

Pain in Children with Cerebral Palsy: A Review

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Abstract: Children with cerebral palsy (CP) face many challenges including impaired motor control and coordination, functional impairment, sensory disturbances, and, sometimes, communication difficulties and cognitive deficits. Pain also may be a problem for children with CP due in part to the inherent deficits associated with the disease, as well as the invasive medical and surgical procedures and rehabilitative activities children with CP undergo on a regular basis. A review of current literature indicates pain is a common experience for children with CP and has been understudied in this population. Further emphasis and research on appropriate assessment and management strategies sensitive to the unique characteristics and limitations of children with CP are warranted.

The reduction in mortality rates related to traumatic childbirth and childhood illnesses or injuries, due in part to medical and technological advances, has resulted in an increasing number of children living with physical disabilities. One such physical disability is cerebral palsy (CP). Children with CP face many challenges including impaired motor control and coordination, functional impairment, sensory disturbances and, sometimes, communication difficulties and cognitive deficits. Pain may be a problem for children with CP as a result of the inherent deficits associated with CP, as well as the invasive medical and surgical procedures and rehabilitative activities children with CP undergo on a regular basis. Ironically, the interventions frequently employed to improve motor control and function, modify deformities, reduce pain, and enhance quality of life can actually cause pain

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or discomfort, at least temporarily (Hadden & von Baeyer, 2002; Nolan, Chalkiadis, Low, Olesch, & Brown, 2000). This article examines issues related to the experience of pain in children with CP by synthesizing current literature. Suggestions for further research and inquiry are provided.

Background

Cerebral Palsy

Cerebral palsy (CP) is a diagnostic label representing a wide range of nonprogressive motor impairments that are identified at birth or in early childhood. A more specific definition identifies CP as "...an umbrella term covering a group of nonprogressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development" (Mutch, Alberman, Hagberg, Kodama, & Perat, 1992, p. 547). In developed countries, CP is the leading cause of childhood physical disability, with more than 10,000 infants and children diagnosed each year with CP in the United States alone (Stanley, Blair, & Alberman, 2000; United Cerebral Palsy [UCP], 2002). While the specific etiology is often unknown, cerebral palsy is thought to be a result of congenital, hypoxic, ischemic, infectious, or traumatic injury or insult to the central nervous system (Dzienkowski, Smith, Dillow, & Yucha, 1996; UCP).

Although some persons with CP also present with sensory and cognitive impairments, the focus of classification is on motor deficits present in all persons with CP. The different presentations of CP vary in the literature and in clinical practice. Blair and Stanley (1985) developed a system with demonstrated reliability that delineates the categories as follows: (a) predominantly spastic, (b) predominantly athetoid, (c) predominantly dystonic, (d) ataxic, and (e) mixed.

Spastic CP is characterized by involuntary spontaneous movement and muscle contraction, in addition to hypertonia and rigidity (Dzienkowski et al., 1996). Spastic CP is the most common, accounting for up to 80% of those diagnosed with CP (Stanley et al., 2000). Uncontrolled, fragmented movements involving the extremities as well as facial and oral musculature are a distinguishing attribute of athetoid CP, which affects about 10%–20% of persons with CP. Slow, twisting, uncontrolled movements in the trunk and extremities are differentiating characteristics of dystonic CP, which

results from malformation, insult, or injury to the extrapyramidal portion of the brain (Nehring, 2000). Ataxic CP is typified by hypotonia in infancy followed by increasing tone, muscle instability, intention tremor and gait disturbances later in life (Dzienkowski et al., 1996; UCP, 2002). Mixed-type CP includes persons demonstrating characteristics or behaviors from two or more of the categories listed above.

Cerebral palsy is also described in topographical terms by the location of motor impairment (e.g., quadriplegic, diplegic, hemiplegic). The Swedish classification system utilizes both the movement disorder and topographical description to delineate type (Mutch et al., 1992). Further standardized classification of motor skills is often done using the Gross Motor Function Classification System (GMFCS), which is specifically designed for children with CP (Palisano et al., 1997). This scale evaluates gross motor skills in both the home and community as well as functional mobility and use of adaptive equipment.

Classification systems allow clinicians and researchers to explore commonalities and differences within and between classifications of persons with CP in terms of impairments, disabilities, handicaps, and secondary conditions such as pain. Regardless of CP classification, children with CP may encounter a variety of pain experiences. To understand the pain problems associated with CP, it is important to have a basic understanding of the nature of pain.

Pain

Pain may be defined as "...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" and is invariably subjective in nature (International Association for the Study of Pain [IASP], 2002; Merskey & Bogduk, 1994, p.210). There are two primary categorizations for pain: acute and chronic. Acute pain is most often caused by tissue damage or irritation related to injury, insult, surgery, or disease and lasts 6 months or less (Engel, 1988; Menefee & Katz, 2002). Chronic pain, or pain without apparent biological value persisting beyond the typical course of a disease or normal healing time for an injury (Turk & Melzack, 1992), is a frequent secondary problem associated with many disabilities including CP (Schwartz, Engel, & Jensen, 1999). Chronic pain may include persistent or ongoing pain as well as recurrent or episodic pain (American Pain Society [APS], 2002). Acute and chronic pain may be accompanied by physical manifestations related to the biological processes as well as short- and long-term emotional and psychosocial ramifications. Chronic pain can affect a person's mood, personality, and social relationships. Persons with chronic pain may also experience depression, sleep disturbance, fatigue, and decreased overall physical functioning (Ashburn & Staats, 1999; Zucconi & Bruni, 2001).

Pain assessment and management are receiving increasing attention and emphasis in healthcare provision. Pain is the fifth vital sign according to the APS (1995). In addition, the Joint Commission on Accreditation of Healthcare Organizations (2002) implemented new standards requiring healthcare professionals to be competent in pain assessment and management. To address the many factors influencing the experience of and adjustment to pain, a biopsychosocial model of pain has been developed. This model accounts for not only the fundamental biological factors related to pain but also psychosocial issues such as coping skills, familial response and support, and personal beliefs (Gatchel & Turk, 1999; Jensen, Turner, Romano, & Lawler, 1994; Novy, Nelson, Francis, & Turk, 1995).

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The multifaceted nature and impact of pain including biological and psychosocial factors are evident in children (McGrath, 1990). Children may struggle to make sense of their pain experiences given their cognitive limitations, developing communication skills, inexperience with pain, and socio-environmental influences. Assessment and management of pain in children also is complicated by these factors (Gaffney & Dunne, 1986; McGrath). To fully understand and examine pain in children with CP, the various common medical and rehabilitative procedures or activities these children undergo (e.g., injections, range of motion exercises) must be taken into account, as well as the complex developmental, psychosocial, and environmental factors that influence their pain experiences.

Pain Research in Children with Cerebral Palsy

Pain in children is a relatively new area of research with historical roots dating only to the early 1970s (Hester, 1993). Inquiry focused on pain in children with developmental or physical disabilities such as CP is severely lacking. Only recently has the secondary condition of pain been researched in adults with cerebral palsy. Results suggest pain is common in this population, with 67%–84% of participants reporting chronic pain (Engel, Jensen, Hoffman, & Kartin, 2003; Schwartz et al., 1999; Turk, Geremski, Rosenbaum, & Weber, 1997) and 18%–56% noting daily pain occurrences (Andersson & Mattsson, 2001; Engel et al.; Schwartz et al.).

Following structured interviews of 20 children with CP, Petrina (2001) noted 70% reported experiencing bothersome pain lasting 1 hour or greater per episode, and 64% described pain as being a problem. Chalkiadis (2001) described children with CP or spasticity as the

largest group of patients referred to a pediatric multidisciplinary pain clinic in Australia. Their complaints included hip and/or back pain associated with spasticity, subluxation, and osteoarthritis. Sleep disturbance also was reported to be a recurrent issue in this population and often dissipated when pain specifically was addressed. Hadden and von Baeyer (2002) noted 67% of parents reported observing pain behaviors in their children with CP within the past month. Assisted stretching was the most common activity of daily living, range of motion the most frequent therapeutic intervention, and needle injection the most identified medical procedure to cause pain (93%, 58%, and 40%, respectively, of those reporting pain). Kibele (1989) also reported pain with stretching was common. Liptak et al. (2001) found children with moderate to severe CP reported significantly higher pain severity compared to national norms using the Child Health Questionnaire (CHQ) as a standardized interview tool (Landgraf, Abetz, & Ware, 1996). These children also scored below the mean in general health, physical functioning, and effect on parents. Using a population-based sample of 408 children with CP, Kennes and associates (2002) demonstrated that severity of CP using the GMFCS did not directly relate to the experience of pain as reported by parents on the CHQ.

Research concerning pain in children with CP has emphasized parent or healthcare professional report, which may or may not accurately reflect the child's experience. Studies that include a component of pain prevalence, assessment, or management in children with CP are focused on outcomes of a surgical procedure, pharmacological intervention, rehabilitative activities, or health-related quality of life (QOL) inquiry. Table 1 lists common experiences that may contribute to pain as a secondary condition in children with CP. A discussion concerning these experiences as well as suggestions for future research follows.

Surgical Pain

A variety of surgical procedures may be performed on children with CP to improve function, decrease muscle tone, or correct deformity. These procedures include but are not limited to selective dorsal rhizotomy, soft tissue releases, tendon lengthening, capsulotomy, fasciotomy, osteotomy, tenotomy, and spinal fusion (Dzienkowski et al., 1996; Nolan et al.,

2000). There is extensive literature on most of these procedures, and overall, successful outcomes have been shown in improved motor function, range of motion, decreased muscle tone and even health-related QOL. If spasticity is a problem, intrathecal baclofen may be administered following surgical implantation of a pump (Van Schaeybroeck et al., 2000). This procedure has been shown to be effective for the treatment of spasticity (Albright, Barron, Fasick, Polinko, & Janosky 1993; Van Schaeybroeck et al., 2000), but it is invasive and little is known about its effects on pain. Significant gastrointestinal or nutritional problems may also necessitate surgical procedures, such as a fundoplication and/or placement of a gastrostomy tube (Nolan et al.). These procedures are intended to improve nutritional support, but may be accompanied by side effects such as infection and gastroesophageal reflux with subsequent pain or discomfort.

Following surgery, structured positioning and rehabilitative protocols are often implemented including splinting, orthotics, and intensive range of motion or functional activities. Furthermore, postoperative

Table 1. Common Potential Contributors to the Experience of Pain in Children with CP

<p>Surgical</p> <ul style="list-style-type: none"> • Selective dorsal rhizotomy • Soft tissue releases • Tendon lengthening • Capsulotomy • Fasciotomy • Osteotomy • Tenotomy • Spinal fusion • Pump implantation for intrathecal baclofen administration • Fundoplication • Gastrostomy tube placement 	<p>Procedural</p> <ul style="list-style-type: none"> • Intramuscular and other medication injections • Administration of anesthesia • Blood draws • Placement of a nasogastric tube • Dental procedures • Enemas 	<p>Gastrointestinal</p> <ul style="list-style-type: none"> • Gastroesophageal reflux • Nausea/vomiting following surgical procedures • Gastrostomy tube-related pain or infection • Abdominal pain
<p>Orthopedic</p> <ul style="list-style-type: none"> • Hip subluxation/dislocation • Cephalad displacement of the patella • Equines of the ankle • Valgus deformities of the ankle • Varus and valgus deformities of the foot • Radial subluxation/dislocation • Cartilage degeneration scoliosis • Pelvic obliquity • Kyphosis • Ordoxis • Contractures • Degenerative arthritis 	<p>Neuromuscular</p> <ul style="list-style-type: none"> • Spasticity • Overuse syndromes • Nerve entrapments • Radiculopathies • Myelopathies • Contractures 	<p>Rehabilitative</p> <ul style="list-style-type: none"> • Range of motion • Home exercise programs • Strengthening • Electrical stimulation • Functional mobility training • Participation in activities of daily living • Splinting and orthotic fabrication and follow-up • Serial casting • Training for use of adaptive equipment • Utilization of standing frames and other positioning devices

problems such as nausea, muscle spasm, constipation, and skin breakdown due to immobility may occur (Nolan et al., 2000). A child may experience pain or discomfort related not only to the surgical procedure or site, but also as a result of associated healing and remobilization interventions. Several research studies and review articles have addressed pharmacological interventions for postoperative pain in children with CP. Studies concerning pain management following selective dorsal rhizotomy have found that the use of pharmacological agents such as morphine (continuous infusion, patient-controlled analgesia, or epidural) and/or a benzodiazepine infusion were effective in treating postoperative pain and muscle spasticity (Geiduschek et al., 1994; Sparkes, Klein, Duhaime, & Mickle, 1989). Despite the attention given to postoperative pain management in children with CP, little has been done to examine non-pharmacological interventions or explore the experience of procedural pain from the child's perspective.

Procedural Pain

Spasticity is a frequent problem for many children with CP (Rosigno, 2002). Hypertonicity can lead to contractures, deformity, and functional impairment (Rosigno). Aside from oral and rectal administration of pharmacologic agents, intramuscular injections of botulinum toxin type A (also known as Botox or Dysport) have proven to be effective in reducing muscle spasms and pain while improving functional status in both adults and children with CP (Graham, 2000; Hart, 2000; Kirshner, Berweck, Mall, Kornthenberg, & Heinen, 2001). These injections produce a dose-dependent chemodeneration of muscle. The relaxation effect typically lasts for approximately 3–6 months (Graham; Hart). Irritation or pain at the injection site has been shown to be the most common side effect (Forssberg & Tedroff, 1997; Hart), lasting up to 1–2 days. This type of procedural discomfort or pain might also be common following other medical interventions frequently experienced by a child with CP such as medication injections, blood draws, nasogastric tube placement, enemas, and administrations of anesthesia. In fact, Hadden and von Balyer (2002) identified needle injection as the most frequently reported painful medical or nursing procedure by parents of children with CP with a mean intensity of 3.1 on a 0–5 scale (0 = no pain; 5 = worst pain possible). The need for repeating these interventions on a regular basis may result in chronic, procedure-related anxiety or distress and emotional strain (McGrath, 1990).

Gastrointestinal-Related Pain

In a study of 58 children with CP, Del Giudice and colleagues (1999) found that 92% of the children had clinically significant gastrointestinal symptoms including abdominal pain (32%). Gastroesophageal reflux (GER) is a

common problem in children with CP, especially those with limited mobility, poor control or coordination of the orofacial musculature, and esophageal dysmotility (Nolan et al., 2000; Samson-Fang, Butler, & O'Donnell, 2003). Surgical procedures to enhance or support nutritional intake, such as gastrostomies and funduplications, are reported to be the second most frequent surgeries experienced by children with CP (Nolan et al.). Impaired oropharyngeal function and GER may contribute to extended mealtimes, fatigue with eating, malnutrition, and the incidence of aspiration pneumonia (Darwish, 1999; Samson-Fang et al.). Theoretically, pain may be associated with each of these conditions due to gastrointestinal discomfort, delayed healing responses, respiratory difficulties, procedure-related pain or discomfort, and possible surgical intervention, resulting in postoperative pain.

Little has been done to examine nonpharmacological interventions or explore the experience of procedural pain from the child's perspective.

Orthopedic-Related Pain

Immobility, spasticity, and congenital deformity may contribute to painful orthopedic conditions. Hodgkinson and associates (2001) reported that 47% of their sample of nonambulatory adolescents and young adults with CP reported hip pain. Hip subluxation and dislocation is a frequent problem associated with CP, especially in children with severe spastic quadriplegia who are nonambulatory (Bleck, 1987). Bagg, Farber, and Miller (1993) demonstrated that dislocated hips caused degenerative arthritis, pain, and decreased movement. Other orthopedic deformities associated with CP are cephalad displacement of the patella, equines of the ankle, valgus deformities of the ankle, varus and valgus deformities of the foot, radial subluxation or dislocation, cartilage degeneration, scoliosis, pelvic obliquity, kyphosis, lordosis, and contractures (Bleck, 1987). These deformities may lead to chronic knee, ankle, foot, upper extremity, back, and neck pain due in part to biomechanical abnormalities, sustained muscle contraction around these joints, poor positioning, skin breakdown, and impaired mobility. A study by Tenuta, Shelton, and Miller (1993) found that 41% of adults with CP who had undergone a triple arthrodesis surgery as a child continued to have pain in adulthood. In addition, osteoarthritis and osteoporosis may be present and produce pain. This pain often begins early in childhood and worsens with age (Bleck). Long and Hart (1995) identified hip, knee, and foot pain as common in youth with CP and attributed these pain problems to multiple factors such as congenital

dislocation, joint stress related to hypertonic muscles, and overuse. These potentially painful orthopedic conditions require careful attention, assessment, and monitoring in order to recommend the best course for appropriate management.

Neuromuscular Pain

Lesions of the motor areas in the brain in association with injury or deformity of the descending motor pathways (corticospinal tracts) result in spasticity in the child with CP (Kandel, Schwartz, & Jessell, 2000). Spasticity is characterized by increased tone, hyperreflexia, clonus, and resistance to stretching (Kandel et al.; Roscigno, 2002). Furthermore, spasticity can contribute to contractures and musculoskeletal deformities due to reduced longitudinal muscle growth (Graham, 2000). Although the mechanism of spasticity-related pain is not well understood, pain may be associated with spasticity as well as the resulting impairment and deformity. Roscigno (2002) provides a comprehensive review of the most frequent pharmacological interventions used to treat spasticity-related pain and a brief overview of surgical interventions for spasticity management in children with CP. Inconsistency in muscle tone, impaired purposeful movement, and other motor aberrations such as twisting/writhing movements and tremors may be the result of injury or abnormality in the basal ganglia. This type of motor impairment may cause upper extremity orthopedic deformities as well as hip dislocations that may be painful (Dzienkowski et al., 1996). Pharmacological agents and surgical interventions are used in the care of children with these types of impairments and pain complaints. Rehabilitative interventions such as occupational, physical, and speech therapy are employed to maximize function and comfort.

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Children with CP often have a limited range of available functional movement and may develop overuse syndromes, nerve entrapments, radiculopathies, and myelopathies. Gajdosik and Cicirello (2001) summarized the contributing factors and potential for pain as well as loss of function related to these secondary conditions.

Chronic shortening and misalignment of muscles as a result of spasticity or restricted movement may lead to contractures, another potentially painful problem (Nehring, 2000). Although range of motion, positioning devices, and splints/orthotics may help to prevent or minimize contractures, these interventions may cause pain or discomfort at least in the short term (Kibele, 1989). This relationship between well-intended, necessary interventions and the adjunct contribution to pain is

also true of many rehabilitative activities performed with children with CP.

Rehabilitative Interventions Related to the Experience of Pain

Children with CP regularly participate in rehabilitative therapies such as occupational, physical, and speech therapy with the intensity and frequency individualized to meet the needs and concerns of the child. Therapeutic interventions are range-of-motion activities, home exercise programs, strengthening, electrical stimulation, functional mobility training, participation in activities of daily living, splinting and orthotic fabrication and follow-up, serial casting, training for use of adaptive equipment, and utilization of standing frames and other positioning devices. Although these activities are intended to improve functional or physical status and minimize disability-related pain, many of these activities may be encumbered by pain or prompt a painful experience in a child with CP. Kibele (1989) reported that one of the most salient negative memories of childhood in adults with CP was the pain related to stretching and bracing in physical therapy. Hadden and von Baeyer (2002) noted parents of children with CP identified assisted stretching as the most frequent activity of daily living observed to be painful (93% of those reporting pain). Furthermore, range-of-motion therapy was noted as the most common, painful activity (58%) with an intensity higher than that of other activities (mean of 2.3 on a 0–5 scale). Many of the rehabilitative interventions such as range-of-motion therapy, positioning devices, and wearing of splints or orthotics are done on a daily if not continuous basis. Children with CP engaged in ongoing rehabilitative efforts may display increasing anxiety, fear, frustration, withdrawal, or distress about these interventions given the potential for associated pain (McGrath, 1990; Turnquist & Engel, 1994). These may result in depression, poor coping, decreased participation in treatment, and limited therapeutic goal attainment (Kibele & Flint, 1990; Tyler, 1990). However, in their study, Miller, Johann-Murphy, and Cate (1997) demonstrated that pain and anxiety in children with CP decreased over time during rehabilitation following selective posterior rhizotomy. The authors noted that special considerations for pain assessment and management were observed, perhaps supporting this decrease. This may not always occur in rehabilitation given therapists' limited knowledge and awareness concerning pain (Turnquist & Engel, 1994).

Two studies, one a survey of pediatric occupational therapists and the other a survey of physical therapists working in orthopedics, revealed that therapists receive inadequate education in their degree programs concerning pain theory and management, which directly affects their knowledge of appropriate pain assessments and interventions (Turnquist & Engel, 1994; Wolff, Michel, Krebs, & Watts, 1991). Enhanced education and clinical focus, in addition to increased knowledge about children's pain experiences, might prove beneficial in minimizing the experience of pain for children with chronic conditions such as CP.

Pain Assessment Issues in Children with CP

Little research exists concerning pain assessment in children with CP. Developmental differences such as cognition and ability to communicate significantly influence children's perception of and response to pain (McGrath, 1990). Motor, cognitive, and communication impairments complicate the task of appropriate pain assessment and should be considered when choosing instruments to evaluate pain. If a child with CP is unable to effectively use a self-report tool, overt responses to pain can be noted using observational rating or behavioral scales. Because pain and anxiety are difficult to separate in the clinical setting, the term "behavioral distress" is often used to capture the verbal, behavioral, and physiological indications of the inseparable elements of pain and anxiety (Katz, Kellerman, & Siegel, 1980; McGrath, 1990).

Pediatric pain assessment tools intended to measure overt behavioral distress are the Children's Hospital of Eastern Ontario Pain Scale (CHEOPS; McGrath et al., 1985), the Observational Scale of Behavioral Distress (OSBD; Jay, Ozolins, Elliott, & Caldwell, 1983), and the Procedural Rating Scale-revised (Katz et al., 1980). Most of these scales have been developed for the assessment of acute pain in typically developing children. Increased attention has been paid to development of observational pain scales for persons with cognitive impairments and communication deficits (Breau, McGrath, Camfield, Rosmus, & Finley, 2000; Fanurik, Koh, Harrison, Conrad, & Tomerlin, 1998). Recently, Collignon and Giusiano (2001) developed a 10-item behavioral observation scale with demonstrated sensitivity and reliability when used with children with severe CP (Cronbach's α) was 0.93 for internal scale coherence; Cohen's k ranged from 0.39 to 0.75 for between-expert consensus and 0.47 to 0.74 for consensus between the scale and the expert panel; sensitivity = 0.76–0.88 and specificity = 0.73–0.88). Items include observable behaviors such as crying, painful expression, protective responses, and moaning. Clinicians and researchers should be aware of these advancements and sensitive to the unique issues concerning pain assessment in children with CP.

Suggestions for Future Research

Despite increasing interest and empirical evidence related to pain assessment and management in children with CP, questions remain unanswered, especially with respect to the occurrence and effect of ongoing painful experiences. Although literature concerning adults with CP suggests that pain is a common secondary condition for persons with CP and often begins in childhood (Schwartz et al., 1999; Turk et al., 1997), little is known about the pain experiences of children with CP from the child's perspective. Future research should explore not only the temporal descriptors and physiological markers of pain in children with CP (e.g., intensity, frequency,

duration, muscle activity, heart rate), but also the functional effect of pain on children with CP in terms of activities of daily living, community participation, quality of life, socialization, active participation in rehabilitative activities, and psychological ramifications. Research concerning the potential differences in pain perception for those with and without a physical disability such as CP also is warranted. It will be important to examine the utility, validity, and reliability of appropriate assessment tools for children of all ages with CP. Consideration needs to be given to the parents' or caregivers' perspectives on the magnitude, scope, and management of their child's pain in order to better understand a child's global experience of pain, as well as implications for family life. Finally, the availability and efficacy of appropriate treatments, both pharmacological and nonpharmacological, should be investigated.

Summary

There are a number of unanswered questions regarding pain in children with CP despite clinical anecdotes suggesting that pain is a significant problem for these children. Though treatment approaches are beyond the scope of this review paper, many are available, including a multitude of pharmacological interventions specific to each problem or complication as well as nonpharmacological interventions such as distraction, relaxation training, biofeedback, and therapeutic massage (McGrath, 1990). If efforts continue to understand the pain experiences of children with CP and to develop appropriate, effective pain assessment and management strategies for these children, their lives and the lives of those around them will be enhanced immeasurably.

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References

- Albright, A.L., Barron, W.B., Fasick, M.P., Polinko, P., & Janosky, J. (1993). Continuous intrathecal baclofen infusion for spasticity of cerebral origin. *Journal of the American Medical Association, 270*(20), 2475–2477.
- American Pain Society (APS). (1995). Quality improvement guidelines for the treatment of acute pain and cancer pain. American Pain Society Quality of Care Committee. *Journal of the American Medical Association, 274*, 1874–1880.
- American Pain Society (APS). (2002). *The assessment and management of acute pain in infants, children, and adolescents and pediatric chronic pain*. Retrieved October 20, 2003 from <http://www.ampainsoc.org/pub/bulletin/sep01/article1.htm>.
- Andersson, C., & Mattsson, E. (2001). Adults with cerebral palsy: A survey describing problems, needs, and resources, with special emphasis on locomotion. *Developmental Medicine and Child Neurology, 43*(2), 76–82.

- Ashburn, M.A., & Staats, P.S. (1999). Management of chronic pain. *The Lancet*, 353, 1865–1869.
- Bagg, M.R., Farber, J., & Miller, F. (1993). Long-term follow-up of hip subluxation in cerebral palsy patients. *Journal of Pediatric Orthopedics*, 13(1), 32–36.
- Blair, E. & Stanley, F. (1985). Interobserver agreement in the classification of cerebral palsy. *Developmental Medicine & Child Neurology*, 27, 615–622.
- Bleck, E.E. (1987). Orthopedic management in cerebral palsy. In *Clinics in developmental medicine No. 99/100*. London: MacKeith Press.
- Breau, L.M., McGrath, P.J., Camfield, C., Rosmus, C., & Finley, G.A. (2000). Preliminary validation of an observational pain checklist for persons with cognitive impairments and inability to communicate verbally. *Developmental Medicine and Child Neurology*, 42, 609–616.
- Chalkiadis, G. A. (2001). Management of chronic pain in children [Electronic version]. *Medical Journal of Australia*, 175, 476–479.
- Collignon, P. & Giusiano, B. (2001). Validation of a pain evaluation scale for patients with severe cerebral palsy. *European Journal of Pain*, 5(4), 433–442.
- Darwish, H. (1999). Living with cerebral palsy and tube feeding: Easier to feed but at what cost? *The Journal of Pediatrics*, 135(3), 272–273.
- Del Giudice, E., Staiano, A., Capano, G., Romano, A., Florimonte, L., Miele, E., et al., (1999). Gastrointestinal manifestations in children with cerebral palsy. *Brain Development*, 21(5), 307–311.
- Dzienkowski, R.C., Smith, K.K., Dillow, K.A., & Yucha, C.B. (1996). Cerebral palsy: A comprehensive review. *Nurse Practitioner*, 21(2), 45–59.
- Engel, J.M. (1988). *Pediatric pain*. Athens, GA: Elliott & Fitzpatrick.
- Engel, J.M., Jensen, M. P., Hoffman, A. J., & Kartin, D. (2003). Pain in persons with cerebral palsy: Extension and cross validation. *Archives of Physical Medicine and Rehabilitation*, 84, 1125–1128.
- Fanurik, D., Koh, J.L., Harrison, R.D., Conrad, T.M., & Tomerlin, C. (1998). Pain assessment in children with cognitive impairment: An exploration of self-report skills. *Clinical Nurse Researcher*, 7(2), 103–119.
- Forsberg, H. & Tedroff, K.B. (1997). Botulinum toxin treatment in cerebral palsy: Intervention with poor evaluation? *Developmental Medicine and Child Neurology*, 40(11), 785–787.
- Gaffney, A., & Dunne, E.A. (1986). Developmental aspects of children's definitions of pain. *Pain*, 26, 105–117.
- Gajdosik, C.G. & Cicirello, N. (2001). Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. *Physical and Occupational Therapy in Pediatrics*, 21(4), 49–68.
- Gatchel, R.J. & Turk, D.C. (Eds.). (1999). *Psychosocial factors in pain*. New York: Guilford Press.
- Geiduschek, J.M., Haberkern, C.M., McLaughlin, J.F., Jacobson, L.E., Hays, R.M., & Roberts, T.S. (1994). Pain management for children following selective dorsal rhizotomy. *Canadian Journal of Anaesthesia*, 41(6), 492–496.
- Graham, H.K. (2000). Botulinum toxin A in cerebral palsy: Functional outcomes. *Journal of Pediatrics*, 137, 300–303.
- Hadden, K.L., & von Baeyer, C.L. (2002). Pain in children with cerebral palsy: Common triggers and expressive behaviors. *Pain*, 99, 281–288.
- Hart, D.A. (2000). Use of botulinum toxin in spasticity. *Physical Medicine and Rehabilitation-State of the Art Reviews*, 14(2), 247–261.
- Hester, N.O. (1993). Pain in children. *Annual Review of Nursing Research*, 11, 105–142.
- Hodgkinson, I., Jindrich, M.L., Duhaut, P., Vadot, J.P., Metton, G., & Berard, C. (2001). Hip pain in 234 non-ambulatory adolescents and young adults with cerebral palsy: A cross-sectional multicentre study. *Developmental Medicine and Child Neurology*, 43(12), 806–808.
- International Association for the Study of Pain (IASP). (2002). *Pain definitions*. Retrieved October 20, 2003 from <http://www.iasp-pain.org/terms-p.html>.
- Jay, S.M., Ozolins, M., Elliott, C.M., & Caldwell, S. (1983). Assessment of children's distress during painful medical procedures. *Health Psychology*, 2, 133–148.
- Jensen, M.P., Turner, J.A., Romano, J.M., & Lawler, B.K. (1994). Relationship of pain-specific beliefs to chronic pain adjustment. *Pain*, 57, 301–309.
- Joint Commission on Accreditation of Healthcare Organizations (JCAHO). (2002). *Standards*. Retrieved August 2, 2002 from <http://www.jcaho.org/news+room/health+care+issues/jcaho+focus+on+pain+management.htm>.
- Kandel, E.R., Schwartz, J.H., & Jessell, T.M. (Eds.). (2000). Spinal reflexes. In *Principles of Neural Science*. New York: McGraw-Hill.
- Katz, E.R., Kellerman, J., & Siegel, S.E. (1980). Behavioral distress in children with cancer undergoing medical procedures: Developmental considerations. *Journal of Consulting and Clinical Psychology*, 48, 356–365.
- Kennes, J., Rosenbaum, P., Hanna, S.E., Walter, S., Russell, D., Raina, P., et al. (2002). Health status of school-aged children with cerebral palsy: Information from a population-based sample. *Developmental Medicine and Child Neurology*, 44, 240–247.
- Kibele, A. (1989). Occupational therapy's role in improving the quality of life for persons with cerebral palsy. *American Journal of Occupational Therapy*, 43, 371–377.
- Kibele, A., & Flint, S. (1990). The challenge of pediatric pain: The role of occupational therapy in multidisciplinary management. *Occupational Therapy Practitioner*, 1, 39–46.
- Kirschner, J., Berweck, S., Mall, V., Korinthenberg, R., & Heinen, F. (2001). Botulinum toxin treatment in cerebral palsy: Evidence for a new treatment option. *Journal of Neurology*, 248(1), 28–30.
- Landgraf, J. M., Abetz, L., & Ware, J. E. (1996). *Child Health Questionnaire (CHQ): A user's manual*. Boston: The Health Institute.
- Liptak, G.S., O'Donnell, M., Conaway, M., Chumlea, W.C., Wolrey, G., Henderson, R.C., et al. (2001). Health status of children with moderate to severe cerebral palsy. *Developmental Medicine and Child Neurology*, 43(6), 364–370.
- Long, T.M., & Hart, K.A. (1995). Pain in children. *Orthopaedic Physical Therapy Clinics of North America*, 4, 503–518.
- McGrath, P.A. (1990). *Pain in children: Nature, assessment, and treatment*. New York: The Guilford Press.
- McGrath, P.J., Johnson, G., Goodman, J.T., Schillinger, J., Dunn, J., & Chapman, J.A. (1985). CHEOPS: A behavioral scale for rating post-operative pain in children. In H.L. Fields, R. Dubner, & F. Certero (Eds.), *Advances in pain research and therapy* (Vol. 9, pp. 395–402). New York: Raven Press.
- Menefee, L.A., & Katz, N.P. (2002) *The PainEdu.org manual*. Newton, MA: Inflexion, Inc.
- Merskey, H., & Bogduk, N. (Eds.). (1994). *Classification of chronic pain: Descriptions of chronic pain syndromes and definitions of pain terms* (2nd ed.). Seattle: IASP Press.
- Miller, A.C., Johann-Murphy, M., & Cate, M. (1997). Pain, anxiety, and cooperativeness in children with cerebral palsy after rhizotomy: Changes throughout rehabilitation. *Journal of Pediatric Psychology*, 22(5), 689–705.
- Mutch, L., Alberman, E., Hagberg, B., Kodama, K., & Perat, M. (1992). Cerebral palsy epidemiology: Where are we now and where are we going? *Developmental Medicine and Child Neurology*, 34, 547–551.
- Nehring, W.M. (2000). Cerebral palsy. In P.L. Jackson and J. Vessy (Eds.), *Primary care of the child with a chronic condition*, (3rd ed.). St. Louis: Mosby.
- Nolan, J., Chalkiadis, G.A., Low, J., Olesch, C.A., & Brown, T.C.K. (2000). Anaesthesia and pain management in cerebral palsy. *Anaesthesia*, 55, 32–41.

- Novy, D.M., Nelson, C.V., Francis, D.J., & Turk, D.C. (1995). Perspectives on chronic pain: An evaluative comparison of restrictive and comprehensive models. *Psychological Bulletin*, *118*, 238–247.
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *39*, 214–223.
- Petrina, T. (2001). Pain in children with cerebral palsy. Unpublished master's thesis, University of Washington: Seattle.
- Roscigno, C.I. (2002). Addressing spasticity-related pain in children with spastic cerebral palsy. *Journal of Neuroscience Nursing*, *34*(3), 123–133.
- Samson-Fang, L., Butler, C., & O'Donnell, M. (2003). Effects of gastrostomy feeding in children with cerebral palsy: An AACPD evidence report. *Developmental Medicine and Child Neurology*, *45*, 415–426.
- Schwartz, L. S., Engel, J. M., & Jensen, M. P. (1999). Pain in persons with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, *80*, 1243–1246.
- Sparkes, M.L., Klein, A.S., Duhaime, A.C., & Mickle, J.P. (1989). Use of epidural morphine for control of postoperative pain in selective dorsal rhizotomy for spasticity. *Pediatric Neuroscience*, *15*(5), 229–232.
- Stanley, F., Blair, E., & Alberman, E. (2000). Cerebral palsies: Epidemiology and causal pathways. In *Clinics in Developmental Medicine No. 151*. London: MacKeith Press.
- Tenuta, J., Shelton, Y.A., & Miller, F. (1993). Long-term follow-up of triple arthrodesis in patients with cerebral palsy. *Pediatric Orthopedics*, *13*(6), 713–716.
- Turk, M.A., Geremski, C.A., Rosenbaum, P.F., & Weber, R.J. (1997). The health status of women with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, *78*, S10–S17.
- Turk, D.C., & Melzack, R. (1992). The measurement of pain and the assessment of people experiencing pain. In D.C. Turk & R. Melzack (Eds.), *Handbook of pain assessment* (pp. 3–12). New York: Guilford Press.
- Turnquist, K.M., & Engel, J.M. (1994). Occupational therapists' experiences and knowledge of pain in children. *Physical and Occupational Therapy in Pediatrics*, *14*, 35–51.
- Tyler, D.C. (1990). Pain in infants and children. In J.J. Bonica (Ed.), *The management of pain* (2nd ed., pp. 538–551). Philadelphia: Lea & Febiger.
- United Cerebral Palsy (UCP). (2002). *UCP net: Cerebral Palsy: Facts & Figures*. Retrieved October 20, 2003 from http://www.ucp.org/ucp_channel/doc.cfm/1/11/10427/10427-10427/447.
- Van Schaebroeck, P., Nuttin, B., Lagae, L., Schrijvers, E., Borghgraef, C., & Feys, P. (2000). Intrathecal baclofen for intractable cerebral spasticity: A prospective placebo-controlled, double-blind study. *Neurosurgery*, *46*(3), 603–615.
- Wolff, M.S., Michel, T.H., Krebs, D.E., & Watts, N.T. (1991). Chronic pain—assessment of orthopedic physical therapists' knowledge and attitudes. *Physical Therapy*, *71* (3), 207–214.
- Zucconi, M., & Bruni, O. (2001). Sleep disorders in children with neurologic diseases. *Seminars in Pediatric Neurology*, *8*(4), 258–275.

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