Survey Results of Pain Treatments in Adults with Cerebral Palsy

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Abstract

Objectives—To identify the types and frequencies of pain treatments used by individuals with cerebral palsy (CP); examine the perceived effectiveness of these treatments; and identify the types of healthcare providers that were accessed for pain-related services.

Design—A cross-sectional survey design was employed. 83 adults (mean age=40.3 years, SD=13.6) with CP indicated their pain location and intensity during the past 3 months. Next, they indicated their use of 24 different pain treatments and the effectiveness of each. Finally, participants indicated the frequency of pain-related healthcare visits to specific providers over the past 6 months.

Results—63% of participants reported experiencing chronic pain and rated their pain intensity over the past week as 5.1/10, on average. The most common pain locations were the lower back, hips, and legs. Physical interventions (e.g., physical therapy, strengthening) were the most common pain treatments reportedly used, and were rated as moderately effective. Many other treatments were also used, and participants sought pain-related care from a variety of providers.

Conclusions—Although participants reportedly accessed pain care from a variety of providers, and perceived that several types of treatments were effective, many of the treatments rated as effective were rarely used or provided. Future research using clinical trial methods would further elucidate the specific pain treatments that are most beneficial for adults with CP.

Cerebral palsy (CP) is a neurodevelopmental condition that is characterized by motor and postural impairments[1]. Although a variety of physical and cognitive symptoms are recognized as being associated with this condition[2], chronic pain has been the subject of particular clinical and empirical attention in recent years. An early study by Turk and colleagues found that over 80% of a sample of women with CP experienced chronic pain in at least one body location[3]. Our research group at the University of Washington has also

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reported high rates of chronic pain in samples of adults with CP. Specifically, Schwartz and colleagues[4] and Engel and colleagues[5] found that approximately two-thirds of their respective samples experienced persistent pain of 3 months duration or longer. Moreover, a large proportion of these individuals reported that they experienced pain on a daily basis. High rates of chronic pain relative to the general public have also been found in a Norwegian sample of individuals with CP[6].

Although persistent pain is a significant problem for many individuals with CP, the extant literature suggests that pain is inadequately assessed and treated in this patient population. One of the first indications of this came from Murphy[7], who demonstrated through five case examples that pain and other medical problems experienced by patients with CP did not receive adequate attention from healthcare providers. Another early study revealed that impairments in communication and cognition, which are common in individuals with CP[1,8,9], pose particular challenges to the accurate assessment and effective treatment of pain in these patients[10].

More recently, our research group has conducted two investigations on pain and its treatment in adults with CP[11,12]. In the first study, Engel and colleagues[11] interviewed 64 adults with CP about their use and perceived effectiveness of a variety of pain treatment options. The participants reportedly used a variety of interventions, many of which were rated as effective in reducing their pain; however, most did not access healthcare providers for pain management services at all[11]. The second study by Jensen and colleagues[12] followed 50 adults with CP over the course of 2 years, with interviews being conducted at 5 points during the study period. Interestingly, although there was an increase in the frequency of use of several pain treatments over time, average pain intensity did not change significantly during the course of the study. Moreover, and consistent with the study by Engel and colleagues[11], the results also indicated that many of the treatments were rarely used by the study participants[12].

The literature reviewed above provides strong evidence that individuals with CP often experience significant and persistent pain, and that this patient population is at high risk of having their pain undermanaged. This is an important issue, given that persistent pain is associated with a range of negative outcomes (e.g., reduced participation, psychological distress, lower quality of life) for individuals with disabilities, including CP (see review by Ehde et al[13]). It is in this context that the current study was conceived. The overall purpose of this study is to expand further our understanding of the types and frequency of pain-related healthcare resources that are used by adults with CP. This is a replication and extension of our previous work that is discussed above[11,12]. Specifically, we have recruited a new and larger sample of individuals with CP for this study. We have also included several types of pain treatments that were not previously assessed but that have become more widely available to patients since our earlier work. Moreover, since our previous studies, there has been a substantial increase in published research on pain in CP. It might be expected that this increased literature is paralleled by a greater availability/use and perceived effectiveness of pain treatments in this patient population. The current study will be able to address this issue.

The three specific aims of the current study were to: (1) identify the types of pain treatments that are currently being used by adults with CP; (2) examine the perceived effectiveness of these treatments; and (3) identify the types of healthcare providers that are accessed for pain-related services. Research in this area may assist healthcare providers in selecting the pain treatments that are most likely to benefit patients with CP. This work may also help elucidate the pain treatments that should be included in future controlled trials.

METHODS

Recruitment and Data Collection Procedures

Both in-person interviews and mailed questionnaires were used for recruitment and data collection. These different strategies reflect a procedural change by our research group over the course of the study. Recruitment and data collection evolved from in-person to postal primarily due to the significant resource burden of the former. The same study questionnaire was used for in-person and postal procedures.

In-Person Interviews—Individuals with CP who had participated in previous studies conducted by our research group[4,5] were recruited through a mailed letter containing information about the current study and inviting them to participate. Additional participants were also recruited through website and flyer postings described in the section below. Individuals who received a mailed letter indicated their interest in participating in the study by either returning self-addressed stamped postcards or by calling research personnel. These potential participants were provided additional study information and scheduled for an interview at either the University of Washington (UW) or in the participant's home, based on their preference. Participants who were interviewed at UW were provided a bus pass or parking validation. Informed consent was obtained from each participant. Participants were then screened for cognitive impairment using the Modified Mini-Mental Status Exam (MMSE)[14]. Individuals who scored 17 or higher (or 14 or higher if they used a communication device) out of a possible 25 points on the MMSE were deemed eligible to participate in the full study. Demographic data only were collected from individuals who did not meet this eligibility requirement. Interviews lasted approximately 60–90 minutes. All participants, including those who were ineligible due to low MMSE score, were paid $25.

Questionnaires Completed by Mail—Participants were also permitted to complete a paper-and-pencil version of the study questionnaire on their own rather than by interview. Potential participants for the paper-and-pencil assessment were recruited via postings on the UW departmental website and recruitment flyers that were posted in UW medical clinics. Individuals contacted study personnel via telephone to indicate their interest in participating. Potential participants were mailed a packet containing information about the study, two copies of the consent form, a basic contact information sheet, the study questionnaire, and a postage paid envelope for return of completed study materials. Participants were directed to read, complete, and return one signed consent form and retain one copy for their records. They were also instructed to complete and return the contact information sheet and questionnaire. Participants who were unable to complete the questionnaire independently due to fine motor difficulties were allowed to obtain assistance from a significant other. Study personnel reviewed all returned materials and contacted participants whose responses were incomplete or unclear. Participants who completed at least part of the questionnaire were paid $25. The mailed version of the questionnaire was identical to the interview version except that it did not include the MMSE assessment of cognitive functioning. All study procedures were approved by the UW Institutional Review Board (IRB).

Participants—Of the 206 prospective participants who had contact with research personnel regarding this study, the majority (n = 169, 82%) were recruited from previous studies conducted by our research group, as described above[4,5]. An additional 34 (16.5%) individuals were recruited through flyers placed in clinics, the department website, or participant discussions with health care providers, study investigators, or previous research participants. An additional 3 (1.5%) individuals who had previously completed a pediatric survey entitled "Surveys of Chronic Pain and Its Effects on Youth with Disabilities" were

contacted when they reached the age of 18 to assess their interest in participating in the current study.

Of the 206 potential participants, 41 (19.9%) could not be contacted by telephone or mail and 6 (3%) were deceased. Of the remaining 159 potential participants, 35 (22%) declined to participate, 28 (17.6%) did not return telephone calls, attend the interview session, or return a completed questionnaire via mail, and one individual was nonverbal and unable to complete the survey in-person. A total of 95 individuals completed either an in-person interview or mailed in a questionnaire. Of the 61 individuals who attended an interview session and consented to participate in the study, 50 met MMSE eligibility criteria described above. One of the 34 questionnaires that were returned by mail was not sufficiently completed; therefore, data from 33 mailed questionnaires were included in the analyses for this study. All together, data from 83 participants were included in the study, which represents a response rate of 52.2% (not including individuals who were deceased or unreachable).

A recent manuscript[2] used data collected from the same group of individuals as those who participated in the current study. However, the current analyses address distinct questions about pain treatment that were not examined in the prior study.

Measures

Participants completed a survey packet or responded to interview questions that assessed multiple domains of quality of life. In addition to those listed below, the survey/questionnaire protocol included separate measures of general health, physical symptoms, community integration, coping, social support, and overall psychological well-being. For the purposes of the current study, only data collected from the following domains were analyzed.

Demographic and Clinical Characteristics—Participants provided information about their demographic characteristics, including sex, age, race and ethnicity, marital status, education level, and employment status. Information was also collected about the participants' CP clinical characteristics, including CP type, areas of the body affected, and use of mobility devices.

Pain Intensity and Location—Participants were first asked if they were currently experiencing any pain, or whether they had experienced any pain in the past 3 months. Those who responded affirmatively to this question then rated their average pain intensity over the past week on a scale from 0 (no pain) to 10 (pain as bad as could be)[15]. In addition, participants indicated the bodily locations where they experienced persistent bothersome pain; this information was elicited by having participants indentify the affected areas from a list of bodily locations.

Pain Treatments and Healthcare Utilization—Participants indicated whether they had ever used each of 24 different pain treatments. They also rated the amount of relief provided by each treatment on a scale from 0 (no relief) to 10 (complete relief). Finally, participants indicated the frequency of pain-related healthcare visits to specific types of providers over the past 6 months. Although self-reported information about past treatment use and helpfulness may be limited by reporting biases, we feel that it is useful to consider this information because: (1) it is likely to be generally consistent with the actual treatments that have been used by individuals with CP, and (2) it reflects real-life clinical encounters where patients are often the primary (or even sole) source of information concerning their past treatments.

Statistical Analyses

Statistics regarding the survey response rate and demographic and clinical information for respondents were computed for descriptive purposes. The proportion of participants who did and did not report pain during the past 3 months was tabulated. The average pain intensity over the past week was then calculated for those who endorsed the presence of pain during the past 3 months. The frequencies of each bodily location in which they experienced pain was also computed for these participants. The frequency of use and average amount of associated relief for the different pain treatments were calculated. Next, the average number of pain-related visits to specific healthcare providers was examined separately for the entire sample and for participants with moderate-to-severe pain (average pain intensity over the past week is ≥ 5 on a 0–10 scale). Finally, additional exploratory analyses were conducted to determine whether treatment usage rates (chi-square analyses), treatment helpfulness ratings (t-tests), and number of visits to specific healthcare providers (t-tests) differed between participants with unilateral vs. bilateral CP.

RESULTS

Participant Characteristics

The final sample (n = 83) was 55% female, with an average age of 40.3 years (SD = 13.6, range = 18 – 74 years). The vast majority of participants self-reported as Caucasian (88%). Approximately 65% of participants had never been married, 27% were married or living with a partner, and the remainder were separated or divorced. Fifty-nine percent of participants reported some level of education beyond high school, and only 13% did not graduate high school or attain a General Educational Development GED equivalent. Approximately 43% of participants were working full- or part-time, and 76% used a wheelchair (manual and/or electric) for mobility.

Almost half of the participants reported spastic CP (47%), with the remainder reporting mixed (29%), athetoid (16%), ataxic (1%), or hypotonic (1%) CP. Eighty percent of participants had bilateral CP, and 19% had unilateral CP. Approximately 6% and 1% of participants did not respond to the above items assessing CP type and affected area, respectively.

Pain Intensity and Location

Approximately 63% of participants indicated that they were currently experiencing pain and/or had experienced pain in the past 3 months. For these participants, the average pain intensity over the past week was 5.1 (SD = 2.4) on the 0–10 scale. Table 1 contains data on the number of participants who reported pain in each of the assessed bodily locations. The most common pain locations were the lower back (71%), hips (58%), legs (58%), and feet (54%). There were no significant differences (all p values > .05) between participants with unilateral and bilateral CP on the presence of current/recent pain, pain intensity, or pain location.

Pain Treatment

Table 2 contains the results of analyses examining the pain treatments used by participants and their perceived effectiveness. These analyses included only those participants (N = 52) who were currently experiencing pain and/or had experienced pain in the past 3 months. Physical interventions were reportedly used by a substantial number of participants, with physical therapy (current use: 56%, past use: 35%), mobility/ROM exercises (current use: 27%, past use: 48%), and strengthening exercises (current use: 23%, past use: 50%) being the most common. These treatments were reported to be moderately effective (range of average relief = 4.6 – 4.7 on a 0–10 scale). Both over-the-counter (OTC) (e.g.,

acetaminophen, ibuprofen) and opioid analgesics were used by a relatively high proportion of participants; these treatments were also reported to be moderately effective (range of relief = 5.0 – 6.2). Self-applied treatments such as heat (current use: 35%, past use: 42%) and ice (current use: 15%, past use: 42%) were also endorsed by many participants, with heat reportedly providing greater pain relief than ice. The only procedural intervention that was assessed – nerve blocks – had been used by very few participants in this sample, and average effectiveness ratings were modest. Psychological modalities (e.g, hypnosis, counseling/psychotherapy) and complementary/alternative treatments (e.g., acupuncture, magnets) were also endorsed by a relatively small number of participants, and there was notable variability in the reported effectiveness of these treatments (see Table 2).

As can be seen in Table 2, eight treatments (physical therapy, heat, massage, opioid medication, chiropractic adjustment, benzodiazepines, TENS unit, and biofeedback/relaxation training) showed lower rates of present use than past use despite relatively high (> 4 on the 0 – 10 scale) helpfulness ratings. To examine this finding further, additional analyses were conducted in which the mean helpfulness ratings of past users were compared to those of current users for each of the 8 treatments. Significant results (t(44) = 2.47, p = .017) were obtained only for physical therapy, with current users (M = 5.9, SD = 2.6) reporting higher helpfulness ratings than past users (M = 3.8, SD = 2.9) of this treatment. Although significant differences were not found for any of the other 7 treatments (all p-values > .05), the cell counts for many of these treatments were small, resulting in low power. In fact, for each of the 7 treatments, current users reported higher helpfulness ratings than past users; and with the exception of benzodiazepines, these differences in mean ratings exceeded 1 unit on the 0 – 10 scale.

Follow-up exploratory analyses examined whether the use of specific treatments differed between participants with unilateral vs. bilateral CP. The results of chi-square analyses were all non-significant (all p-values > .05), indicating no group differences in self-reported use of any of the assessed treatments. Independent samples t-tests were then conducted to examine group differences in mean treatment helpfulness ratings. Similar to those above, the results of these analyses were also non-significant (all p-values > .05), indicating no group differences in helpfulness ratings for any of the treatments.

Pain-Related Healthcare Utilization

Most of the participants with current/recent pain (85%) reported that they had visited a healthcare provider for pain during the last 6 months. As can be seen from Table 3, there was wide variability in the number of visits to different providers for pain-related concerns. Physical and occupational therapists were accessed most often, with an average of 6.6 (SD = 10.7) visits over this 6-month time frame. Primary care providers (specified as physicians, physician assistants, and/or nurse practitioners in the study questionnaire) were seen for an average of 2.4 (SD = 5.6) pain-related visits, and other providers were seen less often. Participants with moderate-to-severe pain (pain intensity ≥ 5/10, N = 33) reported significantly greater pain-related healthcare utilization over the past 6 months compared to those with less severe pain (94% vs. 68%, respectively; p = .040, two-sided Fisher's exact test). Moreover, participants with moderate-to-severe pain reported significantly more pain-related visits to primary care [t(34.72) = 2.63, p = .013] and emergency room [t(50) = 2.16, p < .036] providers, and, in absolute terms, more visits to chiropractic providers although this difference was of marginal significance [t(32) = 1.74, p < .091]. Conversely, there were no statistically significant differences (all p-values > .05) in visits to specific healthcare providers between participants with unilateral vs. bilateral CP.

DISCUSSION

The current study sought to build on our previous work examining the use and perceived effectiveness of various pain treatments by individuals with CP. The overall results of this study can be summarized as follows: (1) participants reported that they used a large variety of treatments for pain; (2) the perceived effectiveness of the treatments varied considerably; (3) many of the treatments that were rated as effective were rarely used by or provided to the participants; and (4) although pain-related healthcare utilization was reportedly high, the specific types of providers that were frequented varied to a great extent. These findings have important implications for selecting interventions to consider when treating individuals with CP and pain, and also for identifying the most fruitful interventions for researchers to study in randomized clinical trials.

Approximately 63% of the current sample reported chronic pain. This is consistent with previous studies examining pain in persons with CP[4,5,11] and highlights the importance of ongoing pain assessment and treatment in this patient population. Treatments that could be characterized as "physical" in nature (e.g., physical therapy, strengthening and stretching exercises) were the most commonly used by participants with chronic pain. This rate of use is considerably higher than that found in our previous two studies[11,12]. We consider this a positive development, given that regular activity is an important component of most comprehensive treatments for chronic pain (reviewed in Jordan et al[16]). The participants in this study also seemed to benefit from these treatments, in that they rated them as being at least moderately effective on average. While physical therapy has long been a major focus of the clinical management of patients with CP, strength training has only recently been considered an important component[16]. There is a growing evidence base that strengthening exercises confer significant benefit for children and adults with CP[17–20]. Although adaptation of such treatments may be necessary, even individuals with the most severe disabilities are likely to benefit from regular physical activity.

Analgesic medications, both over-the-counter and opioid, were also used relatively often. Opioid medications were deemed more effective than OTC medications, although both of these medication classes were rated as being moderately effective overall. Similar rates of use for the two classes of OTC medications (NSAIDs and acetaminophen) were reported, and these rates were relatively consistent for both past and present time frames. The rate of reported use of opioids is fairly consistent with our previous work, which came as somewhat of a surprise given the overall increase in use of opioid medications for chronic pain in recent years[21–23]. Use of opioid medications for chronic pain remains a controversial issue, and the details of this debate are beyond the scope of this paper. However, most practitioners would likely agree that opioid medications should rarely, if ever, serve as the sole treatment for individuals with chronic pain; rather, a multidisciplinary approach that appreciates the biological, psychological, and contextual factors is typically indicated[24]. Our clinical experience tells us that this is especially true for individuals with CP and chronic pain, given the many pain and non-pain issues they encounter.

In addition to considering each pain treatment individually, one might also conceptualize the treatments studies as lying on a continuum from "active" to "passive" treatments. From this perspective, we see that study participants reported relatively high rates of use of the more passive treatments for pain (e.g., medications, modalities such as heat or ice, massage). Physical therapy, the treatment used most often, can have both active and passive components. Unfortunately, many of the treatments that require active participation from patients, such as training in biofeedback and relaxation, are also less likely to be widely available, which makes interpretation of these findings difficult. Whereas some of these active treatments, although available, may not be used because of patient preference, others

may not be used because they are relatively scarce. For example, relaxation training and psychotherapy are two treatments that require active participation on the part of the patient and are often beneficial for chronic pain (see review by Molton et al25). However, such interventions may not be as widely available as other pain treatments. With this in mind, there are currently several research projects underway, by our group and others, examining the feasibility and benefits of providing psychological treatments remotely (i.e., via telephone and/or computer) to individuals with disabilities and chronic pain who might otherwise face significant barriers to accessing these treatments in traditional formats (i.e., face-to-face).

Use of treatments that might be considered alternative/complementary in nature was also assessed. Of these, massage and chiropractic adjustments were the most frequently endorsed, and their effectiveness was rated in the moderate range (approximately 5 on 0–10 scale). Interestingly, although acupuncture was only used by 6% of participants, it had the highest effectiveness ratings of all the alternative/complementary treatments and was rated as providing as much relief as opioid medications. It is possible that selection bias accounts for these findings, in that patients who have high expectations for pain relief from acupuncture are the most likely to seek out and benefit from this treatment[26,27]. Nevertheless, recent research findings suggest that this treatment might be worthwhile as a primary and/or complementary treatment for chronic pain (see review by Hopton & Macpherson[28]). We are not aware of any published data on acupuncture in patients with CP; thus, one should be cautious when interpreting the current results. In the meantime, the current findings indicate that research examining the efficacy of this intervention for individuals with CP and chronic pain is warranted.

The treatment that was rated as providing the most relief was marijuana; however, less than 5% of the sample reported ever using this drug for pain. Although a full account of the legal and medical issues surrounding marijuana use are beyond the scope of the current paper (see Aggarwal et al[29] for review), these data do suggest that a not-insignificant number of patients with CP are using this drug for pain management and are finding it to be at least as effective as other more standard treatments for pain. Unfortunately, we did not assess the route of administration of this drug, which is an important consideration for both legal and medical reasons. Future work could explore these issues more fully.

A number of treatments received relatively low effectiveness ratings (<4 on 0–10 scale), with the lowest ratings given to anticonvulsant medications, gabapentin, and hypnosis. Interestingly, the most invasive treatment assessed in this study – nerve blocks – also received very low effectiveness ratings. One should be cautious when interpreting these findings, given the small sample size of this study and the low base rates of use for many of these treatments. Moreover, many of these treatments are not intended to be used for pain relief, per se, but rather for other issues that are of clinical importance, the improvement of which may indirectly reduce pain. This holds true in particular for psychological interventions (see below). Regardless, more research is needed on these (and all the treatments assessed in this study) treatments to determine which have the greatest potential to provide relief for patients with CP and chronic pain.

It was interesting to note that many treatments that were deemed quite helpful (helpfulness ratings > 4) showed a decreased rate of use from past to present time points. For example, 31% of participants reportedly used chiropractic treatment in the past compared to just 6% who were currently using this treatment, despite the fact that this treatment received an average helpfulness rating of 5.1/10. For each of the 8 treatments that demonstrated this profile, past users gave lower helpfulness ratings than current users. Thus, differential discontinuation of treatment based on perceived helpfulness is likely the primary

explanation for these findings. Nevertheless, other factors may also be at play. For example, an effective treatment might be discontinued for insurance reasons (i.e., treatment is not covered, or only a certain number of treatments are covered). Alternatively, a previously helpful treatment may not be feasible for long-term use; such might be the case for an opioid medication that was initially prescribed for acute pain but is deemed not appropriate for chronic pain management.

It is also important to bear in mind that pain relief, while an important outcome when assessing the effectiveness of treatment, is not the only outcome that should be considered. Increased participation in recreational, social, and other activities is also important, since these domains are critical components of an individual's quality of life (reviewed in Renwick et al30). It is possible that certain treatments, although effective for pain relief, do not translate into improved functioning in other domains. Conversely, as noted above, other treatments – particularly those that are psychological in nature – may exert their effects on psychosocial functioning domains (e.g., depression, anxiety) and have little direct influence on pain intensity. This may be especially true in regards to pain-related coping. Increased use of adaptive pain coping strategies such as task persistence and decreased use of maladaptive strategies such as catastrophizing and inactivity have been shown to be related to improved psychosocial functioning in individuals with CP[31,32]. Research is needed to further explore the relationships between pain treatments, perceived effectiveness, and psychosocial functioning among individuals with CP, as well as determine the treatment delivery models that are best suited to this complex patient group.

Not surprisingly, individuals who reported the highest pain also reported the most healthcare utilization. This is consistent with epidemiological data showing high rates of healthcare utilization among those with chronic pain[33,34]. As one might expect, the biggest utilization differences between participants with moderate-to-severe pain and those with less intense pain was seen for emergency room and primary care providers; however, it should be noted that all of the observed utilization differences were modest in magnitude. These types of providers often serve as the frontline resources for patients in pain[34]. It is interesting to note, however, that physical and occupational therapy providers were accessed most often by this sample. We consider this a positive finding since individuals with CP (with or without chronic pain) have well-documented needs in these domains (see reviews by Anttila et al35 and Steultjens et al36). Unfortunately, we were not able to discern the specific types of services provided by these clinicians, nor their perceived benefits. However, one might speculate that the patients found these services to be of benefit, if rate of use is considered a proxy for perceived benefit. Future work that examines this more closely could inform efforts aimed at the efficient delivery of healthcare resources. Such work could also identify the patients that are most likely to benefit from specific services.

Two additional factors are worth considering in this context. One is related to the statewide variation in access to certain types of providers such as physical and occupational therapists. In several states, a physician referral is needed to obtain physical and/or occupational therapy, and many insurance companies, including Medicare, also have this requirement. This may represent an additional roadblock for individuals with CP who may benefit from treatment but have difficulty obtaining the appropriate referral. A second factor concerns provider expertise and comfort in providing care to adults with complicated, childhood-onset conditions such as CP. The complexities of this issue are beyond the scope of the current study and have been reviewed elsewhere[37]. It is worth noting, however, that this represents yet another potential barrier for adults with CP to access appropriate care for their various needs, and this problem may be compounded for adults with both CP and chronic pain.

Several limitations of this study warrant consideration. First, all of the data were collected from self-report measures, which may be subject to reporting biases. Relatedly, with the exception of pain intensity, the psychometric properties of the measures used in this study have not been evaluated. Second, the two data collection strategies used in this study could have elicited different responses from participants and, thus, influenced the results. However, because systematic differences between the two procedures were not evident, we decided to combine the interview and postal data for sample size and power considerations. Third, while we attempted to include the most up-to-date pain treatments for adults with CP, not every possible treatment option was assessed. For example, botulinum toxin was not included in the current treatment list, but is now regularly used for CP-related spasticity. Moreover, our list may reflect regional differences in the use/availability of certain treatments (e.g., mexiletine, marijuana). Fourth, we were unable to determine the specific reasons why certain treatments were not used by participants. While some treatments may not be widely available to certain participants (e.g., psychological treatment for those living in rural areas), other treatments may not be used despite their availability (e.g., participants who prefer not to take opioid medications). Future research could examine more closely these issues. Finally, the characteristics of the current sample may limit the generalizability of the findings to the broader CP population. In particular, female, Caucasian, and well-educated participants were over-represented in this study[38–40].

Despite these limitations, the current study provides important information regarding the types of pain treatments that adults with CP use, the perceived effectiveness of these treatments, and the pain-related healthcare utilization for this patient population. These findings could inform future research directions, particularly those involving controlled trials for pain treatments.

Acknowledgments

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Table 1

Pain locations for participants reporting current pain and/or pain in the past 3 months (N = 52)

Body location	N	%
Lower back	37	71
Legs	30	58
Hips	30	58
Feet	28	54
Neck	26	50
Shoulder	26	50
Knees	25	49
Hands	22	42
Upper back	21	40
Arms	21	40
Wrists	17	33
Buttocks	17	33
Ankles	16	31
Elbows	13	26
Head	11	21
Abdomen/Pelvis	10	19
Chest	4	8

Table 2

Use and perceived helpfulness of pain treatments

| Treatment | Used for Pain | | Helpfulness |
	Past	Present	(0 – 10 scale)
	%	%	Mean (SD)
Physical Therapy	56	35	4.6 (3.0)
Acetaminophen	37	44	5.0 (3.1)
Heat	42	35	5.5 (2.9)
Mobility/ROM Exercises	27	48	4.7 (2.7)
Strengthening Exercises	23	50	4.6 (2.8)
Aspirin, Ibuprofen, Naproxen	37	35	5.1 (3.1)
Massage	42	21	5.2 (3.1)
Ice	42	15	3.9 (2.9)
Opioid Medication	31	23	6.2 (3.2)
Baclofen	29	12	3.5 (0.7)
Chiropractic Adjustment	31	6	5.1 (3.7)
Benzodiazepine	17	15	5.5 (3.3)
TENS Unit	17	4	5.1 (3.6)
Biofeedback/Relaxation Training	17	4	4.6 (2.9)
Tricyclic Antidepressant	8	10	4.3 (2.9)
Counseling/Psychotherapy	6	8	3.6 (4.1)
Magnets	10	2	3.5 (3.1)
Acupuncture	6	6	6.2 (3.1)
Anticonvulsant	6	6	3.0 (2.2)
Gabapentin	8	2	1.5 (3.0)
Nerve Blocks	8	0	3.8 (4.4)
Hypnosis	6	0	1.3 (1.5)
Marijuana	2	4	6.7 (3.5)
Mexiletine	0	0	N/A

Note: Treatments are ordered from top to bottom based on the sum of their past and present use percentages.

Table 3

Pain-related healthcare utilization during the past 6 months

	Current/recent pain[a]		Moderate-to-severe pain[b]	
Provider type	**# of visits**		**# of visits**	
Physical/occupational therapist	Mean (SD)	Range	Mean (SD)	Range
Primary care	6.6 (10.7)	0–50	6.0 (11.2)	0–50
Other	2.4 (5.4)	0–30	3.6 (6.5)	0–30
Chiropractor	1.9 (7.0)	0–48	2.7 (8.7)	0–48
Emergency room	1.0 (4.0)	0–24	1.5 (5.0)	0–24

[a]All participants who reported current pain and/or pain in the past 3 months (N = 52).

[b]Only those participants who reported their current/recent pain as moderate-to-severe pain (pain intensity ≥ 5/10) (N = 33).