were met.

Pain commencing within the past 3 months was classified as acute. For patients with an ongoing pain-related somatic condition or a somatic condition that was active less than 6 months ago, secondary pain was coded for the affected pain location upon agreement by a pain expert (M.F.). If a patient had secondary pain in a specific location, the algorithm did not assign CPP diagnoses for that location (exclusion criterion).

2.2.1. Residual diagnoses

Residual (ie, “unspecified”) diagnoses were assigned to patients who did not fulfill the diagnostic criteria of a specific diagnosis. These residual diagnoses corresponded to the lowest-level diagnosis for which all criteria were met as outlined in **Figure 2** (residual diagnoses are denoted with an asterisk in **Figs. 2 and 3**). After the logic of ICD-11, each diagnostic level that can be further specified (ie, contains more specific diagnoses at the subsequent

Case vignette 1: residual chronic primary pain

A 12-year-old boy complains of severe headaches twice a week, often leading him to leave school early or stay home for the day. The headaches usually last all day and tend to improve with physical activity. He has been dealing with these headaches for the past 2 years and they have worsened over time. The pain distresses him, especially as he worries about falling behind in school and failing his final year exam. Despite thorough medical examinations, no underlying disease or dysfunction has been identified.

This patient meets the criteria for chronic pain (pain lasting more than 3 months; level 1) and CPP (accompanied by distress or disability, not better accounted for by another chronic pain condition; level 2). Since the headaches occur on fewer than 15 days per month, the patient does not meet the criteria for CP headache or orofacial pain (level 3). Therefore, the patient is diagnosed with residual CPP (ie, CPP, unspecified; located on level 3), named after the lowest level diagnosis for which all criteria were met.

levels) contains residual diagnoses named after it. If at least one criterion is not met, patients will receive a residual diagnosis beneath the last category they met all criteria for (for an example, see **Case vignette 1**). Residual diagnoses in the ICD-11 may include diagnoses such as probable migraine (IChD-3), which are not specified diagnoses of ICD-11.

2.3. Analyses

International Classification of Diseases-10 and ICD-11 diagnoses and their mappings as well as patient characteristics and pain diagnosis comorbidities were analyzed descriptively. In patients who met the CPP criteria for at least one pain location, *t*-tests and χ^2 -tests of demographic and pain characteristics compared those who received only specific CPP algorithm diagnoses with those who received only residual diagnoses. Effect sizes are interpreted as small ($|0.1|$), moderate ($|0.3|$), or large ($|0.5|$).⁵ Interrater reliabilities between the algorithm and HCP diagnoses were calculated using Cohen Kappa ($\kappa < 0.21$ = no agreement, $\kappa < 0.40$ = minimal, $\kappa < 0.60$ = weak, $\kappa < 0.80$ = moderate, $\kappa < 0.90$ = strong, $\kappa > 0.90$ = almost perfect agreement²⁰). HCPs’ ratings of clinical utility were analyzed descriptively across patients and by ICD-11 CPP diagnosis. Multilevel analyses assessed HCP characteristics and changes in their ratings over the 7 months of data collection (ratings nested within HCPs, intraclass correlation coefficient: 0.272-0.300, design effect: 11.7-12.8, restricted maximum likelihood [REML] estimation, and Kenward–Roger approximation were applied to account for small sample size¹⁸). Assessment level predictors (ie, days in study) were split into *within-HCP* (level 1; centering within cluster) and *between-HCP* (level 2; grand-mean centering) variables. All analyses were performed using *R*²² and *RStudio*²⁴ (*R* packages used are described in Supplementary Material S5, <http://links.lww.com/PAIN/C124>).

2.4. Ethical approval

This study was approved by the Witten/Herdecke University Ethics Committee (reference number: 187/2020, October 21, 2020).

3. Results

3.1. Mappings of International Classification of Diseases-10 to 11th revision of the International Classification of Diseases diagnoses

The most common ICD-10 diagnoses assigned by the HCPs were somatoform pain disorder (F45.40) and chronic pain

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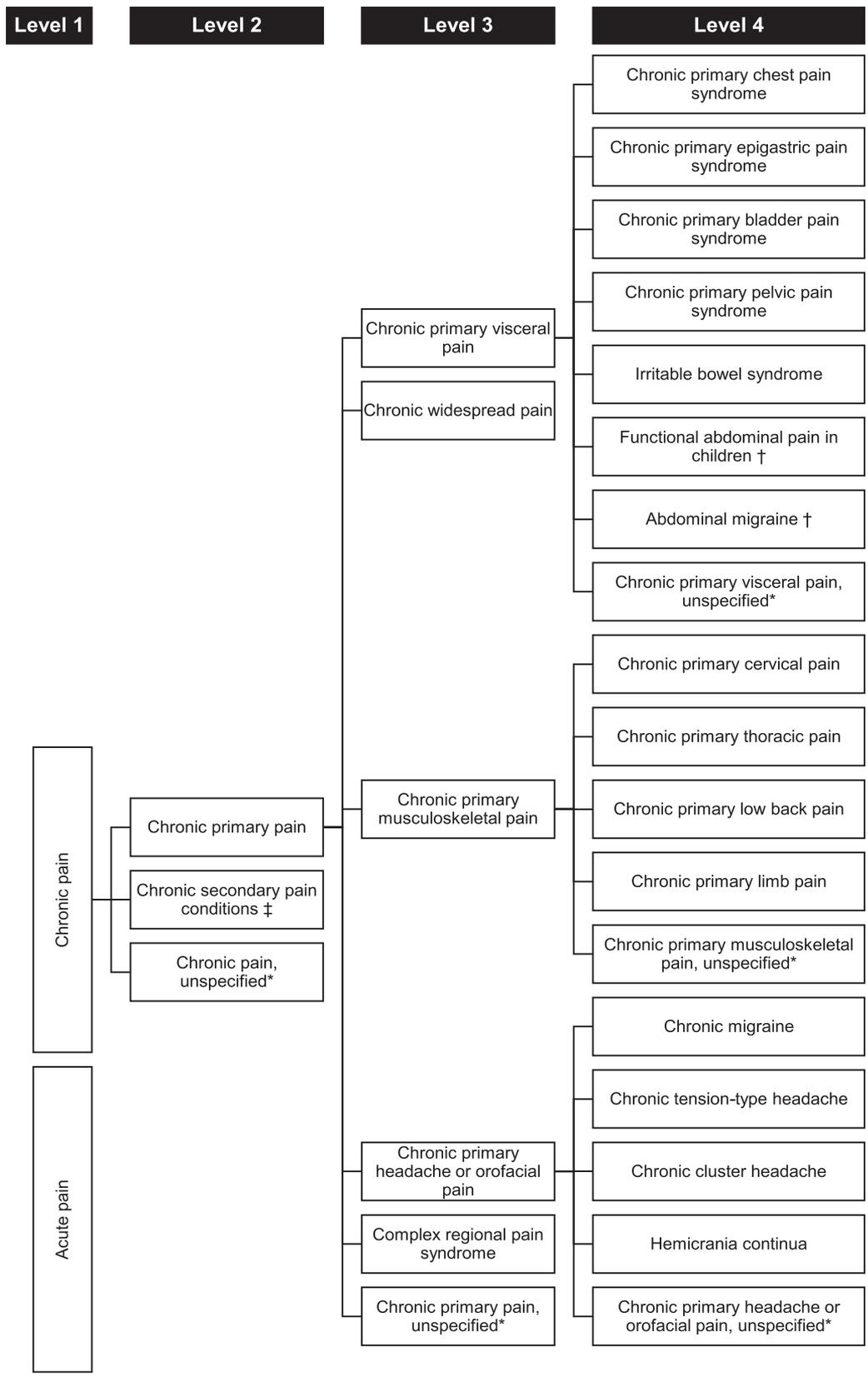


Figure 2. Diagnoses coded by the algorithm and their respective diagnostic levels. Diagnoses are taken from the ICD-11 foundation (“orange” browser, accessed on January 31, 2024). Lower-level diagnoses contain all criteria of upper-level diagnoses along the diagnostic path.* Residual diagnoses are not part of the ICD-11 foundation and were added after the logic of the ICD-11 linearization (“blue” browser): If the pain does not meet the criteria of any diagnosis at a given level but meets all criteria at higher levels along the diagnostic path, an “unspecified” (ie, residual) diagnosis may be given. †In the chronic primary visceral pain chapter of the ICD-11 foundation, some specific diagnoses appear at multiple levels. For simplicity, all of these specific diagnoses were placed on level 4 in this paper, even if they also appear on level 5 in the ICD-11 foundation. ‡Six subcategories combined for clarity and comprehensibility. ICD-11, 11th revision of the International Classification of Diseases.

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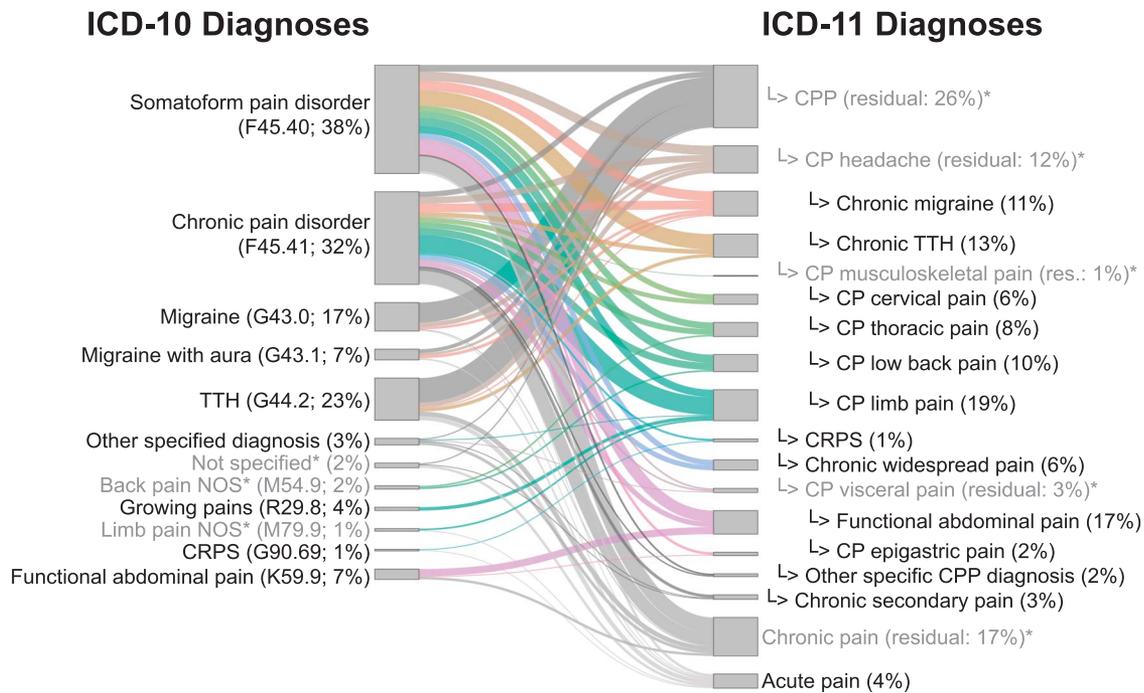


Figure 3. Mappings of ICD-10 HCP diagnoses (left) to ICD-11 algorithm diagnoses (right). Brackets contain diagnosis frequency and ICD-10 code. Paths are color-coded depending on their target, ie, the ICD-11 diagnosis. Arrows indicate diagnostic level in the ICD-11 coding system. Specific diagnoses that would not otherwise appear in the plot or that have a frequency of <1% are aggregated into the “other specific diagnosis” categories (Supplementary Material S8, <http://links.lww.com/PAIN/C124>). The plot displays paths with at least 2 cases. Because of *n*-to-*m* translation, one patient may be represented in multiple paths, leading to differences between diagnosis frequency and displayed path/node sizes. Residual International Classification of Diseases (ICD) diagnoses are marked with an asterisk (*). To explore the data in more detail, please see the corresponding interactive plot in Supplementary Material S6 (<http://links.lww.com/PAIN/C124>). CP, chronic primary; CPP, chronic primary pain; CRPS, complex regional pain syndrome; ICD-11, 11th revision of the International Classification of Diseases; NOS, not otherwise specified; TTH, tension-type headache.

disorder with somatic and psychological factors (F45.41). The algorithms predominantly mapped these diagnoses to location-specific CPP ICD-11 diagnoses. While HCPs were unable to specify their diagnosis in 5.2% of patients using ICD-10, the ICD-11 algorithm allocated a residual diagnosis in 51.2%. On level 2, 16.9% (*n* = 68) received a residual diagnosis, 25.6% (*n* = 103) on level 3 and 14.9% (*n* = 60) on level 4. Residual ICD-11 chronic pain, CP musculoskeletal pain, and CP visceral pain can primarily be traced back to ICD-10 codes F45.40 and F45.41 (somatoform pain disorder and chronic pain disorder with somatic and psychological factors). Meanwhile, residual ICD-11 CPP mostly corresponds to ICD-10 primary headache disorders. Residual ICD-11 CP headache, on the other hand, is linked to about equally both of these categories. Most patients received at least one specific ICD-11 pain diagnosis (*n* = 296; 73.6%). The mappings from ICD-10 to ICD-11 are depicted in **Figure 3** (for an interactive plot, see Supplementary Figure S6, <http://links.lww.com/PAIN/C122>). For an interactive plot displaying only mappings to residual ICD-11 diagnoses, see Supplementary Figure S7 (<http://links.lww.com/PAIN/C123>). An additional robust 2-tailed paired *t* test revealed a small yet statistically significant increase in the number of received diagnoses from ICD-10 to ICD-11 (Yuen test: $t(241) = 2.93, P = 0.004, \xi^2 = 0.14$; see **Table 1** for descriptive statistics).

3.2. Comorbid 11th revision of the International Classification of Diseases pain diagnoses

While most patients (*n* = 239, 59.5%) received a single ICD-11 algorithm diagnosis, 40.5% were diagnosed with at least 2. Especially CP back pain diagnoses more frequently occurred in

combination with other diagnoses than alone (alone: 0%-5%). Multiple spinal segments were often affected simultaneously. Conversely, specific and residual CP headache diagnoses as well as residual CPP were equally likely to occur alone or with other diagnoses (alone: 41.3%-57.3%). All other residual diagnoses (residual chronic pain, CP musculoskeletal pain, and CP visceral pain) typically occurred in conjunction with other diagnoses (alone: 0%-23.1%). Acute pain, chronic secondary pain, chronic widespread pain, and complex regional pain syndrome were more commonly identified as standalone conditions rather than comorbid (alone: 68.8%-100%). The frequencies of diagnoses and their comorbidities are displayed in **Figure 4**.

3.3. Patients with residual chronic primary pain 11th revision of the International Classification of Diseases diagnosis

Nearly all patients fulfilled the criteria for CPP in at least one pain location (*n* = 375; 93.3%; **Table 1**). Among these, the proportion of individuals meeting the CPP criteria was highest for headaches (83.6%; **Table 1**). Across pain locations, 42.7% of patients with CPP received at least one residual ICD-11 CPP diagnosis (39.8% of all patients). This was particularly applicable to headache cases (*n* = 148/239; 61.9%), but also to visceral pain (*n* = 13/98; 13.3%) and back pain (*n* = 3/69; 4.3%). Limb pain was never categorized as a residual CPP diagnosis (*n* = 0/91; 0%). Among patients diagnosed with residual CPP (level 3), the proportion of those who exclusively received residual diagnoses was significantly higher than those who also received specific diagnoses. However, this difference was not significant for the residual CPP diagnoses at level 4 (**Table 2**).

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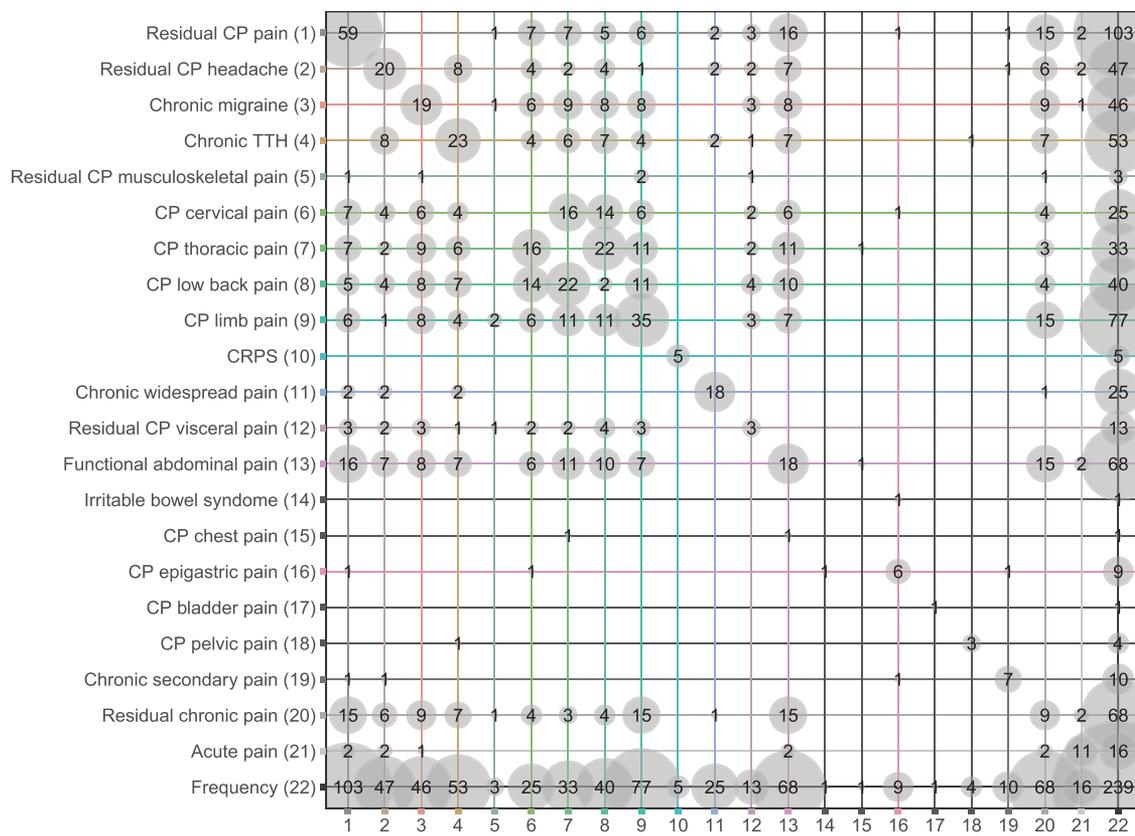


Figure 4. Comorbid ICD-11 algorithm diagnoses. Circles contain absolute frequencies; circle size represents frequency. Diagonal contains frequency of diagnoses occurring alone. The column “frequencies” refers to the total number of this diagnosis within the sample. Diagnoses can have multiple comorbidities. Grid colors are analogous to Figure 3. Example: CP thoracic pain (row 7) was received by n = 33 patients (column 22), never occurred by itself (column 7, n = 0), and was most often comorbid with CP low back pain (column 8, n = 22) and CP cervical pain (column 6, n = 16). CP, chronic primary; CRPS, complex regional pain syndrome; ICD-11, 11th revision of the International Classification of Diseases; TTH, tension-type headache.

For those fulfilling the criteria for CPP in at least one pain location, group comparisons between patients receiving only specific CPP diagnoses and those receiving only residual CPP diagnoses are presented in **Table 2**. Patients with only residual CPP diagnoses were significantly younger ($\Delta = 1.3$ years; $d = 0.412$) and more likely to be boys ($\Delta = 14.3\%$; $h = 0.314$) compared to those with only specific CPP diagnoses. Those with only residual CPP diagnoses reported significantly more headaches ($\Delta = -42.6\%$; $h = -1.136$) but less limb, visceral, or back pain ($\Delta = 24.2-36.5\%$; $h = 0.568-0.847$). Ratings of global pain severity ($\Delta = 1.8$ NRS points; $d = 0.919$), pain intensity ($\Delta = 1.6$ NRS points; $d = 0.677$), emotional distress ($\Delta = 1.7$ NRS points; $d = 0.638$), and functional disability ($\Delta = 1.8$ NRS points; $d = 0.580$) were significantly lower among those with only residual compared to those with only specific CPP diagnoses. No statistically significant differences were observed regarding maximum pain duration.

3.4. Agreement between healthcare professionals and algorithm

Agreement between the HCPs and algorithm was highest regarding chronic widespread pain, functional abdominal pain, and complex regional pain syndrome ($\kappa = 0.661-0.760$). Conversely, the lowest agreement was observed for chronic migraine ($\kappa = 0.268$) and chronic tension-type headache (TTH) ($\kappa = 0.332$). While the algorithm more often diagnosed chronic migraine, HCPs more often diagnosed chronic TTH (**Fig. 5**).

3.5. Clinical utility of 11th revision of the International Classification of Diseases diagnoses

Overall, HCPs considered the ICD-11 to be highly useful for clinical diagnosis, with a median rating of 8 for symptom representation and 9 for certainty and ease of coding (range: 0-10). However, when assigning CP back pain or chronic headache diagnoses, HCPs rated symptom representation lower than the median of all recorded patients. Certainty in their diagnoses and ease of coding were rated higher than the median of all recorded patients when diagnosing chronic widespread pain, and lower when diagnosing chronic migraine, CP thoracic, or CP cervical pain (**Fig. 6**).

Multilevel models predicting HCPs’ clinical utility ratings revealed no statistically significant effects of the time HCPs spent in the study or of their years of experience outside the pain field. However, the longer an HCP had worked in pain, the greater their subjective difficulty in diagnosing the patients. Although not statistically significant, similar effects emerged regarding HCPs’ perceptions of how well the diagnoses represented a patient’s symptoms and how certain they were about the given diagnoses (**Table 3**).

4. Discussion

The current study investigated the representation of the ICD-11 in pediatric patients attending a tertiary care pain center, with a particular emphasis on CPP diagnoses. Under the ICD-10 system, most patients were diagnosed with chronic pain

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Table 2
Descriptive statistics of patients receiving specific or residual 11th revision of the International Classification of Diseases chronic primary pain diagnoses by the algorithm.

Sample characteristics	Total CPP sample* (N = 375)	Specific only† (n = 215)	Residual only‡ (n = 101)	Both resid. & specific§ (n = 59)	Specific vs residual	
					Effect size	<i>P</i> _{adjusted}
Age	13.2 (3.1)	13.6 (3.2)	12.3 (3.1)	13.5 (2.9)	0.412	0.001
Sex (girl)	271 (72.3%)	165 (76.7%)	63 (62.4%)	43 (72.9%)	0.314	0.016
Maximum pain duration						0.253
3-6 months	11 (2.9%)	7 (3.3%)	3 (3.0%)	1 (1.7%)	0.016	
6-12 months	39 (10.4%)	30 (14.0%)	6 (5.9%)	3 (5.1%)	0.273	
1-2 years	68 (18.1%)	41 (19.1%)	22 (21.8%)	5 (8.5%)	-0.067	
2-3 years	48 (12.8%)	25 (11.6%)	16 (15.8%)	7 (11.9%)	-0.123	
> 3 years	209 (55.7%)	112 (52.1%)	54 (53.5%)	43 (72.9%)	-0.027	
Pain location						
Head	273 (72.8%)	117 (54.4%)	98 (97.0%)	58 (98.3%)	-1.136	<0.001
Limb	130 (34.7%)	102 (47.4%)	11 (10.9%)	17 (28.8%)	0.847	<0.001
Visceral	133 (35.5%)	82 (38.1%)	14 (13.9%)	37 (62.7%)	0.568	<0.001
Back	111 (29.6%)	72 (33.5%)	6 (5.9%)	33 (55.9%)	0.742	<0.001
Global pain severity (HCP)	6.8 (2.0)	7.4 (1.7)	5.6 (2.1)	6.9 (1.7)	0.919	<0.001
ICD-11 pain severity ratings						
Pain intensity (n = 346)	5.6 (2.4)	6.2 (1.9)	4.6 (3.0)	5.4 (2.2)	0.677	<0.001
Emotional distress (n = 345)	4.8 (3.0)	5.5 (2.7)	3.8 (3.3)	4.1 (3.0)	0.638	<0.001
Functional disability (n = 346)	5.5 (3.1)	6.2 (2.8)	4.4 (3.5)	4.8 (2.8)	0.580	<0.001
Residual CPP algorithm diagnoses	Residual CPP diagnosis (n = 160)		Residual only (n = 101)‡	Both resid. and specific (n = 59)§	Residual vs both	
					Effect size	<i>P</i> _{adjusted}
CPP, residual	103 (64.4%)		73 (72.3%)	30 (50.8%)	0.445	0.015
CP headache, residual	47 (29.4%)		25 (24.8%)	22 (37.3%)	-0.272	0.144
CP visceral pain, residual	13 (8.1%)		5 (5.0%)	8 (13.6%)	-0.305	0.083
CP musculoskeletal pain, residual	3 (1.9%)		0 (0.0%)	3 (5.1%)	-0.455	0.061

Cells contain mean (SDs) for numeric variables or absolute (relative) frequencies for categorical variables. Frequencies are relative to the respective sample, eg, 54.4% of patients with only specific CPP diagnoses experienced headaches compared to 97% of those with only residual CPP diagnoses. Patients may have multiple residual CPP diagnoses. χ^2 - and *F*-tests were applied as appropriate (*P*-values were adjusted for multiple testing using Benjamini–Hochberg correction; *P*_{adjusted} < 0.05 and corresponding effect sizes are set in bold; *F*-package *compareGroups*). Effect sizes are Cohen *d* (numeric) or *h* (categorical).

* Meets the CPP criteria for at least one pain location (pain for longer than 3 months; emotional distress or functional disability present; not better accounted for by another chronic pain condition).

† Patient received only specific CPP diagnoses.

‡ Patient received only residual CPP diagnoses.

§ Patient received both specific and residual CPP diagnoses.

|| 0–10 NRS; sample size for those with only specific CPP diagnoses is n = 200, and for those with only residual CPP diagnoses is n = 91 for all 3 items.

CP, chronic primary; HCP, healthcare professional; ICD-11, 11th revision of the International Classification of Diseases; NRS, numeric rating scale.

diagnoses classified as mental disorders (ICD-10-GM: F45.40/F45.41); the introduction of a dedicated chronic pain chapter in the ICD-11 saw more patients distributed across location-specific chronic pain diagnoses. This shift may enhance the recognition of chronic pain as a distinct medical condition and help reduce associated stigma.²⁶ There was a noticeable increase in the number of different ICD-11 diagnoses compared to ICD-10, particularly for highly comorbid back pain diagnoses specific to individual spinal segments. Children and adolescents often express generalized discomfort across their entire back rather than pinpointing a specific segment.⁶ The necessity for such detailed segmental representation within the pediatric population is disputable, given that the recommended treatment is consistent across locations (ie, multimodal).⁸ This is further supported by the HCPs' lower clinical utility ratings when assigning CP back pain diagnoses in the current sample. Moreover, diagnosis names including "musculoskeletal" and "visceral" imply a clear biological etiology, which is unusual for CPP in children.^{1,25} It may be more practical to advocate for an overarching diagnosis, such as CP back pain—presently absent in the ICD-11—which could be assigned in cases of pain across multiple spinal regions. Beyond back pain, there could be clinical advantages to coding the upper-level "CPP" diagnosis for cases presenting with CPP in multiple locations (eg, head, back,

abdomen). This approach would facilitate clearer communication of diagnosis, central sensitization underlying the condition, and recommended treatment to patients and their caregivers.

Compared to ICD-10, the ICD-11 system now enables systematic specification of CPP. The chronic pain chapter strives to provide precise diagnoses for a wide range of patients with chronic pain while minimizing the number of cases labelled as "unspecified" in primary and specialized care.²⁶ While most pediatric patients in the current tertiary care sample received a specific ICD-11 pain diagnosis (73.6%), a significant proportion also received residual diagnoses (51.2%; of those with CPP: 26.9% exclusively residual, 15.7% both residual and specific). These findings are noteworthy given the inclusion of many highly disabled patients in need of treatment. While the chronic pain chapter not only aims to specify such cases (see criteria of CPP), these children may also need a specified diagnosis to facilitate treatment reimbursement. This contrasts the findings of previous research, where only 0.5%–4.9% were deemed unspecified when coding to level 2 or 3.^{2,7,34} These studies, however, were conducted among adults with a higher prevalence of chronic secondary pain. Nevertheless, had the current sample been coded to level 2, as recommended for primary care¹⁵ (Fig. 2), 16.9% would have received a residual chronic pain diagnosis. It is, therefore, plausible that difficulties arise within the CPP chapter,

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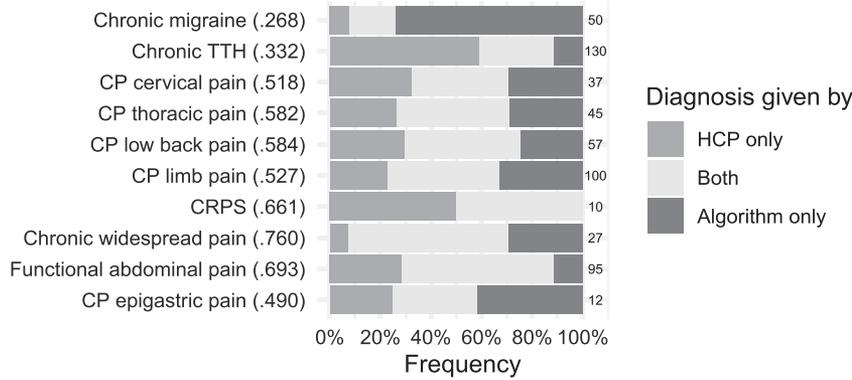


Figure 5. Comparisons of healthcare professional (HCP) and algorithm diagnoses. Bars display relative frequencies of given diagnoses. Absolute frequencies of patients receiving the respective diagnosis by either source are displayed on the right (N = 402). Brackets contain Cohen Kappa as a measure of agreement between HCP and algorithm. Kappa calculations include the displayed cases and those where both HCP and algorithm did not allocate the respective diagnosis. Only diagnoses with enough cases to calculate Kappa are included. CP = chronic primary; CRPS = complex regional pain syndrome.

which is predominantly used in the current sample, and/or that children are not sufficiently represented within the ICD-11.

It is particularly noteworthy that in this study, patients with primary headaches were prone to receiving residual CPP diagnoses. This phenomenon can be attributed to an additional time criterion required for chronic headache diagnoses, which is not mandated for the other CPP diagnoses: headache occurring for at least 2 hours on at least 15 days per month.²¹ This observation is significant because patients with headaches are most likely to meet the CPP criteria and have the lowest comorbidity rates, resulting in many patients receiving only a residual CPP diagnosis. A potential consequence of this is that health insurance providers in countries using the ICD-11 for reimbursement may refuse to pay for specific treatments if the diagnosis is residual, depriving these children of necessary treatment despite distressing and/or disabling pain. Furthermore, patients who received solely residual diagnoses were generally younger, more frequently boys, and reported lower pain severity. These patients may not be as advanced in the chronification process and their pain not yet extended to other locations beyond headache, which would make it easier for them to receive a specific diagnosis. Residual chronic pain, which can be present longer than 3 months although is not necessarily distressing or disabling, often occurs alongside CPP. These instances may represent cases where pain spreads from one main pain location to other locations or less disabling/distressing locations. Embracing a more holistic approach to chronic pain management may involve considering these additional pain locations as part of an overarching CPP condition if it better explains the patient's experience of pain. For instance, a patient presenting with chronic TTH, CP back pain, and visceral pain may benefit from integrating these pain experiences. Treating each pain location separately without considering the broader context could lead to unnecessary diagnostics, iatrogenic effects, and pain somatization.^{4,16}

This study includes diagnoses from 2 reliable sources: criteria-based algorithms and ICD-trained HCPs working in a specialized pain center. The agreement between diagnoses was minimal to moderate, suggesting these diagnostic criteria may be inconclusive in pediatrics. Both sources, algorithmic decisions derived from quantitative data and HCPs' decisions incorporating clinical judgment, are valid. Future research should aim to pinpoint the criteria contributing to inconsistencies and propose modifications based on scientific evidence from pediatric populations.

The high clinical utility ratings of the ICD-11 system were consistent with a previous international field study.¹⁴ When diagnoses such as chronic widespread pain and functional abdominal pain were given, HCPs rated clinical utility as high and there was strong agreement between HCPs and algorithms. This

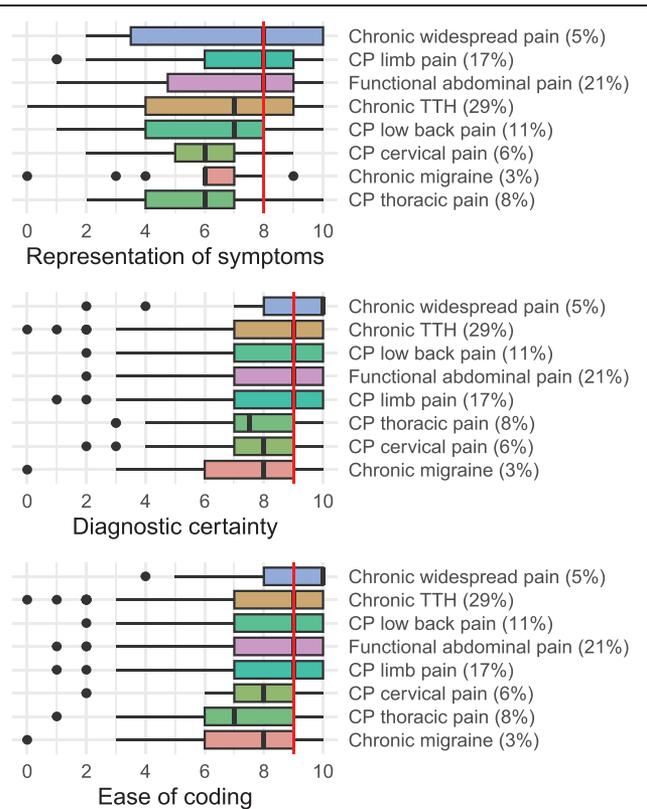


Figure 6. Boxplots of clinical utility ratings of ICD-11 diagnoses given by healthcare professionals (HCPs). Healthcare professionals rated how well their ICD-11 diagnoses (frequencies in brackets) represented each patient's symptoms, how certain they were about the given diagnoses, and how easy the coding was (NRS: 0 "not at all"—10 "completely"). HCPs rated each item once per patient, reflecting their global assessment across all given diagnoses for that patient. Red vertical lines mark the overall median. CP, chronic primary; ICD-11, 11th revision of the International Classification of Diseases; NRS = numeric rating scale; TTH, tension-type headache.

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Table 3
Results of multilevel models of healthcare professionals' clinical utility ratings.

Model	Coefficient (SE)	Standardized coefficient (SE)	95% CI	t	df	P
Representation of symptoms						
Days in study (level 1)	-0.02 (0.07)	-0.01 (0.04)	-0.10 to 0.07	-0.29	391.46	0.768
Days in study (level 2)	-0.19 (0.42)	-0.03 (0.07)	-0.19 to 0.12	-0.45	13.65	0.661
HCP experience outside pain	0.06 (0.07)	0.11 (0.12)	-0.16 to 0.38	0.95	8.70	0.370
HCP experience in pain	-0.20 (0.09)	-0.40 (0.18)	-0.88 to 0.08	-2.20	4.72	0.082
Diagnostic certainty						
Days in study (level 1)	0.07 (0.06)	0.05 (0.05)	-0.04 to 0.14	1.16	391.90	0.248
Days in study (level 2)	-0.31 (0.33)	-0.07 (0.07)	-0.21 to 0.08	-0.96	18.02	0.348
HCP experience outside pain	0.05 (0.05)	0.09 (0.11)	-0.14 to 0.33	0.90	9.67	0.389
HCP experience in pain	-0.17 (0.06)	-0.40 (0.15)	-0.82 to 0.01	-2.69	4.05	0.054
Ease of coding						
Days in study (level 1)	0.10 (0.06)	0.07 (0.05)	-0.02 to 0.16	1.59	391.95	0.114
Days in study (level 2)	-0.30 (0.34)	-0.06 (0.07)	-0.20 to 0.08	-0.88	18.45	0.389
HCP experience outside pain	0.06 (0.05)	0.13 (0.10)	-0.10 to 0.36	1.23	9.71	0.249
HCP experience in pain	-0.18 (0.06)	-0.41 (0.15)	-0.82 to -0.01	-2.84	3.99	0.047

Ratings are nested within HCPs ($N_{\text{ratings}} = 402$, $N_{\text{HCPs}} = 10$; REML estimation and Kenward–Roger approximation implemented in R packages *lme4*, *lmerTest*, and *parameters*). Ratings were collected over the course of 7 months. Days in study were divided by 30 (approximating months) and split into level 1 (cluster-mean centered) and level 2 (grand-mean centered) variables. $P < 0.05$ are set in bold.

CI, confidence interval; HCP, healthcare professional; REML, restricted maximum likelihood.

could be due to the ability of chronic widespread pain to capture pain broadly, especially for patients with multisite pain. Similarly, the clinical utility of functional abdominal pain may be enhanced by providing HCPs with pediatric criteria from the Rome IV system (not yet integrated within ICD-11), suggesting that pediatric-informed adjustments to adult ICD-11 diagnoses could improve their clinical utility in pediatrics. No significant changes in clinical utility ratings over the data collection period were observed, indicating that HCPs have stable opinions regarding symptom representation, diagnostic certainty, and ease of coding of ICD-11 pain diagnoses. However, longer clinical experience in the pain field may be associated with greater dissatisfaction with clinical utility. While the ICD-11 chronic pain chapter endeavors to be easy to use,²⁶ the current study suggests potential shortcomings that may only be apparent to experienced users. As this study involved a small sample of HCPs from a specialized pain center, future investigation should include a diverse group of pediatric HCPs to identify potential issues and generate guidelines for applying ICD-11 criteria, ensuring that the chronic pain chapter is convenient for users of all experience levels.

4.1. Strengths and limitations

The major difference between the current study and other ICD-11 field studies is that this study codes to the lowest diagnostic level using a computer-based algorithm.^{2-4,7,10,14,19,34} While the algorithmic approach allows for identifying coding problems regarding individual criteria, it may not fully reflect clinical reality because of its strict adherence to diagnostic rules. Nevertheless, HCPs can unintentionally introduce bias when coding patients. The current study thus integrated algorithms with HCP-based coding to mitigate human bias, provide better insights into clinical utility, and help identify areas for improvement. Another limitation is that HCPs in this study rated clinical utility globally for each recorded patient, not at the individual diagnosis level. Healthcare professionals, however, generally assigned only one or two diagnoses per patient, so these global ratings should reasonably estimate individual diagnosis utility and that of the overall process of assigning multiple diagnoses.

4.2. Conclusion and recommendations

In the ICD-11, chronic pain is defined as multifactorial with biological, psychological, and social factors contributing to its onset and persistence.^{26,32} This definition may enhance the adoption of a biopsychosocial model of chronic pain among pediatric HCPs internationally, enabling them to better communicate this model to patients and their families.¹⁷ Moreover, the CPP chapter's recommendation to code specific pain locations to the lowest level could improve comparability in international research and morbidity statistics.²⁶ At the same time, the high prevalence of residual diagnoses may impede families' comprehension of the mechanisms underlying their child's pain. Chronic primary pain is common among children and adolescents,^{1,9,25,28} and the inability to accurately code their conditions could lead to their invisibility within healthcare systems.^{27,33} To address this issue, it is essential to identify necessary adaptations at both the structural and criteria levels of the new diagnostic chapter and ensure alignment with other diagnostic systems. Pediatric patient representation could be further improved by adding pediatric coding notes to existing adult diagnoses.²⁹ This approach has been successfully implemented in the ICD-11 in other areas, such as for attention deficit hyperactivity disorder in the mental and behavioral disorders chapter.³⁰ Combined with the option for the most appropriate diagnostic level depending on the setting (eg, research, morbidity statistics, primary/specialized care), these adjustments could improve pediatric pain visibility, facilitate communication of a biopsychosocial concept of pain, and increase the likelihood that pediatric pain patients worldwide receive reimbursement for necessary treatments.

Conflict of interest statement

B.K. reports consulting fees from the International Association for the Study of Pain (IASP), outside the submitted work. B.K. and A.B. were involved in the IASP Task Force that developed the classification, during which Philipps University Marburg received a grant toward their salaries from the IASP. The remaining authors have no conflicts of interest to declare.

Data and syntaxes available upon request from the authors.

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