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RESEARCH ARTICLE

The Pain in Dystonia Scale (PIDS)—Validation in Craniofacial and Upper Limb Dystonia

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ABSTRACT: Background: Pain is one of the most disabling non-motor symptoms in adult-onset isolated dystonia (AOID). The Pain in Dystonia Scale (PIDS) was developed and validated in cervical dystonia. Its applicability to other focal subtypes remains unknown.

Objectives: To validate the PIDS in patients with craniofacial and upper limb dystonia, expanding its use beyond cervical dystonia.

Methods: We conducted a two-phase cross-sectional validation study in independent cohorts from Calgary, Canada and Italy. The Calgary pilot cohort ($n = 20$) included participants with craniofacial and/or upper limb dystonia who completed the PIDS twice for test–retest reliability and a battery of comparator scales. The Italian cohort ($n = 109$) was recruited through the Italian Dystonia Registry and completed the PIDS after cross-cultural adaptation. Internal consistency, test–retest reliability, construct validity, and distribution properties were assessed using established psychometric standards.

Results: Pain was highly prevalent (90.0% Calgary; 96.3% Italy), with anatomical distribution varying by dystonia subtype. Internal consistency was high across both cohorts (Cronbach's alpha 0.82–0.96), with minimal floor and ceiling effects. Test–retest reliability in the pilot cohort was excellent (ICC = 0.85). Construct validity was supported by strong correlations between PIDS scores and established pain and quality-of-life measures. Functional impact and pain modulators were consistently reported across cohorts, with stress identified as the most frequent aggravating factor and rest and stretching as common relieving factors.

Conclusions: The PIDS demonstrates reliability, validity, and feasibility in craniofacial and upper limb dystonia, supporting its adoption for evaluating dystonia-related pain in clinical and research settings across the main focal subtypes.

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Adult-onset isolated dystonia (AOID) includes several focal forms, most commonly cervical dystonia (CD), craniofacial and upper limb dystonia. These conditions are characterized by sustained or intermittent muscle contractions leading to abnormal postures and movements. Beyond motor symptoms, AOID includes a range of non-motor features, particularly pain, depression, and anxiety, that can markedly impair quality of life and functional independence.[1–3] Pain is consistently reported as one of the most disabling non-motor symptoms, with a prevalence ranging from 54.6% to 88.9% in CD, typically affecting the neck, shoulders, and upper back. In other forms of AOID, the prevalence of pain remains less well defined, and its mechanisms appear multifactorial, involving both musculoskeletal strain and alterations in central pain modulation, though these processes are still incompletely understood.[4,5]

Despite the high prevalence and burden of pain in focal dystonia, available assessment tools are not tailored to the specific features of AOID and lack the granularity to capture pain across subtypes, leaving a critical gap in validated, disease-specific instruments able to evaluate the full complexity of dystonia-related pain. The Pain in Dystonia Scale (PIDS) was developed to address this gap.[6] It provides a multidimensional evaluation of pain, capturing intensity and anatomical distribution, as well as functional consequences and the role of aggravating and relieving factors.[1] Building on our prior validation in CD, the present study expands the applicability of the PIDS to patients with craniofacial and upper limb dystonia, offering a comprehensive tool to characterize pain in these understudied subtypes.

Methods

This was a cross-sectional, multi-phase study designed to evaluate the psychometric properties of the PIDS in adults with AOID either focal or as part of a segmental/multifocal dystonia. We focused on patients with focal blepharospasm (BSP), focal oromandibular dystonia (OMD) and focal upper limb dystonia (ULD), as well as segmental/multifocal dystonia involving one or more of these craniofacial or upper limb regions, with potential involvement of other regions (eg, neck) Hemidystonia and generalized dystonia were excluded due to their distinct etiological profiles and broader motor involvement. Genetic characterization was not completed, as the study focused on validating a pain assessment instrument rather than on etiological classification of dystonia. The study comprised three stages: item generation, scale development, and validation—in line with the original PIDS methodology demonstrating the same phases in CD validation. The current manuscript centers on the validation phase for craniofacial and upper limb dystonia; item generation and development details were previously published.[6]

The PIDS is a self-administered instrument with three sections. Section 1 assesses pain severity in seven anatomical regions (neck, shoulders, eyes, jaw, arms, legs, mid/lower back), capturing worst and average pain intensity, frequency, and average daily duration for each region (subscore from 0 to 30 each). Section 2 evaluates the functional impact of pain on daily activities including eight items (eg, sleep, household tasks, social and leisure participation) using a 0–3 Likert scale (score range 0–24). Section 3 also uses a 0–3 scale and measures external pain modulators, including eight aggravating (score range 0–24) and 11 relieving factors, (score range 0–33).

The PIDS validation in craniofacial and upper limb dystonia was conducted in two independent cohorts. The pilot sample was recruited at the Movement Disorders Clinic, University of Calgary, Canada, with participants diagnosed with craniofacial and/or upper limb dystonia using international consensus criteria. Exclusion criteria included inability to consent, DSM-5-defined dementia, or pain from unrelated etiologies such as malignancy or severe osteoarthritis. All participants provided written informed consent. The study was approved by the University of Calgary Research Ethics Board (REB19-2111).

In the pilot cohort, participants completed the final PIDS twice over a short interval to assess test–retest reliability. They also completed a battery of reference instruments: the TWSTRS Psychiatric Screening subscale (TWSTRS-PSYCH),[7,8] Global Dystonia Severity Rating Scale (GDS),[9] Brief Pain Inventory–Short Form (BPI-sf),[10] and the Quality of Life Scale (QOLS), as used by the American Chronic Pain Association (ACPA-QOLS).[11] Demographic and clinical data were collected (age, sex, medical comorbidities, dystonia subtype and duration, treatments received and family history of dystonia).

The expanded validation cohort comprised multiple Italian centers participating in the Italian Dystonia Registry.[12] The original PIDS version (English) was translated into Italian by the group at the Department of Neuroscience and Translational Biomedicine, University of Bari, Italy, using forward-backward methods and expert reconciliation, following standard cross-cultural adaptation guidelines. No major adaptations were needed. Inclusion and exclusion criteria were identical to those applied in Calgary. Participants completed the final PIDS and provided demographic and disease-specific data. Unlike the pilot group, no retest or external comparator scales were used in this cohort.

In both cohorts, PIDS assessments were performed at least 3 months after the most recent botulinum toxin injection to minimize acute treatment-related effects on pain.

Sample size was guided by standard psychometric principles, targeting an item-to-subject ratio of 8–10 participants per item.[13] Statistical analysis was performed using STATA version 18. Comparisons between the Calgary and Italian populations on continuous variables were performed using the t-test or Mann–Whitney *U*-test, as appropriate, and the *z*-test to compare proportions. For test–retest reliability, intraclass correlation coefficients (ICC) were computed, with values ≥0.7 considered satisfactory. Internal consistency was assessed using Cronbach's alpha. Convergent validity was examined in the pilot sample using Spearman correlation coefficients between PIDS scores and established pain and quality-of-life

measures. Scale acceptability was defined as <5% missing data. Distribution properties were assessed by comparing means and medians, with differences <10% considered acceptable. Floor and ceiling effects were considered acceptable if observed in fewer than 15% of participants.

Results

Demographic and Clinical Features of the Populations

The Calgary pilot cohort ($n = 20$) and the Italian Dystonia Registry cohort ($n = 109$) had similar distributions in sex, age, disease duration, botulinum toxin treatment frequency, and reported family history of dystonia (Table 1). Conversely, the two cohorts differed in post-secondary education (higher in the Italian cohort) and age at onset (higher in the Calgary cohort). Oromandibular dystonia accounted for 22.9% of the Italian cohort but was not the presentation of any of the 20 patients in the Calgary cohort ($P = 0.02$; Table 1).

Pain Prevalence and Characteristics

No participants had missing PIDS items across both cohorts. Pain was highly prevalent (90.0% Calgary, 96.3% Italian registry; Table 2). When present, the anatomical distribution of pain was widespread in both cohorts. In the Calgary cohort, 55.0% reported pain in one to three body regions and 35.0% in four or more regions. In contrast, in the Italian cohort, 92.4% reported pain in one to three regions, while only 7.6% reported pain in four or more. Pain distribution patterns differed by dystonia subtype. Pain in eyes and neck/shoulders were relatively more frequently reported in the Calgary cohort and upper limbs in the Italian cohort, likely due to the different dystonia distribution between the two cohorts. As reflected in PIDS subscale scores from the larger Italian cohort, pain in craniofacial dystonia most often affected the eyes (mean subscore 10.3), neck/shoulders (6.25), mid/lower back (4.5), and jaw (3.26), whereas, in upper limb dystonia, the highest subscores were observed in the arms (7.23), neck/shoulders (8.04), and mid/lower back (5.99).

The total PIDS score differed slightly between the two cohorts, yielding a median of 10.8 (IQR 8.6–22.8; range 0–93.5) for the Calgary cohort and a median of 22.33 (IQR 10.0–42.0;

TABLE 1 *Demographic and clinical characteristics of participants in the pilot (Canada) and expanded (Italy) cohorts*

	Pilot cohort (Calgary, Canada) $n = 20$	Expanded evaluation cohort (Italy) $n = 109$	*P* value
Demographics and clinical features			
Female sex, *n* (%)	12 (60.0)	77 (70.6)	0.34
Age, mean ± standard deviation (years)	64.3 ± 12.6	62.0 ± 15.5	0.27
Post-secondary education, *n* (%)	5 (25.0)	65 (59.6)	0.004
Age at onset, mean ± standard deviation (years)	53.5 ± 12.5	48.7 ± 17.1	<0.0001
Disease duration, mean ± standard deviation (years)	10.7 ± 8.6	13.8 ± 11.9	0.15
Ongoing botulinum toxin treatment, *n* (%)	17 (85.0)	78 (71.6)	0.21
Family history of dystonia, *n* (%)	4 (20.0)	13 (11.9)	0.27
Anatomical distribution of dystonia (either focal or segmental/multifocal dystonia)			
BSP, *n* (%)	14 (70.0)	61 (56.0)	0.24
Focal, *n*	11	30	
Segmental/Multifocal, *n*	3	31	
OMD, *n* (%)	0	25 (21.1)	0.02
Focal, *n*	0	3	
Segmental/Multifocal, *n*	0	22[a]	
Upper limb dystonia, *n* (%)	6 (30.0)	49 (45.0)	0.21
Focal, *n*	5	23	
Segmental, *n*	1	26[b]	

Abbreviations: BSP, blepharospasm; OMD, oromandibular dystonia; ULD, upper limb dystonia; SD, standard deviation.
[a]17 of these 22 are also counted within the 31 patients with Segmental/Multifocal BSP.
[b]9 of these 26 are also counted within the patients with Segmental/Multifocal BSP ($n = 5$) and within the patients with Segmental/Multifocal OMD ($n = 3$).

TABLE 2 *Prevalence of pain and related characteristics*

	Pilot cohort (Canada) $n = 20$	Expanded evaluation cohort (Italy) $n = 109$
Reported pain (%)	18 (90.0)	105 (96.3)
Pain distribution when present (%)		
• Neck and shoulders	13 (70.0)	64 (58.7)
• Eyes	12 (65.0)	60 (55.0)
• Jaw	8 (45.0)	24 (22.0)
• Upper limbs	7 (40.0)	55 (50.5)
• Lower limbs	5 (25.0)	33 (30.3)
• Mid and lower back	8 (45.0)	51 (46.8)
Pain in 1 body part (%)	4 (20.0)	45 (41.3)
Pain in 2 body parts (%)	4 (20.0)	29 (26.6)
Pain in 3 body parts (%)	3 (15.0)	23 (21.1)
Pain in 4 body parts or more (%)	7 (35.0)	8 (7.6)
Median (interquartile range) PIDS Score (Total)	10.8 (8.6–22.8)	22.3 (10.0–42.0)
• Craniofacial dystonia group	$n = 14$ 14.3 (10.3–22.8)	$n = 69$ 23.7 (12.0–42.7)
• Upper limb dystonia group	$n = 6$ 9.1 (8.6–17.3)	$n = 40$ 16.3 (12.0–42.7)
Median (interquartile range) Modulating factors sub-scores		
• Aggravating factors	6 (4.5–11)	6 (4–10)
• Relieving factors	6.5 (3.5–8.5)	7 (3–10)
Median (interquartile range) Functional impact sub-score	4.5 (0–9.5)	4 (1–8)

Abbreviations: *n*, number of participants; PIDS, Pain in Dystonia Scale.

range 0–134.3) for the Italian cohort. Pain was more severe in the craniofacial dystonia subgroup compared to the upper limb dystonia subgroup in both Calgary and Italian cohorts.

The subscore for functional impact was very similar across the two cohorts (Table 2). The distribution of the frequency of the activities that were impacted by pain yielded slight differences between the two cohorts. In the Calgary cohort, outdoor leisure activities were the most impacted (55.0%, $n = 11$), with all other activities yielding a prevalence of impact within a range of 40–50% of individuals. In the Italian cohort, pain had a functional impact on physical exercise (71.9%, $n = 78$), social participation (71.8%, $n = 76$), sleep (65.9%, $n = 72$), household tasks (65.8%, $n = 73$), and outdoor leisure (62.3%, $n = 66$); over half also reported interference with driving, work, and personal relationships.

The subscores for functional impact, pain-aggravating and pain-relieving factors were very similar across the two cohorts (Table 2), as well as very similar between the two types of factors in both cohorts. Most reported aggravating factors in the two cohorts included stress and manipulation or massage, while rest, sleep, and stretching were the most frequently reported relieving factors. Most participants (76.5%) reported more aggravating than relieving factors, 12.9% reported more relieving than aggravating, and 10.6% reported equal influence.

In the larger cohort (Italian), we also explored the relationship between pain-modulating factors and sex and between pain severity and effect of pain-modulating factors and of functional impact. The percent score for pain-triggering factors was higher in females (mean = 40.9, SD = 22.9) than in males (mean = 26.3, SD = 24.3, $P = 0.02$). This difference did not correspond to statistically significant differences in pain distribution across body regions. Specifically, when comparing subscores for each anatomical region, while some regional means were descriptively higher in females (eg, eyes: 2.15 ± 2.76 vs. 1.38 ± 2.24; mid/lower back: 2.28 ± 2.80 vs. 1.64 ± 2.30) these differences did not reach statistical differences after correction for multiple comparisons ($P > 0.05$ for all regions). Pain-relieving percent scores did not differ significantly by sex (females: 22.2 ± 10.1; males: 17.7 ± 12.0; $P = 0.1$).

Pain severity was positively correlated with functional impact ($r = 0.49$), triggering factors ($r = 0.43$), and relieving factors ($r = 0.37$). Triggering and relieving scores were strongly correlated with one another ($r = 0.65$), and the external modulation

index (sum of aggravating and relieving factors' subscores) was also associated with pain severity ($r = 0.34$).

PIDS Validation

Score distributions were mildly skewed (1.45 and 1.38 in the Calgary and Italian cohorts, respectively). Floor and ceiling effects scored approximately 10% in both cohorts. The internal consistency of the total score was good and almost identical (0.82 and 0.83) across the two cohorts (Table 3). Internal consistency was also high across all body regions, ranging between 0.72 and 0.97. This yielded very similar values across the two cohorts, with the lowest Cronbach's alpha for the neck/shoulders region in both cohorts. Similarly, the internal consistency related to Section 2 (functional impact) and 3 (External Modulators) was, respectively, excellent (Cronbach's alpha = 0.94 for the Calgary cohort and 0.96 for the Italian cohort) and good (Cronbach's alpha = 0.80 for the Calgary cohort and 0.83 for the Italian cohort) in both cohorts.

Test–retest reliability and construct validity could be measured only in the pilot Calgary cohort. Test–retest reliability was high (intra-class correlation coefficient: 0.85; Table 3). Construct validity was supported by strong positive correlations between total PIDS scores and BPI-sf pain interference ($\rho = 0.77$, 95% CI: 0.46–0.93), worst pain ($\rho = 0.74$, 95% CI: 0.40–0.91), and TWSTRS-PSYCH ($\rho = 0.75$, 95% CI: 0.38–0.91). Moderate correlations were observed with current pain ($\rho = 0.64$, 95% CI: 0.24–0.85) and average pain ($\rho = 0.45$, 95% CI: 0.01–0.74). As expected, a strong negative correlation was found with the ACPA-QOLS ($\rho = -0.77$, 95% CI: −0.92 to −0.40).

Discussion

This study confirms the reliability and broader applicability of the PIDS in assessing pain across multiple focal forms of adult-onset isolated dystonia. Building on prior work in CD, we demonstrate that the PIDS performs well in both craniofacial and upper limb dystonia, with strong internal consistency, minimal floor and ceiling effects, and good correlation with established measures of pain and quality of life.[6]

TABLE 3 *Psychometric validation of the PIDS in the pilot and expanded cohorts. Test–retest reliability (in the Canadian cohort) is reported using intraclass correlation coefficients (ICCs). Internal consistency is measured using Cronbach's alpha for the total score and individual sections. Construct validity is evaluated via Spearman correlation coefficients with other clinical scales*

	Pilot cohort (Calgary, Canada) $n = 20$	Expanded evaluation (Italy) $n = 109$
Ceiling effect	10.1%	10.5%
Floor effect	10.1%	9.7%
Test–Retest Reliability (ICC)	0.85 (CI: 0.74–0.93)	NA
Internal consistency-Cronbach's Alpha (95% CI)		
Total	0.82 (0.71–0.90)	0.83 (0.79–0.87)
Neck and shoulders	0.72 (0.55–0.90)	0.78 (0.72–0.83)
Eyes	0.88 (0.77–0.97)	0.86 (0.81–0.90)
Jaw	0.94 (0.93–0.96)	0.92 (0.89–0.95)
Upper limbs	0.76 (0.68–0.91)	0.81 (0.76–0.87)
Lower limbs	0.97 (0.87–0.99)	0.92 (0.90–0.95)
Mid and lower back	0.93 (0.85–0.98)	0.89 (0.84–0.93)
Functional impact	0.94 (0.90–0.97)	0.96 (0.95–0.97)
External modulators	0.80 (0.68–0.89)	0.83 (0.79–0.86)
Construct validity—Correlation coefficient (95% CI)		
BPI-sf pain interference	0.77 (0.46–0.93)	NA
BPI-sf current pain	0.64 (0.24–0.85)	NA
BPI-sf average pain	0.45 (0.01–0.74)	NA
BPI-sf worst pain	0.74 (0.40–0.91)	NA
TWSTRS-PSYCH	0.75 (0.38–0.91)	NA
Correlation with ACPA-QOLS	−0.77 (−0.92 –0.40)	NA

Abbreviations: ACPA-QOLS, American Chronic Pain Association–Quality of Life Scale; BPI-sf, Brief Pain Inventory–short form; CI, Confidence Interval. ICC, Intraclass Correlation Coefficient; NA, Not available; PIDS, Pain in Dystonia Scale; TWSTRS-PSYCH, Toronto Western Spasmodic Torticollis Rating Scale–Psychiatric subscale.

The results of this study confirm that the scale's multidimensional structure—assessing for pain intensity, anatomical distribution, functional impact, and modulators—is clinically meaningful. The observed anatomical pain patterns aligned with dystonia subtype, reinforcing the scale's relevance to clinical presentation. The greater pain severity in craniofacial dystonia, compared with upper limb dystonia observed in both cohorts, may reflect the high sensory representation and functional salience of craniofacial regions, as well as sustained muscle activity that may amplify pain perception; however, at this stage these explanations remain hypothetical. Functional interference was common, underscoring the significant burden of pain even in focal dystonia forms.

A key strength of this study is its two-phase validation design, involving independent cohorts from different countries and languages, with slightly different demographic and clinical profiles, thus enhancing generalizability. Psychometric properties were robust across both cohorts, and the absence of missing data in the larger sample supports its feasibility in clinical settings. The smaller sample size of the pilot cohort from the Calgary site, and the lack of availability of data on test–retest reliability and construct validity from the larger Italian cohort are the main study limitations. We simplified the Italian data collection, supported by the highly consistent results obtained in the pilot cohort and the original publication, and we sought to counterbalance these limitations by presenting data from the two independent populations together. Finally, and interestingly, despite differences in dystonia subtype distribution between cohorts, the PIDS demonstrated consistent psychometric performance across populations, supporting its robustness and applicability in heterogeneous clinical settings.

Now, with the PIDS validated across all major forms of focal dystonia, next steps will involve assessing the scale's responsiveness to change over time and its utility in treatment trials. The inclusion of behavioral and environmental modulators within the PIDS framework also provides the opportunity to advance more comprehensive, patient-centered care strategies that move beyond pharmacologic interventions. In this context, the consistently high prevalence of pain observed across cohorts underscores the clinical importance of systematic pain assessment in adult-onset isolated dystonia and should inform both clinical practice and future research, including efforts to better characterize mechanistic, postural, and qualitative dimensions of dystonia-related pain.

Author Roles

(1) Research project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution, C. Review and Critique; (3) Manuscript: A. Writing of the first draft, B. Review and Critique. Roles: design, execution, analysis, writing, editing of final version of the manuscript.

V.B.: 1A, 1B, 1C, 2A, 2B, 3A, 3B.
V.V.: 1C, 3B.
B.A.: 1C, 3B.
M.M.M.: 1C, 3B.
A.M.: 1C, 3B.
D.B.: 1C, 3B.
F.M.: 1C, 3B.
L.A.: 1C, 3B.
F.D.B.: 1C, 3B.
R.E.: 1C, 3B.
C.S.: 1C, 3B.
L.M.: 1C, 3B.
F.V.: 1C, 3B.
A.P.: 1C, 3B.
A.F.G.: 1C, 3B.
A.C.: 1C, 3B.
F.B.: 1C, 3B.
G.C.: 1C, 3B.
C.A.A.: 1C, 3B.
C.T.: 1C, 3B.
M.P.: 1C, 3B.
N.T.: 1C, 3B.
G.D.: 1A, 1B, 1C, 2A, 2B, 3A, 3B.
D.M.: 1A, 1B, 1C, 2A, 2B, 3A, 3B.

Disclosure

Ethical Compliance Statement: This study was approved by the University of Calgary Research Ethics Board (REB19-2111). The patient provided written informed consent for participation in this work and for the publication of relevant clinical information. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request. ■

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