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ORIGINAL RESEARCH

Pain in Nonverbal Children with Medical Complexity: A Two-Year Retrospective Study

Findings reveal the importance of including childhood ailments as potential pain sources.

Pain is the cardinal symptom of many medical conditions; eliciting a patient's history of pain is critical in making provisional diagnoses that prompt further investigation. But many children with medical complexity either can't communicate pain verbally or have great difficulty in doing so.[1] Cohen and colleagues have defined children with medical complexity as those who may have a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment, a technological dependence for activities of daily living, or a combination thereof.[2] Similarly, in our study and for the purposes of this article, we define children with medical complexity as those having a cognitive–chronological age mismatch, profound developmental delays, limited or no verbal abilities, and multisystem diagnoses, and who are completely dependent on others for care. Like neurotypical children, children with medical complexity are at risk for pain from ambulatory care–sensitive conditions such as fractures, otitis media, pneumonia, and urinary tract infections[3]—but they tend to experience pain more frequently, often on a daily or weekly basis.[1] They are also more likely to be hospitalized for such conditions. A large Canadian study found that hospitalization rates for ambulatory care–sensitive conditions were six to eight times higher among children with an intellectual disability than among those without such disability.[4] And children with medical complexity may be at greater risk for pain from persistent sources, such as pain following episodes of spasticity and central or peripheral neuropathic pain.[5]

Although children with medical complexity account for between 5% and 10% of all hospitalizations, they account for 22% to 29% of hospital charges and up to 43% of hospital deaths.[6, 7] They're also likely to be readmitted. One study found that 15% of children with congenital heart disease were readmitted within 31 days of discharge.[8] Another study of children with complex chronic conditions found that 22% with one such condition and 89% with four or more such conditions required readmission within one calendar year.[9]

Assessing pain in this population can be challenging, leading to delays in the identification of the source of pain and in pain management.[10, 11] Such challenges are usually associated with difficulties in interpreting patient behaviors or in discerning which unexpected behaviors are indicative of pain.[1, 12, 13] Delays in recognizing and addressing pain may contribute to increased morbidity when the source of pain (such as a surgical abdomen) requires an emergent intervention.[14]

More than 40 pain assessment tools have been developed for use in infants and children who cannot provide self-report.[15] Despite the availability of these tools, the evaluation of pain in children with medical complexity remains challenging, in part because a

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ABSTRACT

Purpose: Children with medical complexity experience frequent pain. But it can be challenging to recognize unexpected behaviors as pain related, especially in the absence of self-report. Often these children undergo extensive workups aimed at diagnosing the sources of pain. This study had three objectives: to describe the signs and symptoms parents of nonverbal children with medical complexity found worrisome, to describe the sources of pain in these children, and to describe nursing pain assessment practices in this population.

Design and methods: Retrospective chart review was used to identify the initial presenting symptoms, sources of pain, and nursing documentation for 46 children with medical complexity who were admitted with a chief concern of pain to a 395-bed pediatric teaching hospital in the northeastern United States.

Results: Irritability, pain, feeding intolerance, and "not acting like herself [or himself]" were common parent-reported symptoms that prompted further evaluation. On average, five diagnostic studies were taken to identify a source of pain, and four specialty services were consulted during the admission. Nursing assessments of pain were documented approximately every three hours; the mean pain intensity score documented was 1.1 out of 10. The discharge diagnoses included infection (including urinary tract infection), seizures, constipation, chronic pain, failure to thrive, dehydration, and subdural hematoma.

Conclusions: The discharge diagnoses covered a wide range. A systematic approach to pain evaluation could help to ensure that the diagnostic process is both thorough and efficient. Common childhood ailments such as constipation or urinary tract infection, as well as other causes, must be considered when diagnosing pain in this population. Practice implications include consulting parents regarding changes in a child's behavior.

Keywords: assessment, developmental disability, medical complexity, nonverbal children, pain, pediatrics

wide range of pain-associated behaviors exists.[14, 16] Neurotypical children tend to have a narrower range of such behaviors, making pain easier to identify.[17] When experiencing pain, some children with medical complexity may appear to seek comfort and present as irritable and inconsolable, while others may present as quiet, somnolent, or withdrawn.[14, 16] Moreover, some may display behaviors not usually associated with pain, such as noises and expressions consistent with laughter.[16] (For a list of select pain assessment tools and indications for use, see Table 1.)

In this population, comparing a child's current behavior with baseline and parent-reported pain behaviors can be useful and is recommended.[14, 16] Research indicates that parents can reliably identify and differentiate their child's usual behaviors from behaviors indicative of pain.[14, 16, 18] For instance, a parent might report that a child "isn't acting like herself [or himself]." Certain social behaviors such as "tries to hide or bury self" or "withdraws with arms over head" are also known to be associated with pain.[14] Given the challenges in assessing pain in this population, identifying the source of the pain often also involves an extensive medical workup to confirm or rule out specific ailments.

Study purpose. Our purpose was threefold: to describe the signs and symptoms that parents of nonverbal children with medical complexity found worrisome, to determine the sources of pain in these children, and to identify nursing pain assessment practices in this population. Because the care of nonverbal children with medical complexity is interdisciplinary, it's imperative that clinicians understand both the medical and nursing processes related to pain evaluation. For example, a nursing assessment of worsening pain upon initiation of feeding or during a diaper change may direct further medical evaluation to identify the source.

METHODS

Sample and setting. Before data collection began, the study team obtained approval from the hospital's institutional review board, with a waiver of consent for retrospective chart review of the electronic health record (EHR). The sample included children with medical complexity admitted to a 395-bed pediatric teaching hospital in the northeastern United States with a chief concern of pain behaviors of unknown origin. Patients younger than 25 years of age who were admitted between June 1, 2012, and June 30, 2014, under the care of the Complex Care Service (a specialty service caring for children with medical complexity) were eligible for inclusion.

Based on chart review, the study team identified 68 patients admitted during the study period with at least one of four diagnostic codes—those for ill-defined condition, general pain, abdominal pain, and altered mental status—for possible inclusion. Attending physicians enter these diagnostic codes in patient charts during the billing process. A diagnosis of altered

Table 1. Select Pain Assessment Tools and Indications for Use

Tool	Assessment Method	Population Age	Strengths	Limitations	Web Link
For use in both children with medical complexity[a] and neurotypical children					
r-FLACC	• Behavioral • Observational	≥ Newborn	Simple to use	Not based on baseline behavior of child	www.mghpcs.org/eed_portal/Documents/Pain/Pediatric/FLACC_scale.pdf
NCCPC-R, NCCPC-PV	• Behavioral • Physiologic	3–18 years	Comprehensive	• Takes time to populate • Not based on baseline behavior of child	NCCPC-R: www.community-networks.ca/wp-content/uploads/2015/07/PainChklst_BreauNCCPC-R2004.pdf
For use in children with medical complexity					
INRS	• Multidimensional; based on caregiver response • Observational	≥ 3 years	• Weights pain behaviors • Includes baseline behaviors	Takes time to populate	www.marthaaqcurley.com/inrs.html
PICIC	Behavioral	No age range noted	Simple to use	• Requires further testing • Not based on baseline behavior of child	N/A
Pediatric Pain Profile	• Behavioral • Observational	1–18 years	• Simple to use • Includes baseline behaviors	• Reversed scoring • Takes time to populate • Requires further testing	www.ppprofile.org.uk
For use in neurotypical children					
McGill Pain Questionnaire	Self-report	≥ 13 years	Inexpensive to reproduce	Numerical rating may be difficult for younger children	www.gem-beta.org/public/DownloadMeasure.aspx?mid=1348%20
Numeric Rating Scale	Self-report	≥ 8 years	• Quick and simple to use • Inexpensive to reproduce	Numerical rating may be difficult for younger children	N/A
Oucher	Self-report	3–12 years	Quick and simple to use	Numerical rating may be difficult for younger children	www.oucher.org/the_scales.html
Visual Analog Scale	Self-report	≥ 8 years	• Quick and simple to use • Inexpensive to reproduce	Lower reliability in patients with literacy challenges	www.trialdatasolutions.com/tds/howto/vas.jsp
Wong–Baker FACES Pain Rating Scale	Self-report	3–8 years	• Quick and simple to use • Preferred by children • Inexpensive to reproduce	Could confound pain intensity with emotion or affect	www.wongbakerfaces.org

INRS = Individualized Numeric Rating Scale; N/A = none available; NCCPC–PV = Non-Communicating Children's Pain Checklist–Postoperative Version; NCCPC-R = Non-Communicating Children's Pain Checklist–Revised; PICIC = Pain Indicator for Communicatively Impaired Children; r-FLACC = revised Face, Legs, Activity, Cry, Consolability scale.

[a] Children with medical complexity as defined in this article.

mental status was included because it's used in this population when a caregiver seeks medical care after observing a nonverbal person behaving in an unexpected manner.

The inability to obtain a child's self-report of pain or illness history and presenting symptoms prolongs the evaluation process.

Exclusion criteria included having more than very limited verbal ability, since being able to self-report subjective symptoms allows for a more focused medical evaluation; being admitted for reasons other than pain evaluation; and being able to identify pain sites and characteristics. Twenty-two children were thus excluded. Forty-six remaining patients met the inclusion criteria. Some had very limited verbal ability (they could say "mama" and "dada") but were unable to communicate their pain history, pain location, or aggravating and alleviating factors by any means (verbally, nonverbally, or with the use of assistive technology). All subjects were medically complex and dependent on caregivers and medical devices for care. (Such dependence might include, for example, receiving nutrition via feeding tubes and relying on others to meet basic needs, such as bathing, dressing, and toileting.)

Data collection and analysis. Demographic data (age, sex, underlying conditions, and length of stay) were extracted from the EHR. The reason for admission (as described in the admission notes), number of previous admissions for pain evaluation, physical examinations, consultative services, diagnostic studies, and discharge diagnoses were collected to facilitate description of the assessment process.

The pain assessment tool used, frequency of pain assessments, and documented pain scores throughout hospitalization were also collected. At the study site, hospital policies guided the use of pain assessment tools. For children unable to verbalize pain, the Individualized Numeric Rating Scale (INRS) was identified for use. The INRS is an 11-point scale built through parent–provider collaboration; it's based on a child's usual behaviors when not in pain and on pain behaviors identified by parents or guardians and other caregivers.[18] (See Table 2 for a sample INRS.) For preverbal and neurotypical children younger than age seven, the revised Face, Legs, Activity, Cry, Consolability (r-FLACC) scale is used. The r-FLACC is an 11-point behavioral scale that also incorporates parent- or guardian-identified pain behaviors. With children who can verbally convey pain, the use of the Wong–Baker FACES Pain Rating Scale and the Numeric Rating Scale (NRS), both 11-point scales, are identified for use. Though not intended for use with nonverbal patients, these tools were also sometimes used with the study sample, perhaps to facilitate proxy report. In our study, a "unique nursing pain assessment" was defined as one or more documented assessments per each incidence of documentation. For example, a pain scale score recorded at the same "time stamp" as a qualitative description (such as "crying") was considered a single assessment.

The study team also reviewed admissions with a chief complaint of pain behaviors of unknown origin outside the specified date range, in order to better understand the context of this type of admission. That said, only data charted within the study date range were included for analysis. Because EHR documentation of measures of cognition, language, or disability existed for only a few subjects, those variables were not included. Three of us (BLQ, JCS, DM) manually extracted and classified data from individual patient charts to a data matrix. Checks for consistency in data transcription practices and for accuracy of transcribed data were employed. Analysis included calculating descriptive statistics using Microsoft Excel version 15.

Table 2. A Sample INRS Built Collaboratively by Parents or Guardians and Providers

Pain Rating	Pain Behaviors
10 = worst possible pain	Quiet, rigid, eyes closed
9	Crying loudly
6	Crying, arms and legs rigid
5 = moderate pain	No longer will eat
4	Moaning, legs straight and rigid
2	Whimpering
0 = no pain	Laughing, smiling

INRS = Individualized Numeric Rating Scale.
Note: Although an INRS scale allows for the possibility of assigning a number from 0 to 10 to a given behavior or behaviors, not all numbers are necessarily assigned.

Table 3. Sample Demographics, N = 46

Characteristics	n (%)	Mean (SD)	Range
Female Male	24 (52) 22 (48)	–	–
Age, years	–	13.3 (6.2)	0.6–25
Length of stay, days	–	9.7 (11.7)	1–64.4
Pain prior to admission, days	–	10 (21.2)	0–90
Prior PCP visit for pain of unknown origin	34 (74)	1.2 (1.3)	0–6
Prior ED visit for pain of unknown origin	40 (87)	1.3 (1.2)	0–7
Prior admission for pain of unknown origin	46 (100)	1.3 (0.9)	1–7
Chronic conditions present before admission[a]			
Seizure disorder	21 (46)	–	–
Cerebral palsy	16 (35)	–	–
Weakness or paralysis	12 (26)	–	–
Has a VP shunt	7 (15)	–	–
Causes of medical complexity			
Hypoxic ischemic encephalopathy	11 (24)	–	–
Neonatal infections	6 (13)	–	–
Chromosomal abnormalities	7 (15)	–	–
Congenital brain abnormalities	4 (9)	–	–
Cause not identified	18 (39)	–	–

PCP = primary care provider; VP = ventriculoperitoneal.

[a] Most children had more than one such condition.

RESULTS

Sample. In accordance with the inclusion criteria, all 46 subjects had a cognitive–chronological age mismatch, profound developmental delays, limited or no verbal abilities, and multisystem diagnoses, and were completely dependent on others for care. None was able to self-report pain. The mean age was 13.3 years (range, 0.6 to 25). Although most subjects were younger than 21 years, we also included three patients ages 21 to 25 years, since many children with medical complexity remain in the care of families and pediatric providers even after the age of 21.

Most of the subjects had several previously diagnosed chronic conditions. The most common were seizure disorders (n = 21; 46%) and cerebral palsy (n = 16; 35%). The most common identified cause of medical complexity was hypoxic ischemic encephalopathy (n = 11; 24%); in many cases no cause had been identified (n = 18; 39%). The study sample represented about 10% of patients admitted to the Complex Care Service during the study period (46 of 454 patients) and less than 1% of all patients hospitalized at the study site during that period (46 of 52,086 patients). A total of 30% (n = 14) of the study sample required ICU care during their hospitalization, compared with just 6% of all patients admitted to the facility during the same time period. (See Table 3 for the sample demographics.)

Presenting symptoms. The most commonly reported symptoms prompting parents to seek medical evaluation were abdominal pain or distention (n = 20; 43%), parental recognition of pain (n = 16; 35%), and irritability (n = 15; 33%). Many children had visited their primary care provider (mean, 1.2 visits) or the ED (mean, 1.3 visits) for the same complaint before the studied admission. Patients experienced worsening symptoms of pain for a mean of 10 days before the studied admission, and patients were hospitalized for a mean of 9.7 days. (For more on presenting symptoms and resulting diagnoses, see Table 4.)

Sources of pain. The most common discharge diagnoses were infection, including urinary tract infection (n = 14; 30%); constipation (n = 9; 20%); and increased seizure activity related to low levels of antiepileptics (n = 6; 13%). Three of the children experiencing infection-related pain were ultimately diagnosed with urinary tract infections. Ten children (22%) had several conditions ruled out before they were determined to have chronic pain conditions. Children with a diagnosis of chronic pain had the longest mean length of stay (17.6 days; range, 3 to 64). Children in all diagnostic groups had presented with pain-associated symptoms of irritability, feeding intolerance, changes in mental status, and emesis. (For more on pain assessment and discharge diagnoses, see Table 5.)

Forty-four children (96%) had at least one diagnostic study performed during the evaluation process, with 39 children (85%) undergoing at least one X-ray. The majority of X-rays (62%) yielded results that led to diagnosis. Although the findings of most other diagnostic studies were within normal limits, the X-ray findings were helpful in ruling out certain conditions. Consultation with specialty services was common, with a mean of four consultations per admission. The most commonly consulted services were neurology (n = 22; 48%) and gastroenterology (n = 18; 39%). (For more on diagnostic studies and specialty consultations, see Table 6.)

Pain assessment. A total of 3,303 pain assessments were documented, including both 2,870 tool-based assessments and 433 nurse-documented pain observations. On average, nurses documented seven pain assessments per patient per day.

Table 4. Patients' Presenting Symptoms and Subsequent Discharge Diagnoses

Presenting Symptoms[a] n (%)	**Discharge Diagnoses n (%)**							
	Infection[b] 11 (24)	Chronic pain 10 (22)	Constipation 9 (20)	Seizures 6 (13)	UTI 3 (7)	Failure to thrive 3 (7)	Dehydration 3 (7)	Subdural hematoma 1 (2)
Abdominal pain or distension 20 (43)	5	5	6	1	1	2	–	–
Irritability 15 (33)	8	6	5	3	3	1	3	1
Parental recognition of pain 16 (35)	8	6	5	2	2	–	2	1
Feeding intolerance 14 (30)	3	1	5	1	1	1	1	1
Change in mental status 10 (22)	6	2	1	2	1	1	1	1
Emesis 8 (17)	4	1	1	1	1	1	3	1
Fever 5 (11)	5	–	–	–	2	–	–	–
Diarrhea 2 (4)	–	–	–	–	1	–	1	–
Breath holding 1 (2)	–	1	1	1	–	–	–	1
Increased muscle tone or spasticity 1 (2)	–	1	1	1	–	–	–	1

UTI = urinary tract infection.

[a] Many children presented with multiple symptoms; [b] non-UTI.

Note: Parents and other caregivers observed irritability, feeding intolerance, changes in mental status, and emesis in children across all diagnostic groups. This table displays the variability in subjects' pain display across different ailments.

Table 5. Patients' Pain Assessments and Discharge Diagnoses

Discharge Diagnosis	Patients n (%)	LOS in Days per Patient	Median LOS in Days (range)	Tests per Patient	Pain Assessments per Day	Median Pain Score (0–10)[a]
Infection[b]	11 (24)	8.6	6 (1.9 –24.8)	2.5	7.7	4
Chronic pain	10 (22)	17.6	5.5 (3–64.4)	1.6	7.3	5
Constipation	9 (20)	7.3	3.9 (1.2–26)	2.1	9	4
Seizures	6 (13)	6.3	7.1 (3.1–12.9)	1.8	6.3	5
UTI	3 (7)	4.8	4.2 (1.8–8.5)	1.5	7.6	5
Failure to thrive	3 (7)	4.6	3.3 (2.1–8.4)	2.3	7.8	4
Dehydration	3 (7)	8.5	4.9 (3–17.6)	0.7	8.1	5
Subdural hematoma	1 (2)	3.6	3.6	2	4.4	0

LOS = length of stay; UTI = urinary tract infection.

[a] Pain scores of 0 or "sleeping" were not included in the calculation; [b] non-UTI.

Note: This table shows lengths of stay, tests, pain assessments, and pain scores organized by each discharge diagnosis following an admission for pain of unknown origin. Infections and constipation were determined as the source of pain for 50% of the study sample.

Most tool-based assessment scores were quantified using a scale of 0 to 10 (n = 2,685; 94%). If the patient was asleep at the time of assessment, this was sometimes documented nonnumerically as "sleeping" (n = 185; 6%) (see Figure 1). The mean pain intensity score on the 0 to 10 scales was 1.1 (SD, 2.33). "Sleeping" was excluded from this calculation in order to permit analysis of the numeric data. When we also excluded "no pain" scores of 0, the mean pain intensity score was 4.7 (SD, 2.5).

Another 433 pain assessments (13%) were nurse-documented observations related to pain. Among the most common were "no evidence of pain" (n = 250, 58%), "calm" (n = 60, 14%), "expresses pain" (n = 29, 7%), and "crying/cannot comfort" (n = 25, 6%). Other documented observations included "increased heart rate/blood pressure" (2%), "pain improved" (2%), "parent observation of pain" (2%), and "muscle spasms" (1%). "Localizes pain," "restless," "guarding," and "screaming" were documented in fewer than 1% of the subjects.

On average, nurses documented pain every 3.5 hours (range, 0 to 20.5). The most commonly used method of pain assessment was the r-FLACC (n = 2,387, 72%). The Wong–Baker FACES Pain Rating Scale (n = 137, 4%), the INRS (n = 95, 3%), and the NRS (n = 66, 2%) were also used.

When pain was quantified as greater than 4 on a 0-to-10-point scale (n = 334), a majority of reassessments were performed within two hours (n = 196, 59%). For pain scores greater than 4 with a documented intervention, 82% (n = 161) showed a documented reduction in pain intensity of 30% or more within two hours. Across the entire patient sample, the mean pain score on admission was 1.7 (range, 0 to 9; SD, 2.41), and 0.1 at discharge (range, 0 to 5; SD, 0.7). On scales of 0 to 10, after excluding scores of 0 or "sleeping," nurses documented the highest median pain scores for children diagnosed with chronic pain, urinary tract infections, and seizures. For all three subgroups, the median score was 5.

Elicit parent or caregiver knowledge of the child in order to guide assessment and evaluation, when possible.

DISCUSSION

The evaluation of pain in children with limited or no verbal abilities presents challenges. A thorough history and examination should guide evaluation, and the risks of missing a specific pain source must be weighed against the level of invasiveness of diagnostic tests.[1] Many of the discharge diagnoses we found (such as constipation and urinary tract infections) are also common among verbal patients and can be readily identified and managed in a primary care setting. But for the subjects in our study, we observed relatively long lengths of stay (mean, 9.7 days) and a high rate of ICU admissions (30%), many consultations with specialists (mean, 4 consultations per admission), and multiple diagnostic studies (96% of children had at least one). Not surprisingly, since chronic pain is diagnosed by exclusion, patients whose source of pain was determined as such had longer lengths of stay.

There are several reasons for the increased use of acute care services by children with medical complexity. The inability to obtain a child's self-report of pain or illness history and presenting symptoms prolongs the evaluation process. The child's medical complexity usually necessitates multiple diagnostic studies to rule out potentially life-threatening conditions. For example, this population of children often has medical "hardware" (such as ventriculoperitoneal shunts, intrathecal pumps, or spinal rods) in place. Depending on how the patient presents, malfunction or infection of the hardware may have to be systematically ruled out.[19] Such evaluations take time. It's also worth noting that targeted evaluations may offer opportunities for other medical issues to be identified or evaluated. For example, one study subject with a urinary tract infection was found to have electrolyte imbalances, which required some changes in medications and additional days of inpatient observation.

Across the sample, nurses scored pain quite low even as an admission related to pain was in progress. In some cases, although a pain rating was documented, the tools or methods used to assess pain were not. Although the INRS is identified for use in assessing pain in children with medical complexity at the study site, this tool guided only 3% of pain assessments. It's possible that its use was hindered by nurses' perception that collaborating with parents to build the tool will be time consuming.[20, 21] Many nurses documented use of the NRS and the Wong–Baker FACES Pain Rating Scale. Though these scales aren't typically used for children with medical complexity, they may have been used to facilitate proxy reports of pain. In general, though, proxy ratings often underestimate pain,[22, 23] which can contribute to management disparities.[24-26] Moreover, it wasn't clear whether a nurse or a parent had served as the proxy.

Practice recommendations. Identifying and addressing areas for practice improvement when caring for children with medical complexity is of vital importance, particularly since the prevalence of chronic complex conditions in children is reportedly rising.[19] Clinicians may require continuing education related to the use of pain evaluation techniques for these children. Teachers, nurses, and other professionals providing care to children with medical complexity have called for more education on the subject.[27, 28]

Like all patients, nonverbal children with medical complexity require a balance of standardized and individualized care. Some health care providers may view standardizing the care of these children as impossible to achieve. Although individual approaches to care are important, some standardization can occur. When providing care to such children who are admitted for pain of unknown origin, consider the following recommendations.

Elicit parent or caregiver knowledge of the child in order to guide assessment and evaluation, when possible. In our study, as in others,[14, 16] parents were able to identify pain behaviors and to seek care when appropriate. Providers can proactively elicit information about pain from parents and caregivers by asking questions, including:

- What are your child's behaviors when not in pain (baseline)?
- How do you know when your child has pain?
- Can you differentiate between your child's mild, moderate, or severe pain?
- Can you link your child's pain behaviors to values on a numeric scale, with 1 indicating mild pain and 10 indicating the worst possible pain?

Table 6. Diagnostic Studies and Specialty Consultations, N = 46

Diagnostic Study	Study Patients n (%)	Abnormal Findings n (%)
X-ray	39 (85)	24 (62)
Ultrasound	15 (33)	5 (33)
CT scan	15 (33)	5 (33)
ECG	11 (24)	0 (0)
EEG	11 (24)	3 (27)
MRI	7 (15)	2 (29)
Endoscopy	4 (9)	0 (0)
Consultation with Specialty Services		
Neurology	22 (48)	–
Gastroenterology	18 (39)	–
Orthopedics	10 (22)	–
Pain treatment	9 (20)	–
Neurosurgery	8 (17)	–
Gynecology	8 (17)	–
General surgery	6 (13)	–
Palliative care	6 (13)	–
General pediatrics	5 (11)	–
Psychiatry	3 (7)	–

CT = computed tomography; ECG = electrocardiogram; EEG = electroencephalogram; MRI = magnetic resonance imaging.

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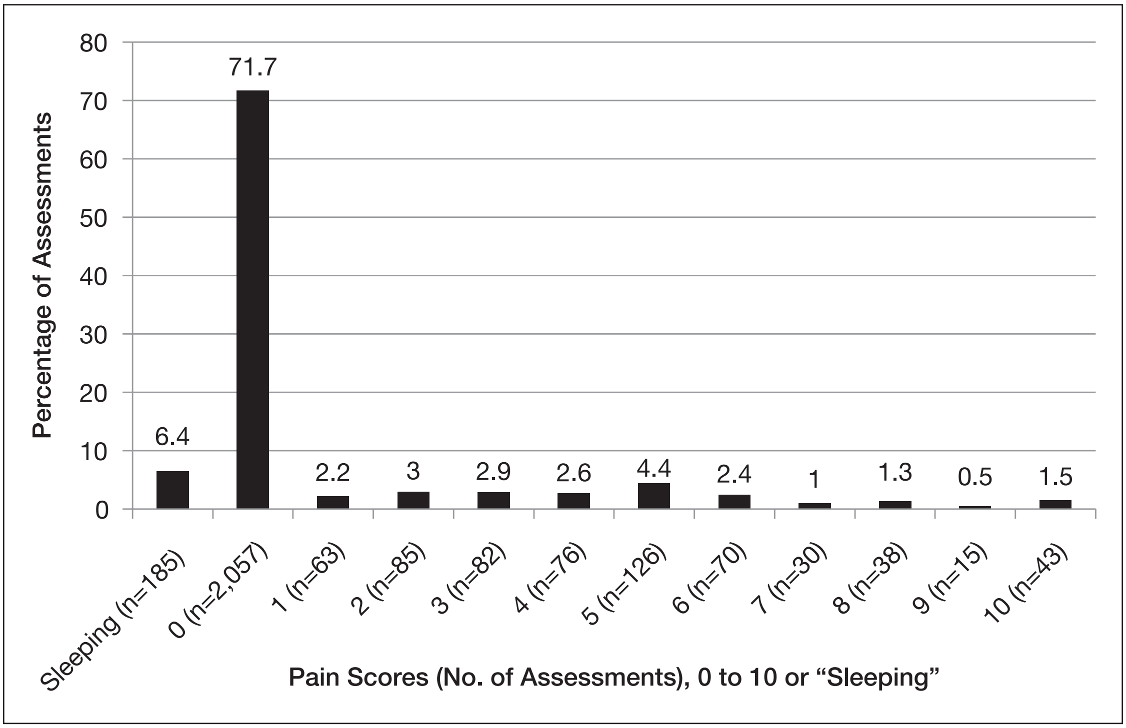
Figure 1. Distribution of Tool-Based Pain Assessment Scores, n = 2,870



Assess for the presence of pain even when a child appears to be sleeping, or when there are indications of a change in mental status (changes in mood or affect, or the appearance of unexpected or unusual behaviors). Children in pain may sleep to avoid social interaction and decrease stimulation and activity.[14] In our study, 22% of the subjects presented for pain evaluation because of a change in mental status—parents or guardians thought they weren't acting like themselves.

Clinicians may require continuing education related to the use of pain evaluation techniques for these children.

Use pain assessment tools best matched to the patient's cognitive abilities. With children who can self-report pain intensity, the accuracy of such report will depend on the child's ability to understand seriation (the ability to order objects or numbers) as described by Piaget.[29] With nonverbal children with medical complexity who cannot self-report, use tools that incorporate parent or guardian input, such as the INRS.[18] If parent–provider collaboration for building an INRS is not possible, use observational tools.[12] Regardless of the tool used, be sure to document the method of pain assessment.

Rule out life-threatening sources of pain, and don't overlook common sources of pain such as infection, constipation, neuropathy, and subtherapeutic levels of medications.

Study limitations. The study sample may be considered small (less than 50 patients) for a hospital-based study. This may affect the generalizability of findings. It's worth noting that researchers in this area must often work with small sample sizes because relatively few children meet the defined criteria for medical complexity. This study relied on data obtained through retrospective chart review; limitations include missing charts, incomplete documentation, and variances in the quality of documentation. It's possible that in some cases, the actual care provided exceeded documented care in both frequency and quality.

CONCLUSIONS

The final discharge diagnoses covered a wide range. A systematic approach to pain evaluation could help to ensure that the diagnostic process is both thorough and efficient. Common childhood ailments such as constipation or urinary tract infection, as well as other causes, must be considered when diagnosing pain in nonverbal children with medical complexity.

Implications for clinical practice include consulting parents regarding changes in a child's behavior.

Although children with medical complexity represent a small percentage of the pediatric population, they use a high proportion of health care services. When pain assessment is inadequate or lacking, these children suffer unnecessarily. Continuing to study pain assessment in this population is important. Further multisite studies are needed, as these would offer researchers opportunities to work with larger sample sizes and would permit greater confidence in the generalizability of findings. Researchers should also consider including children with complex chronic conditions who have some verbal abilities and can self-report. Having their added perspective might broaden our understanding of the pain experiences of children with medical complexity. ▼

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REFERENCES

1. Hauer J, et al. Pain assessment and treatment in children with significant impairment of the central nervous system. *Pediatrics* 2017;139(6).
2. Cohen E, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics* 2011;127(3):529-38.
3. Hauer J. Identifying and managing sources of pain and distress in children with neurological impairment. *Pediatr Ann* 2010; 39(4):198-205.
4. Balogh R, et al. Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability—a population perspective. *J Intellect Disabil Res* 2010;54(9):820-32.
5. Hauer JM, Solodiuk JC. Gabapentin for management of recurrent pain in 22 nonverbal children with severe neurological impairment: a retrospective analysis. *J Palliat Med* 2015; 18(5):453-6.
6. Berry JG, et al. Trends in resource utilization by children with neurological impairment in the United States inpatient health care system: a repeat cross-sectional study. *PLoS Med* 2012; 9(1):e1001158.
7. Simon TD, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics* 2010;126(4):647-55.
8. Mackie AS, et al. Hospital readmissions in children with congenital heart disease: a population-based study. *Am Heart J* 2008;155(3):577-84.
9. Berry JG, et al. Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals. *JAMA* 2011;305(7):682-90.
10. Hauer JM, et al. Gabapentin successfully manages chronic unexplained irritability in children with severe neurologic impairment. *Pediatrics* 2007;119(2):e519-e522.
11. Hill DL, et al. Point prevalence study of pediatric inpatients who are unable to communicate effectively about pain. *Hosp Pediatr* 2014;4(6):382-6.
12. Quinn BL, et al. Pain assessment in children with special needs: a review of the literature. *Except Child* 2015;82(1):44-57.
13. Quinn BL, et al. Pediatric pain assessment by drawn faces scales: a review. *Pain Manag Nurs* 2014;15(4):909-18.
14. Solodiuk JC. Parent described pain responses in nonverbal children with intellectual disability. *Int J Nurs Stud* 2013; 50(8):1033-44.
15. Crellin DJ, et al. Systematic review of the Face, Legs, Activity, Cry and Consolability scale for assessing pain in infants and children: is it reliable, valid, and feasible for use? *Pain* 2015;156(11):2132-51.
16. McGrath PJ, et al. Behaviours caregivers use to determine pain in non-verbal, cognitively impaired individuals. *Dev Med Child Neurol* 1998;40(5):340-3.
17. Herr K, et al. Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. *Pain Manag Nurs* 2011;12(4):230-50.
18. Solodiuk JC, et al. Validation of the Individualized Numeric Rating Scale (INRS): a pain assessment tool for nonverbal children with intellectual disability. *Pain* 2010;150(2):231-6.
19. Russell CJ, Simon TD. Care of children with medical complexity in the hospital setting. *Pediatr Ann* 2014;43(7):e157-e162.
20. Hunt KA, Franck LS. Special needs require special attention: a pilot project implementing the paediatric pain profile for children with profound neurological impairment in an in-patient setting following surgery. *J Child Health Care* 2011;15(3): 210-20.
21. Quinn BL, Smolinski M. Improving school nurse pain assessment practices for students with intellectual disability. *J Sch Nurs* 2017:1059840517722591.
22. McNamara MC, et al. Effect of education on knowledge, skills and attitudes around pain. *Br J Nurs* 2012;21(16):958-64.
23. Prkachin KM, et al. Underestimation of pain by health-care providers: towards a model of the process of inferring pain in others. *Can J Nurs Res* 2007;39(2):88-106.
24. Malviya S, et al. Difficult pain assessment and lack of clinician knowledge are ongoing barriers to effective pain management in children with cognitive impairment. *Acute Pain: International Journal of Acute Pain Management* 2005;7(1):27-32.
25. McGuire BE, Kennedy S. Pain in people with an intellectual disability. *Curr Opin Psychiatry* 2013;26(3):270-5.
26. Voepel-Lewis T, et al. The reliability and validity of the Face, Legs, Activity, Cry, Consolability observational tool as a measure of pain in children with cognitive impairment. *Anesth Analg* 2002;95(5):1224-9.
27. Quinn BL. 'It's not easy': school nurse pain assessment practices for students with special needs. *Pain Manag Nurs* 2016; 17(2):119-31.
28. Quinn BL, Serna RW. Educators' experiences identifying pain among students in special education settings. *J Sch Nurs* 2017: 1059840517747974.
29. Piaget J. Development and learning. *J Res Sci Teach* 1964; 2(3):176-86.