VIEWPOINT

Non-motor Symptom Scales in Pediatric Movement Disorders: A Call for Diagnostic-Specific Tools

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The importance of considering non-motor symptoms (NMS) in the assessment of patients with movement disorders is widely recognized.[1] In adults, symptoms such as pain, sleep disturbances, anxiety, fatigue, and cognitive dysfunction can be systematically evaluated, sometimes with validated, condition-specific scales.[2,3] For example, the Pain in Dystonia Scale (PIDS) has been recently developed for pain assessment across the spectrum of adult-onset isolated dystonia.[4] In children, however, the evaluation of NMS remains inconsistent, fragmented, and poorly standardized.[1] Yet, NMS are often disabling and have substantial consequences for the quality of life of children with movement disorders and their families.[5] In a recent scoping review,[6] we provide a timely overview of NMS scales used in children with movement disorders, focusing on the three most prevalent conditions, namely dystonia, tics, and cerebral palsy (CP).[7-9] We identified *a large and heterogeneous set of instruments* across 382 studies. They were mostly borrowed from neurological conditions typically presenting in adulthood and other pediatric psychiatric conditions, leaving one to wonder whether they have similar accuracy and clinical relevance also in pediatric movement disorders. Here, we advocate for the development of condition-specific, developmentally appropriate, and clinically meaningful tools, and outline key priorities for achieving this goal.

Current Landscape and Gaps

A major finding of our review was the heterogeneity of NMS assessment tools in children with movement disorders.[6] Among the included studies, we catalogued more than 500 distinct rating instruments, and only about 60 were used in more than one study. Very few were designed for pediatric movement disorders, and full psychometric validation in the target populations was uncommon (10 studies, 7%). This leads to a paradox. Numerous instruments are available, yet their precision and disease-specific relevance are often uncertain, and disorder-specific NMS scales remain scarce. As a result, clinicians and researchers frequently default to generic measures rather than condition-sensitive tools.

For example, in the domain of sleep, 13 distinct tools were used across 24 studies, predominantly parent-reported questionnaires such as the Children's Sleep Habits Questionnaire (CSHQ), the Sleep Disturbance Scale for Children (SDSC), and the Pediatric Sleep Questionnaire (PSQ), together with objective methods (actigraphy, polysomnography).[10-12] Questionnaires based on child self-report appeared only sporadically (eg, Insomnia Severity Index),[13] and clinician-administered tools were rare and mainly cited in reviews (eg, bedtime issues, excessive daytime sleepiness, awakenings, regularity/duration, snoring).[14] In the domain of pain, a similarly wide range of approaches were used, including clinician-rated scales (eg, Faces Legs Activity Cry Consolability), self-

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reported instruments (eg, the Wong-Baker FACES scale), and parent-reported questionnaires (eg, the Pediatric Pain Profile).[15-17] Among these domains, feasibility—including administration time, responsiveness, and clinical utility—is poorly reported in children with cerebral palsy, and population-specific clinical thresholds (eg, score cutoffs for case identification/severity or minimally important change values) are seldom available, limiting the use for treatment decisions and monitoring.[12,18,19] Only a few studies used NMS scales to inform treatment or monitor response,[6] and routine implementation remains limited in both practice and research.[12,16,20,21]

Across sleep and pain specifically—and similarly across the other NMS domains we reviewed— studies rarely reported age adaptation or developmental tailoring. Many instruments depend on verbal self-report, abstract reasoning, or executive functions that can be altered in children with moderate-to-severe CP or in some forms of complex dystonia. Only a few tools are usable in nonverbal children or those with intellectual disability.[22] Normative data stratified by age or developmental stage are also seldom available, limiting interpretability across childhood and adolescence.

Across all domains and diagnostic groups, only 10 studies (7%) provided full psychometric validation in the target population with evidence of content and construct validity, reliability, and sensitivity to change.[6] Most studies reported only internal consistency or convergent validity, and many used instruments originally validated in unrelated contexts (eg, oncology, epilepsy, general pediatrics), which undermines measurement validity and interpretability in children with movement disorders. Because tool choice is inconsistent, psychometrics are incomplete, and developmental tailoring is insufficient, comparisons across studies remain tenuous and clinical translation is limited.

Table 1 summarizes these cross-cutting limitations and pragmatic avenues for improvement.

The Limitations of Transdiagnostic Approaches

A natural response to this methodological heterogeneity is to call for greater standardization of assessment across childhood movement disorders.[23,24] Transdiagnostic instruments can be valuable as they facilitate cross-study and cross-condition comparisons, can serve as pragmatic screening tools, and may reduce respondent and clinician burden—and in certain domains (eg, generic sleep disturbance indices), a single scale might capture broad features adequately. However, our findings indicate that a single transdiagnostic tool is unlikely to be sufficient on its own.[6] Standardization is desirable, but condition-salient non-motor features still require diagnosis- and development-sensitive assessment, and two situations should be distinguished. When a scale is used outside the population, its reliability, validity, and accuracy remain unknown. In that case, targeted psychometric evaluation in the relevant disorder and developmental strata is indicated. *De novo* tool development is reserved for situations where feasibility is poor or psychometric performance proves inadequate.

Although certain NMS domains—such as pain, sleep disturbances, behavioral symptoms, and mood issues—are common across disorders, their expression, clinical relevance, and impact vary widely depending on the underlying condition.[25] For example, in dystonia, symptoms like mental health issues and pain are frequently reported in relation to motor severity and treatment response.[15,26,27] In Tourette syndrome, psychiatric symptoms such as obsessive-compulsive behaviors, hyperactivity/impulsivity, and irritability often overshadow the tics themselves and are frequently the primary reason for consultation.[28-30] In cerebral palsy, NMS such as gastrointestinal symptoms,[31,32] sleep disturbances,[33] and communication discorder[34] can have a greater impact on the quality of life than the motor features per se.[35]

What Should We Do Now? Recommendations for the Field

We propose five concrete priorities to guide the future of NMS assessment in pediatric movement disorders. These recommendations are rooted in clinical needs, informed by our review, and inspired by ongoing initiatives in related fields.

Embrace Diagnostic and Developmental Specificity

We advocate for a modular framework. We propose the concept of one instrument with two layers: a short, non-specific core tool covering all NMS domains for all children, then add-on modules chosen by condition and developmental profile. The core preserves comparability, and modules provide condition-salient, actionable subscores.[36,37] Crucially, these tools must be adapted to different developmental stages. For example, proxy-based tools may be suitable in early childhood or in children with limited communication, whereas self-reported items can be introduced progressively in older or cognitively able patients. Normative values stratified by age and developmental profile are needed to enable meaningful interpretation.

TABLE 1 *Summary of unmet needs in current non-motor symptom (NMS) assessment tools for pediatric movement disorders*

Domain	Observed issues (from the review)	Consequences	Suggested actions
Tool heterogeneity	Large and heterogeneous set of instruments reported across 382 studies; limited re-use/standardization; many tools borrowed from adult neurology, general pediatrics or psychiatry.	Between-study comparisons are fragile; clinical translation is limited.	Harmonize core domains and reporting; move toward a modular approach rather than a single universal tool.
Validation	Few studies provided full psychometric validation in the target population; most reported only internal consistency or convergent validity; some tools validated in unrelated contexts.	Questionable reliability/interpretability for children with movement disorders.	Plan clinimetric programs across ages/diagnoses (content and construct validity, reliability, sensitivity to change).
Developmental appropriateness	Age/developmental adaptations seldom reported; many tools rely on verbal self-report/executive functions; few instruments usable in nonverbal children or those with intellectual disability; age-banded norms often lacking.	Inapplicability in children with cognitive/communication impairment; limited interpretability across childhood/adolescence.	Provide proxy vs. self-report tiers, communication-adapted/clinician-rated options, and age-stratified norms.
Clinical relevance and feasibility	Instruments often time-consuming, hard to act on, and rarely linked to clinical thresholds; only a few studies used NMS scales to inform treatment or monitor response; uptake limited in practice and research.	Low routine use; limited decision support for clinicians/families.	Design for clinic: brief tools with clinical cutoffs and decision-oriented outputs; define MCIDs; digital delivery/EMR integration and pre-visit PROMs with parent-proxy versions.
Standardization vs. diagnosis-specific needs	Standardization is desirable, but a single transdiagnostic tool is unlikely to suffice; condition-salient NMS features vary across dystonia, tics, and CP.	Purely generic tools risk missing clinically meaningful, disorder-specific signals.	Hybrid model: a brief transdiagnostic core for comparability + diagnosis-specific, developmentally adapted modules.

Abbreviations: NMS, non-motor symptoms; MCID, minimal clinically important difference; EMR, electronic medical record; PROMs, patient-reported outcome measures; CP, cerebral palsy.

Co-Design Tools with Children and Families

Pediatric assessment is already shifting beyond clinician-centered viewpoints, yet more steps are required to fully realize this change. Tools developed without the direct input of patients and caregivers risk overlooking what truly matters to families. Children consistently highlight fatigue, peer relationships, self-esteem, perceived stigma, and involvement in everyday life at home, school, and in the community as major determinants of quality of life, whereas these domains are often absent from current instruments.[6] We recommend adopting a co-design approach with involvement at every stage of tool development: from item generation to cognitive testing and pilot validation. Methods can include semi-structured interviews, visual mapping techniques, and the integration of caregiver panels and youth advisory boards, and Delphi questionnaires to build consensus among expert stakeholders, including children and young people and their families. Although this is best practice, it is often underused because access to lived-experience partners is limited, and time and budgets are constrained. Practical steps include compensated caregiver and youth panels, partnerships with patient organizations for rapid iteration, and preplanned co-design steps in study protocols and budgets. Importantly, co-designed tools are more likely to be acceptable, feasible, and relevant in real-life settings.

Establish NMS Assessment as a Distinct Research Priority

Non-motor symptom evaluation in children with movement disorders must be recognized as a standalone methodological field, deserving of dedicated funding, training, and international collaboration. Just as the adult NMS field matured through initiatives like the MDS Non-Motor Subgroup,[37] a similar infrastructure may be needed in pediatrics. We call for the creation of a pediatric NMS taskforce, ideally under the supervision of relevant societies, to (1) define consensus domains and core outcomes, (2) provide psychometric guidelines, and (3) promote cross-cultural validation. Training workshops, special interest groups, and international registries could accelerate harmonization and benchmarking.

Design for Real-World Clinical Usability

Even robust scales fail in practice if they are too long, complex, or not actionable. Tools should be brief, linked to clinical thresholds, and produce clear reports for families and care planning. Digital formats—including tablet- or web-based versions, adaptive questionnaires, and integration into electronic medical records —should be prioritized. For example, electronic collection of patient-related outcome measures with parent proxy versions when needed before clinic visits could allow clinicians to review NMS profiles in advance, flag red zones, and track progress over time. This approach is effectively used in adult Movement Disorders clinics.

Link NMS Evaluation to Research and Treatment

NMS assessment must become more integrated into the therapeutic process, not merely descriptive. Tools should be validated for sensitivity to change, tested against clinical interventions, and used as both outcome measures and stratification tools in research. At present, few studies in pediatric movement disorders evaluate NMS in clinical trials, and when they do, outcomes are often nonspecific or insensitive.[6] We suggest including NMS endpoints systematically in upcoming interventional studies. This also means defining minimal clinically important differences (MCID) for each domain—an essential step for using scales in longitudinal monitoring and precision care. Importantly, this shift from description to action aligns with a broader trend toward patient-centered outcome measures across child neurology.

Conclusion

Children with movement disorders live with more than motor symptoms. Pain, sleep problems, behavioral difficulties, fatigue, and mood disturbances are pervasive, disabling, and yet sometimes overlooked in routine clinical care. Our review exposes the deep mismatch between the burden of NMS and the set of tools currently available to measure them.[6] This gap is not merely academic. It has direct consequences for care delivery, quality of life, and therapeutic equity. Without appropriate tools, non-motor symptoms remain under-recognized, under-treated, and under-researched. This perpetuates a cycle in which clinicians lack data and families feel unheard. It is time for the field to act. We call on the movement disorders community—clinicians, researchers, patient organizations, and scientific societies—to launch a coordinated, international effort to address this unmet need. ■

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Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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