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Survey Results of Pain Treatments in Youths with Cerebral Palsy

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Abstract

The purpose of this study was to identify current interventions used in the pediatric population to decrease cerebral palsy (CP)-related pain by surveying children with CP and their parents in two focus areas: first, regarding pain related to CP and second, interventions sought in conjuncture with CP-related pain symptoms. The first portion of this study centers on if the child had CP-related pain in the last three months and location of the worst reported pain. The second portion of this study reports what interventions have been used, how often these interventions were administered, if the intervention is still being used, and how helpful each intervention is perceived to have been. 62 children, 29 females and 39 males, with a medical diagnosis of CP that were between the ages of 8-21 and 98 parent respondents participated in this study in two waves of data collection. The results of the data indicated parent reports of pain in the last three months in 77 of the 98 parent respondents and 41 of the 62 child respondents with more pain reported in the head (46%), neck (44%), and chest (28%) areas and the worst pain locations reported in the legs (26%), feet (21%), back (13%), and knees (13%). The most sought and still used interventions included Tylenol (74%, 77%), physical/occupational therapy (73%, 72%), braces/orthotics (67%, 50%), and stretching (67%, 90%). These interventions were rated between 3.67 and 5.0 on a 5-point scale of perceived effectiveness. This study presents four main findings from this data: that youths with CP feel pain related to CP symptoms throughout their bodies, that the main pain locations for the most severe pain are located in the lower extremity, that interventions with higher rated perceived helpfulness are used less frequently then interventions with moderate ratings on the perceived helpfulness scale, and that the pain reported interferes with the child's number of daily activities. These findings are significant in that knowing what is perceived to be helpful can assist in guiding medical professionals to recommend interventions and provide base information for future studies to expand on effective interventions to decrease pain in youths with CP.

Keywords: Pain; Cerebral palsy; Health services accessibility

Introduction

Cerebral palsy (CP) is a disorder of the developing brain that affects body movement, posture, and muscle coordination [1]. Some of the primary risk factors of CP include a lack of oxygen to the fetus before or during the birthing process, and a bacterial infection of the mother or fetus that attacks the central nervous system (United Cerebral Palsy). Cerebral palsy is the most prevalent motor disorder in the current youth population [2]. The Center for Disease Control and Prevention (CDC) reports worldwide population-based studies report the prevalence of CP ranging from 1.5 to more than 4 per 1,000 live births or youths of a designated age [3].

Surgical, procedural, gastrointestinal, orthopedic, neuromuscular, and rehabilitative agents are all potential sources of pain [4]. Clients suffering from pain can experience depression or anxiety. Healthcare professionals should strive for their clients to achieve optimal functional ability and engagement in desired occupations. Preliminary research in youths and established research in adults with CP show a chronic pain rate of 72% [5]. This implies that the rate of chronic pain is relatively stable throughout the lifespan of these individuals. In addition, CP and its relation to chronic pain in youths is an under-investigated area. The paucity in research begs for further exploration. It is also important to research this specific topic to know if the individual is suffering from pain and how to decrease its impact on daily life and participation. This impact is known as pain interference. There are seven categories of pain interference: general activity, mobility, sleep, mood, socialization, work, and enjoyment of life [6]. Understanding this impact is critical for healthcare practitioners to treat clients appropriately and effectively.

Effectiveness of interventions should be measured in order to achieve optimal outcomes for clients with chronic pain related to CP. Before effectiveness can be identified, it is important to identify what treatments exist for pain in persons with cerebral palsy. This can be completed by determining the frequency, duration, current use, and effectiveness of the treatment.

Pain treatments and their effectiveness for individuals with CP have been most thoroughly researched with the adult population. One survey had 83 adult participants with CP self-report the treatment methods they were currently using, had used in the past,

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Table 1: This table demonstrates the pain locations for youth participants indicating current pain and/or pain in the past three months (N = 39; data were missing for two participants).

Overall Pain Locations	N	Percentage
Head	18	46%
Neck	17	44%
Chest	11	28%
Shoulders	15	38%
Back	24	62%
Arms	9	23%
Hands	11	28%
Bottom/Hips	12	31%
Belly/Pelvis	12	31%
Legs	26	67%
Feet	16	41%
Other (Knees)	5	13%

Both waves (39 respondents).

and their perceived effectiveness on pain reduction. Physical therapy interventions such as range of motion exercises, and strengthening exercises were moderately effective. Over the counter and opioids were also moderately effective. Several participants used self-administered heat and ice, finding that heat provided greater pain relief than ice. A small portion of participants found psychologic modalities such as hypnosis and counseling to be effective as well. Alternative treatments such as acupuncture were effective for a similarly small sample [7].

Other medications used for CP-related pain reduction include anti-spastics (e.g., Baclofen), anticonvulsants, gabapentin, nerve blocks, marijuana, anticholinergies, anti-inflammatories, antidepressants, stool softeners, and psychiatric drugs such as benzodiazepines and tricyclic antidepressants [7]. Along with this, other interventions include chiropractic adjustment, TENS Unit, Biofeedback or relaxation training, and magnets. The TENS Unit is used in a therapeutic manner by producing an electric current to stimulate nerves [8].

Cognitive-behavioral approaches also exist, helping clients develop coping strategies to modify thoughts and behaviors that occur with pain. Social environmental intervention is another option, using the influence of therapists' coping behaviors on youths during therapy [9]. It has been found that therapists exhibiting coping-promoting behaviors during therapeutic activities such as stretching encourage similar positive behaviors in their clients [9]. Participation in weekly light, moderate, and vigorous strengthening and stretching exercise has shown significant improvement in gross motor functioning [10].

The successful completion of the aims in this study will change the concepts, methods, technologies, treatments, services, or preventative interventions driving the health profession.

Pain in children with CP is under recognized, undertreated, and negatively affects quality of life [11]. By expanding the current knowledge base of cerebral palsy related pain, health professionals will be able to identify common ineffective interventions. In addition, modification of current technologies or intervention methods can treat individuals' pain more effectively.

Table 2: This table demonstrates the worst pain location for each youth participant over the past three months (N=38; data were missing for three participants).

Worst Pain Locations	N	Percentage
Head	2	5%
Chest	2	5%
Shoulders	1	2.6%
Back	5	13%
Arms	2	5%
Hands	1	2.6%
Bottom/Hips	1	2.6%
Belly/Pelvis	2	5%
Legs	10	26%
Feet	8	21%
Other (Knees)	5	13%

Both waves (38 respondents).

Methods

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 because of 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 Questionnaires Completed by Mail. Individuals who received a mailed letter indicated their interest in participating in the study by either returning self-addressed stamped postcards or calling research personnel. These potential participants were provided additional study information and scheduled for an interview at either the 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 Q14 if they used a communication device) of a possible 25 points on the MMSE were deemed eligible to participate in the full study. Demographic data were collected only from individuals who did not meet this eligibility requirement. Interviews lasted approximately 60Y90mins. All participants, including those who were ineligible because of 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

Table 3: This table contains parent responses regarding treatment types, their perceived helpfulness, and whether or not the treatment is still being used. Parent responses from waves 1 and 3 were combined. Wave 3 had more options for treatments; if one of the respondents from Wave 1 described a Wave 3 option under "other", that data was added to the more specific category (thermotherapy, orthotics, and stretching). "Other" responses included acupuncture, Ativar, Baclofen, Botox, chiropractic, horseback riding, ibuprofen, kinesiotape, massage pillow, neurontin, prolosic, valium, verapamil, and electrical stimulation.

Treatment Sought	N (Total Respondents)	Percentage of People who Sought Treatment	Perceived Helpfulness on a Scale from 0-5	Percentage that Still use Treatment
PT/OT	73	73%	3.49	72%
Counselling/Psychotherapy	72	13%	1.78	22%
TENS Unit	69	3%	2.50	0%
Therapeutic Massage	73	29%	4.25	52%
Amitriptyline/Nontriptyline	72	3%	5.00	50%
Opiate/Narcotics	72	25%	4.33	6%
NSAIDS	72	65%	3.50	77%
Tylenol	72	74%	3.43	77%
Ice Therapy	14	14%	3.50	50%
Thermotherapy	15	20%	3.67	100%
Hydrotherapy	14	50%	3.71	29%
Massage	14	64%	4.11	78%
Exercise	14	64%	3.50	89%
Brace/Orthotic	15	67%	3.20	50%
Splint	14	43%	3.00	50%
Distraction	14	29%	3.67	100%
Relaxation Training	14	7%	5.00	100%
Stretching	15	67%	3.00	90%
Joint Mobilization	14	14%	5.00	100%
Other	72	28%	3.80	75%

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 because of 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.

Results

Participant characteristics

After the exclusion of incomplete survey data and primary diagnoses unrelated to the study's purpose, the total number of youth participants was 68 and the total number of parent participants was 98. While the parents were not asked about the gender of their children, the combined youth sample included 29 females and 39 males. Of the combined parent sample, 78 surveys were completed by the child's mother, 12 by the father, 1 by both mother and father, 5 by the grandmother, 1 by both grandparents, and 1 by the female adoptive parent. The first wave of parent data demonstrated that the age range of their children was 8 to 21 years (mean = 13.91, SD = 3.310) and the second wave had a youth age range of 8 to 20 years (mean = 13.71, SD = 3.738).

Pain intensity and location

77 of 98 parents (78.57%) reported that their child was currently or has in the past three months experienced pain, compared to 41 of 62 youth participants (66.13%) self-reporting pain during the same time period. The first wave of youth participants reported a mean "worst pain location" rating in the past week of 4.32/10 with a mean "overall pain" rating of 2.98/10 over the same time period. The second wave of youth participants reported a mean "worst pain location" rating during the past week of 6.8/10. Youth participants were most likely to report pain in their head (46%), neck (44%), and chest (28%); participants were permitted to choose more than one location for overall recent pain experienced. See Table 1 for overall pain locations. In terms of worst pain location, the most common were legs (26%), feet (21%), back (13%), and knees (13%). See Table 2 for worst pain locations.

Pain treatment and pain-related healthcare utilization

Of the 77 parents reporting that their children have recently experienced pain, 61 (79.22%) sought related treatment. See Table 3 for all treatments used recently, their perceived helpfulness per parent report, and whether or not the treatments were still being used at the time of data collection. The most common treatments included tylenol (sought by 74%, still used by 77%), physical therapy and/or occupational therapy (sought by 73%, still used by 72%), braces/orthotics (sought by 67%, still used by 50%), and stretching (sought by 67%, still used by 90%). The aforementioned treatments had a range of perceived effectiveness from 3.00-3.49/5.00. While pursued by fewer participants, thermotherapy, distraction, relaxation training, and joint mobilization had high rates of perceived helpfulness (ranging from 3.67-5.00) and at the time of data collection were still being used by all respondents who had originally sought out those treatments. 67 parent respondents reported that their child had visited a healthcare provider primarily due to pain in the past three months. These visits were to physicians and/or nurse practitioners, physical and/or occupational therapists, counselors/psychologists, alternative healthcare providers, emergency departments, hospital overnights, operations, and others.

Discussion and Conclusion

The following summarizes the results from this study: (1) youths with cerebral palsy feel pain, ranging from their head to their feet; (2) the most severe pain location in the body are in the lower extremity; (3) the treatments with the highest frequency count have a score of 3.4-3.5 on the 0-5 perceived helpfulness scale, while the treatments with a higher perceived helpfulness have a lower frequency count; and (4) the pain interferes with the children's number of daily activities and participation. The types of treatment sought and actual helpfulness perceived by those using the treatment is significant as it allows for health care professionals to better treat cerebral palsy related pain more. These findings are also significant due to the fact of limited studies regarding interventions and youths with CP.

The highest amount of treatments sought includes some sort of physical contact between the patient and person providing the intervention. These include physical and/or occupational therapy, stretching, massage, exercise, distraction, therapeutic massage, and joint mobilization. This finding is concurrent with findings in a previous study for adults with cerebral palsy [7]. A large number of participants still use these interventions, and most treatments received a perceived helpfulness rating above 3.50.

Medications, both over the counter and prescription, also had a high a high frequency count of youths using this type of intervention. The medications noted by respondents in order of greatest use include Tylenol, NSAIDS, opiate/narcotic, and amitriptyline. With the exception of opiate/narcotics, most participants still use these medications, and all medications received a perceived helpfulness rating of at least 3.50.

A few limitations occur in this study: (1) respondents had the option of choosing more than one type of treatment sought; (2) participants could have other comorbidities not known to this study; and (3) a parent or caregiver responded to the perceived helpfulness of an intervention instead of the child who received the treatment.

In conclusion, children with cerebral palsy feel pain throughout the entire body. This study found the pain interferes with the children's number of daily activities. This finding parallels outcomes in other studies [11]. Further research into some of the treatments perceived to be very helpful but not widely used (relaxation training and joint mobilization, etc.) could allow for more widespread use of these treatments and higher quality of life for youths with cerebral palsy.

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