Original Research

Caregiver-Reported Pain Management Practices for Individuals With Cerebral Palsy

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Abstract *Objective:* To investigate types and intensity of pain experienced by individuals with cerebral palsy (CP) and common pain-relieving approaches used by caregivers.

Design: The approach was cross-sectional, using standardized interviews.

Setting: Individuals with CP were recruited from a specialty health care hospital.

Participants: Eighty-six individuals (N=86; mean age, 17.2 years; male, 58%) with CP and complex communication needs participated.

Interventions: Not applicable.

Main Outcome Measures: Pain type, mean pain intensity (MPI) (graded on a scale of 0=no pain to 10=worst possible pain), and mean pain relief (MPR) (graded on a scale of 0=intervention did not help at all to 10=intervention completely relieved pain) were assessed by caregiver report as part of the Dalhousie Pain Interview for each type of pain experienced in the previous 7 days.

Results: Caregivers reported that 58 participants (67%) had experienced pain in the previous 7 days. MPI was 7.7±1.8 when the pain was worst in the previous 7 days. The 2 most common types of pain included musculoskeletal pain (n=70) and gastrointestinal pain (n=11). The most frequent treatment to relieve musculoskeletal pain was changing positions (n=27, MPI=5.1±2.3, MPR=6.6±2.1), medication (n=25, MPI=7.4±1.6, MPR=5.3±1.9), and massage (n=19, MPI=6.7±1.9, MPR=5.2±1.7). To treat gastrointestinal pain, medication was typically used (n=4, MPI=4.8±1.4, MPR=5.5±1.0), although no treatment was just as common (n=4, MPI=4.5±2.3).

Conclusions: The results indicate that musculoskeletal pain is prevalent in individuals with CP, and changing physical positions and providing medication are strategies most used by caregivers.

Cerebral palsy (CP) is a group of disorders affecting movement, balance, and posture. Pain is a common and debilitating comorbidity to CP.[1] Pain has the potential to affect many aspects of life including mobility, communication, learning, and quality of life.[2-4] More than one source of pain is often present, and common etiologies of pain in CP include gastrointestinal, musculoskeletal, rehabilitative-related, and procedural pain.[3,5,6]

Individuals with CP experience acute and chronic pain.[6] Pain can be difficult to identify because of communication difficulties and cognitive impairments often associated with CP.[7] Furthermore, indicators of pain in individuals with severe CP (eg, moaning, self-injury) can also be exhibited when the individual is not in pain, making it difficult for caregivers to identify pain.[8] Consequently, barriers to treating pain in individuals with CP may include lack of caregiver and provider knowledge about pain in those with CP (and other populations with developmental disability), as well as uncertainty about the identification and effectiveness of pain treatments.[6]

Standardized approaches to pain assessment are necessary to evaluate the presence and severity of pain and to facilitate appropriate treatment when needed. Self-report of pain is appropriate for individuals with CP without cognitive impairment. However, depending on the severity of communication impairment, self-report may be limited or even impossible to obtain in individuals with severe CP. Within the last decade, several proxy-report assessment tools have been developed for use for individuals with severe cognitive and communication impairments.[9] These tools facilitate gathering evidence-based assessments of pain to inform and direct pain management practices. The available tools provide practical approaches to measuring pain across settings, including at home, in respite settings, and in outpatient clinics (e.g., the Paediatric Pain Profile)[10]; in research studies (eg, Non-communicating Children's Pain Checklist,[11] Dalhousie Pain Interview,[12] Brief Pain Inventory[13]); and during inpatient hospital stays and/or acute pain episodes (e.g., Revised Faces Legs Activity Cry Consolability scale).[14] It is unclear whether the existing proxy-reported assessment tools are routinely used in clinical practice or daily life, adding to the difficulty of identifying and managing pain in individuals with severe CP.

Despite the knowledge that pain is a persistent and debilitating problem for many individuals with CP, there is limited research investigating treatment approaches and pain-relieving and exacerbating factors. A small, but incomplete, literature exists on the efficacy of indicated clinical treatment approaches, such as botulinum toxin injections, intrathecal baclofen pumps, casting and orthoses, physical therapy, and orthopedic surgery to reduce pain.[15-21] These studies are intended to guide clinical decision making around medical intervention. However, little evidence is available to guide individuals with CP and their caregivers how to manage pain on a daily basis. Evidence exists specific to adults with CP who were adequately able to self-report their pain experiences. Adults with CP reported that their pain was exacerbated by weather, fatigue, and overexertion.[22] Pain was typically reduced when lying down, sleeping, staying active, exercising, and stretching[21,22] and managed using whirlpool, physical therapy, ultrasound, medication (opioids and over-the-counter), heat/ice, and transcutaneous electrical nerve stimulation.[21,23] One study investigated pain management practices in youth with CP ages 8-18 years[24] and reported that walking, running, and immobilization exacerbated pain, while rest and massage or changes in position relieved pain. The majority of this sample was able to self-report their pain (84%) and were ambulatory (85%).

There is a gap on research evidence specific to daily pain management approaches in individuals with CP who cannot self-report their pain and who are nonambulatory, despite the well-documented increase in pain prevalence associated with greater motor impairment.[3] The goal of this study was therefore to use caregiver proxy-report to investigate type and efficacy of common treatment approaches and to explore daily events and circumstances precipitating pain exacerbation in individuals with CP.

Methods

Participants

After Institutional Review Board approval, study participants were children and adults recruited from a specialty children's rehabilitation hospital. Participants scheduled for an initial intrathecal baclofen (ITB) pump implant surgery were invited to participate. Inclusion criteria included participants who (1) had a diagnosis of CP and (2) were between 3-40 years of age. Participants were not excluded based on communication level. A total of 87 participants were consecutively enrolled in the study; however, one caregiver did not complete the questionnaires (n=1). Participants completing the study included 86 individuals with CP (58% male; mean age, 17.2 years; median age, 14.5 years; range, 6-38 years). The majority of participants had a CP diagnosis of quadriplegia (77%) and relied on wheeled mobility (Gross Motor Function Classification System levels IV-V, 86%). Caregivers reported that 41 participants (48%) had a mild/moderate cognitive impairment, and 34 participants (40%) had a severe/profound cognitive

impairment. Further demographic information is presented in table 1.

Procedures

After informed consent was obtained, questionnaires were completed via proxy-report during ITB surgery. For 30 participants, parents completed questionnaires together in a collaborative fashion, with 83% of those couples being the biological parents, 13% being the adoptive parents, and 3% being the stepparents. For 48 participants, 1 parent completed the questionnaires independently; 81% of those were mothers and 19% were fathers. For 8 participants (9.3%), parent/guardian-specific information was missing. Proxy-report was used because the majority of individuals with CP in this sample had cognitive and/or motor impairments limiting their ability to communicate and provide self-report.

Measures

Demographic questionnaire
Caregivers of the participants were asked to report on the age, sex, race, type of CP, Gross Motor Function Classification System level, and gestational age at birth (see table 1). These demographic characteristics were confirmed via chart review.

Dalhousie Pain Interview
The Dalhousie Pain Interview[12] was used to assess type and general description of pain, possible cause, duration, and intensity of pain participants had experienced in the last 7 days. The survey consists of 10 items that were repeated for each type of pain reported and was delivered via interview/survey script. Caregivers were asked to describe the cause of the participant's pain, which was then categorized by the researcher as accidental, gastrointestinal, musculoskeletal, neurologic, stretching, positioning, equipment, spasm, other, or unknown. Pain intensity for each type of pain before any relief strategies was rated on an 11-point scale (0=no pain, 10=worst pain possible). Mean pain intensity (MPI) scores and SD were computed for each type of pain. Pain originally classified as spasm pain (n=13, 18.6%), positioning pain (n=1, 1.4%), and stretching pain (n=1, 1.4%) were combined with musculoskeletal pain (n=55, 78.6%) (see table 1). These types of pains were grouped because there was substantial overlap in caregiver descriptions of these pain types and relief factors did not differ between subtypes.

Of all the types of pain, there were 27 instances (30%) in which caregivers used medication and nonpharmacologic approaches in conjunction to relieve pain.

For each pain type reported, pain relief approaches (if any) were documented. Caregivers reported pain-relieving approaches they used, which were then categorized by the researcher as distraction, massage, relaxation, medication, change positions by caregivers, comfort or physical closeness, stretching/mobility/exercise, or other. Caregivers were asked to determine how well the intervention relieved the participant's pain using an 11-point scale (0=intervention did not help at all, 10=intervention

Table 1	Sample characteristics
Characteristics (N=86)	n (%) or Mean ± SD
Age (y)	
Mean ± SD	17.21±7.68
Range	6-38
Sex	
Male	49 (58.1)
Female	37 (41.9)
Race/ethnicity	
White	68 (79.1)
Black	4 (4.65)
Asian	2 (2.33)
Hispanic/Latino	3 (3.49)
Hmong	0 (0.00)
Native American	4 (4.65)
Other	5 (5.81)
Type of cerebral palsy	
Quadriplegia	66 (76.7)
Triplegia	7 (8.14)
Diplegia	9 (10.5)
Hemiplegia	2 (2.33)
Other	2 (2.33)
Gross Motor Function Classification System level	
I (ambulant without assistance)	0 (0)
II (ambulant without assistive devices, wheelchair required outside home)	3 (3.49)
III (ambulant with assistive devise, self-mobile in wheelchair with limitations)	6 (6.99)
IV (nonambulatory, self-mobile in wheelchair with limitations)	16 (18.6)
V (nonambulatory, self-mobility very limited)	58 (67.4)
Not reported	3 (3.49)
Gestational age at birth	
Term (37-40wk)	40 (46.5)
Moderate to late preterm (32 to <37wk)	10 (11.6)
Very preterm (28 to <32wk)	16 (18.6)
Extremely preterm (23-27 wk)	18 (20.9)
Unknown	2 (2.33)
Cognitive impairment	
No impairment	10 (11.6)
Mild/moderate	41 (47.7)
Severe/profound	33 (38.4)
Not reported	2 (2.3)

completely relieved pain). Mean pain relief (MPR) scores and SD were computed by calculating the average pain relief score corresponding to each treatment approach. For almost every pain type, this sample of caregivers described only 3 distinct approaches to pain relief. Thus, we report on the MPR scores for the top 3 methods described for each type of pain.

When medication (over-the-counter or opioid analgesics) was cited as a pain-relieving approach, medical record chart review was conducted to document the type of medication participants were prescribed for at-home use at the time of the study.

Using the Dalhousie Pain Interview, chronic pain experience was documented. Chronic pain was defined as pain that may come or go but lasts longer than 6 months. Caregivers were asked to describe the participant's pain and identify the onset of chronic pain. Caregivers were also asked to describe a day when their child's pain hurt very badly and when their pain hurt less. These days were described in terms of pain intensity (11-point scale; 0=no pain, 10=worst pain possible), and the child's behavioral/ physical characteristics observed. Caregivers were asked for the circumstances/experiences or events that precipitated pain were documented. Descriptors and precipitating factors were summarized using narrative word count.

Results

Fifty-eight participants (67%) had experienced at least one type of pain in the previous 7 days. Musculoskeletal pain (including spasms, positioning, and stretching pain) was the most common type of pain reported (70 instances), with some caregivers describing multiple locations of musculoskeletal pain (eg, hips, back) with overall pain intensity of 5.8±2.6. Musculoskeletal pain was typically chronic pain that had developed 8±9.4 years prior to study participation and had been experienced, on average, for 78±157.3 hours in the previous week. The most common pain-relieving treatment approach used by caregivers for musculoskeletal pain was changing positions (n=27) (fig 1). Caregivers who changed their child's position to alleviate musculoskeletal pain rated their child's pain as MPI of 5.1±2.3 and reported that changing positions provided MPR of 6.6±2.1. Caregivers who used medication (n=25) rated their child's musculoskeletal pain as MPI of 7.4±1.6 and estimated that medication provided MPR of 5.3±1.9. Caregivers who used massage (n=19) rated their child's musculoskeletal pain as MPI of 6.7±1.9 and felt that massage provided MPR of 5.2±1.7. In some cases, no treatment was provided (n=9) even when pain was rated at MPI of 4.9±2.3 (table 2). The most common type of pain among all age groups and types of CP in our sample was musculoskeletal pain (table 3).

Gastrointestinal pain was the second most common type of pain reported (n=11). Medication was used to treat gastrointestinal pain (n=4, MPI=4.8±1.4, MPR=5.5±1.0), although no treatment was just as common (n=4, MPI=4.5±2.3).

Caregivers also reported neurologic pain (n=3) and "other" pain, which included menstruation pain, pain associated with illness, and dental pain (n=4 (see table 2). Across all pain types, medication was commonly used to treat pain, and 33 caregivers (57%) noted its use and provided MPR of 7.1±2.2 when MPI was rated 6.4±1.9. Medications used to treat pain across all pain types included acetaminophen (n=11, 25%), diazepam (n=8, 18.2%), ibuprofen (n=7, 15.9%), and opioids (n=2, 4.54%) (fig 2, table 4). Nonpharmacologic approaches were used by 28 caregivers (48%) across pain types with MPR scores of 6.5±2.7 when MPI was rated 5.3±2.6. Changing positions was most frequently used (n=28, 36%), followed by massage (n=22, 28%), stretching/mobility/exercise (n=8, 10%), and distraction (n=8, 10%). For 12
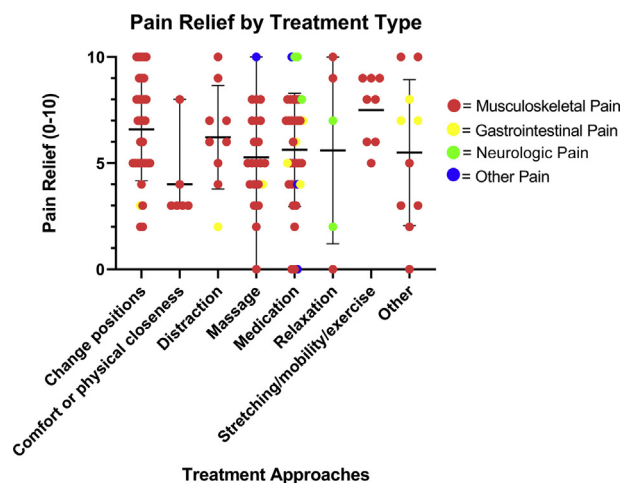

Fig 1 MPR scores associated with all pain treatment approaches reported. MPR scores range from 0 meaning "no pain" to 10 meaning "worst pain possible." Data points are color coded by pain type, and each data point represents an individual response. Mean and SD are represented by the bar and whiskers.

participants (21%) no treatment was provided for their pain, and their caregivers rated their child's pain MPI of 4.2±2.1. Of the 33 caregivers who used medication to treat pain, 26 (78.8%) of those caregivers used a combination of medication and nonpharmacologic approaches to relieve their child's pain.

Fifty-three caregivers (62%) reported their child lived with chronic pain. Chronic pain type largely overlapped with the pain that had occurred in the previous 7 days. Specifically, chronic pain was described as musculoskeletal (n=40, 75%) as well as gastrointestinal (n=4, 7.5%), and the onset occurred, on average, 8.4±7.0 years prior to study participation. The majority of caregivers (n=40, 75%) noted that their child's chronic pain was better on some days than others. On a day when pain was worst, the MPI was 7.7±2.2 (scored 0-10; range, 2-10). Common characteristics used to describe participants on days when pain was worst included crying (n=8, 31%), whiny (n=7, 27%), irritable/angry (n=6, 23%), uncomfortable/ discomfort (n=3, 12%), and frustrated (n=2, 8%). Experiences or circumstances that precipitated days when pain was worst included poor positioning (n=6, 15%), increased activity/exercise (n=5, 13%), weather changes (n=4, 10%), and illness (n=4, 10%). Caregivers were often unaware of what circumstances precipitated increased pain (n=7, 17%) or the question was left blank (n=14, 35%).

On a day when pain was best, 84% of participants had some level of pain (n=43) with MPI rated 2.4±2.0 (scored 0-10; range, 0-10). Common descriptors for participants on days when pain was best included happy (n=17, 38.6%), smiling (n=8, 18.1%), laughing (n=7, 15.9%), alert/interactive (n=6, 13.6%), relaxed (n=3, 6.8%), and engaged (n=3, 6.8%). Events or experiences that precipitated days when pain was best included nice weather (n=3, 8.5%), music (n=3, 8.5%), therapy (n=3, 8.5%), swimming (n=2, 5.7%), and stretching (n=2, 5.7%).

Table 2   Mean pain intensity (MPI) and mean pain relief (MPR) score for each type of pain and associated treatment approach

Type of Pain	Treatment Approach (n)	MPI Before Treatment ± SD[*]	MPR ± SD[†]
Accident (n=2)	No treatment: 2	3.5±2.5	-
Gastrointestinal (n=11)	Distraction: 1	9.0	2.0
	Change position: 1	6.0	3.0
	Massage: 1	2.0	4.0
	Medication: 4	4.8±1.4	5.5±1.0
	Other: 3	7.0±0.7	7.3±0.4
	No treatment: 4	4.5±1.3	-
Musculoskeletal (n=70)	Change positions: 27	5.1±2.5	6.7±2.5
	Comfort or physical closeness: 4	5.6±3.1	4.0±2.0
	Distraction: 7	6.4±2.9	6.7±1.9
	Massage: 20	6.8±2.1	5.1±2.1
	Medication: 25	7.4±2.1	5.3±2.3
	Relaxation: 3	6.0±2.8	6.3±4.5
	Stretching/mobility/exercise: 8	5.1±1.6	7.5±1.5
	Other: 7	7.3±2.2	4.7±3.6
	No treatment: 9	4.9±2.8	-
Neurologic (n=3)	Medication: 3	6.7±0.9	9.3±0.9
	Relaxation: 2	7.0±1.0	4.5±2.5
Other (n=4)	Massage: 1	10.0	10.0
	Medication: 3	4.7±3.5	4.7±3.6
	No treatment: 1	4.0	-

[*] MPI is graded on a scale of 0=no pain to 10=worst possible pain.
[†] MPR is graded on a scale of 0=intervention did not help at all to 10=intervention completely relieved pain.

Caregivers were often unaware circumstances precipitating reduced pain (n=7, 20%) or the question was left blank (n=15, 43%).

Discussion

Pain in CP is a long-recognized problem, but approaches specific to effective management practices, particularly under typical day-to-day circumstances with caregivers, is not well understood. The results of this study, with respect to pain type, are consistent with prior study findings and clearly document that within a 7-day window, musculoskeletal pain and gastrointestinal pain were the most frequently reported pain types.[3,25] The most frequently reported pain-relieving approaches included medication administration and nonpharmacologic approaches, such as changing positions and massage.

Medication was frequently used to treat pain in this sample. When examining treatment of pain in individuals with CP, Hirsch et al.[21] reported that medication was most often used to treat pain, and opioid medication was deemed most effective. While pharmacologic approaches may be effective, medication may have undesirable adverse effects. Individuals with complex medical conditions, such as CP, are more likely to experience medication-related adverse effects and often have other physical comorbidities that complicate medication prescribing.[26,27] For those with impaired cognitive or communication ability, medication adverse effects may be overlooked or misunderstood.[26] Because of these risks, it is important to explore additional or alternative nonpharmacologic pain relief treatment approaches. Interestingly, the majority of parents reported using a nonpharmacologic approach in addition to administering medication.

In this study and in past literature, nonpharmacologic approaches such as changing positions, stretching, and massage were used to alleviate pain.[21,22,24] Our results indicated that nonpharmacologic approaches (massage, stretching, changing positions) resulted in MPR similar or better than medication (see table 2). These results differed from Hirsch et al.[21] This difference may be related to our reliance on proxy-report because of the limited communication abilities of the participants in our sample. Hirsch et al.[21] collected data via self-report from participants with CP with adequate communication and cognitive abilities to do so. Further research is needed to explore the effectiveness of nonpharmacologic pain management approaches in CP; these modalities could result in effective pain management on their own or in conjunction with pharmacologic approaches.

Approximately 62% of this sample's caregivers reported their child was living with chronic pain. This finding is consistent with previous studies examining pain in individuals with CP and highlights the importance of pain assessment and treatment in this population.[4,21,22] Despite the availability of many pain-relieving treatment options, individuals with CP continue to experience pain. Unfortunately, even on days when pain was at its best, individuals with CP were typically not living pain-free.

Caregivers described participants using "crying," "whiny," and "irritable" when pain was worse. Dudgeon et al.[28] identified common pain descriptors used by individuals with non-CP physical disability-related pain. Narrative word counts included "intense," "miserable," "horrible," and "discomforting."[28] While different, descriptors across studies had a similar valence. Our study

Table 3 Mean pain intensity (MPI) and associated mean pain relief (MPR) by medication type

Medication Type	MPI ± SD[*]	MPR ± SD[†]
Musculoskeletal (n=24)		
Acetaminophen (n=9)	6.8±3.0	5.9±2.8
Acetaminophen+codeine (n=1)	6.0	7.0
Diazepam (n=6)	7.5±2.5	7.2±2.1
Hydroxyzine (n=1)	3.0	10.0
Ibuprofen (n=3)	6.3	5.0
Oxycodone (n=1)	10.0	7.0
Unknown medication type (n=11)	6.6±2.8	4.8±2.3
Gastrointestinal (n=4)		
Diazepam (n=2)	7±2.5	6.5±0.5
Ibuprofen (n=1)	5.0	4.0
Unknown medication type (n=1)	5.0	5.0
Neurologic (n=3)		
Acetaminophen (n=1)	1.0	2.0
Ibuprofen (n=2)	6.0±0.0	9.0±1.0
Unknown medication type (n=1)	8.0	10
Other (n=2)		
Acetaminophen (n=1)	5.0	4.0
Ibuprofen (n=1)	5.0	4.0
Unknown medication type (n=2)	9.5±0.5	8.0±4.0

* MPI is graded on a scale of 0=no pain to 10=worst possible pain.
† MPR is graded on a scale of 0=intervention did not help at all to 10=intervention completely relieved pain.

relied on proxy-report; thus, descriptors were focused on observations caregivers could make about the participant rather than self-reporting a subjective experience.

Similar to Schwartz et al.,[22] our sample reported on circumstances, experiences, and events that exacerbate pain in individuals with CP. In our sample and that of Schwartz et al.,[22] overexertion and weather changes exacerbated pain. Schwartz et al.[22] reported that exercise was the most common activity that relieved pain, but this was not found in our sample. This was likely because of the differences in severity of CP and associated ambulatory status. Previous studies have found that ambulatory adults with CP experience less pain with exercise, while non-ambulatory adults experience greater pain.[29,30] Stretching appeared to be associated with pain reduction in both samples.[22] The majority of caregivers were unaware of what circumstances and experiences precipitated pain fluctuations, whereas adults with CP who self-reported were usually able to report on perceived precipitating factors. Not only is pain more prevalent and difficult to detect in individuals with severe CP, but identifying pain precipitating factors is a challenge. Thus, adjusting daily habits and activities to reduce pain flare-ups is extremely difficult if not inherently impossible. Future research investigating pain precipitating factors in individuals with severe CP is needed to improve chronic pain management.
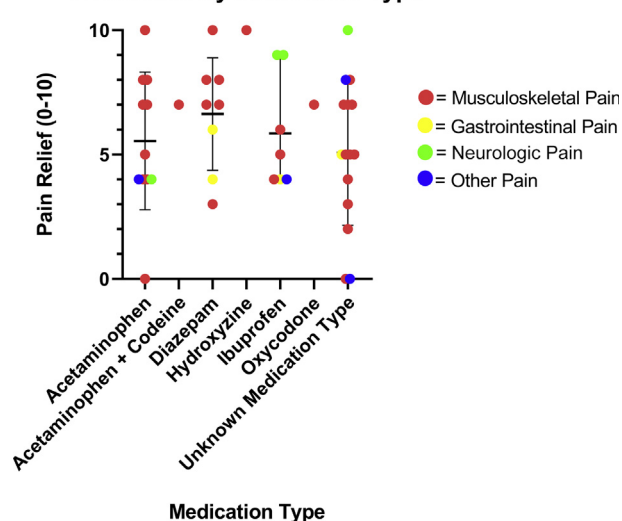
Pain Relief by Medication Type

Fig 2 MPR scores associated with different pain medications used to relieve pain. MPR scores range from 0 meaning "intervention did not help" to 10 meaning "intervention completely relieved pain." Data points are color coded by pain type, and each data point represents an individual response. Mean and SD are represented by the bar and whiskers.

Study limitations

Study-specific limitations include, first, the use of caregiver proxy-report. Relying on some form of proxy-reporting is unavoidable in studies involving individuals who cannot self-report and has become a standard measurement approach in clinical and nonclinical settings. With that acknowledged, it is likely that there are biases operating on the part of the reporter. Such factors need to be investigated in future research specific to individuals living with medically complex developmental disabilities who are dependent on others for their care. Second, participants

Table 4 Two most common pain types by age and CP diagnosis

Characteristics (n)	Pain Type	n (%)
Age		
<11 y old (n=17)	Musculoskeletal	12 (70.6)
	Gastrointestinal	5 (29.3)
11-17 y old (n=41)	Musculoskeletal	36 (87.8)
	Gastrointestinal	5 (12.2)
≥18 y (n=28)	Musculoskeletal	22 (78.6)
	Gastrointestinal	4 (14.3)
Type of CP		
Diplegia (n=8)	Musculoskeletal	5 (62.5)
	Gastrointestinal	3 (25.0)
Triplegia (n=7)	Musculoskeletal	2 (28.6)
	Gastrointestinal	2 (28.6)
Quadriplegia (n=66)	Musculoskeletal	61 (92.4)
	Gastrointestinal	5 (7.57)
Other (n=2)	Musculoskeletal	2 (100)

enrolled in this study were recruited from a specialty rehabilitation hospital who were undergoing ITB pump placement and were not a random sample of the population of individuals with CP. The results are study-specific and may not be representative of all individuals with CP. Data were collected from caregivers while their child was undergoing surgery. We are unsure to what extent caregivers may have been experiencing stress related to the surgery, which may have affected these data. Lastly, when collecting medication usage from the participant's medical record, not all participants had pain medication listed.

Conclusions

Chronic musculoskeletal pain is a common and persistent problem for individuals with CP. Medication and non-pharmacologic interventions were frequently used and considered helpful at managing pain at home. The majority (84%) of individuals who reported chronic pain experienced some level of pain even when pain was at its best. From a clinical and community care perspective, there remains much to be learned about pain management practices that could inform future research designed to document in detail and systematically curate the practice-based evidence for pain management and CP.

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Acknowledgments

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