

## Pain in Children with Cerebral Palsy

Written by Karen Sauve, MSc, PT, 2010.

### Introduction

This document contains a brief overview of information regarding pain in children with cerebral palsy. It is intended to provide clinicians with relevant background information on this topic.

### How was the literature review completed?

An electronic search was performed in the spring of 2010. Keywords used in the search included: 'pain' and 'cerebral palsy.'

### What is pain?

Pain: subjective, multifaceted, distracting, disabling. Pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage."<sup>1</sup> The experience of pain is believed to be subjective, individual and dependent on one's prior experience.<sup>2</sup> Thus, commonly used definitions of pain highlight the "personal, sensory, emotional and contextual nature" of pain, relying on one's ability to communicate this experience.<sup>3</sup> Houlihan and colleagues<sup>2</sup> indicated that "by 18 months of age, most children have a word for pain and pain intensity can be described by children with a cognitive age of 4 years" (pg.305).

The American Pain Society<sup>4</sup> characterizes pain as the "fifth vital sign",<sup>(p76)</sup> after temperature, blood pressure, pulse and respiratory rate, indicating the serious nature and sequelae of pain. Consequently, Engel and colleagues<sup>5</sup> urged clinicians to assess pain routinely in their clients.

Pain is a recognized issue or secondary impairment in persons with cerebral palsy (CP) – starting in childhood, persisting throughout adolescence and into adulthood. CP is a group of non-progressive conditions which affect movement and posture causing activity limitation.<sup>6</sup> Of particular concern in this population is the experience of chronic pain, defined as "pain without apparent biologic purpose persisting beyond the typical course of a disease or typical healing time for an injury".<sup>5(p74)</sup> Lauder and White<sup>7</sup> specified that pain is deemed chronic if it is "persistent or near constant longer than 3 months".<sup>(p416)</sup>

The purpose of this paper is to provide a brief overview of the literature regarding the prevalence, causes and implications of chronic pain in children and adolescents with CP. Further, this paper will review commonly used outcome measures in the assessment of pain in this population and discuss suggested management options.

### What is the prevalence of pain in children and adolescents with CP?

It is believed that 25% of all children and adolescents experience chronic pain.<sup>5</sup> This statistic increases in children with disabilities; 64.6 to 78% of children with CP were reported by their caregivers to experience pain, depending on the sample.<sup>8-10</sup> Two studies examined the prevalence of self-reported pain in children and adolescents with CP. Engel and colleagues<sup>5</sup> surveyed a group of 20 participants with CP, aged 6-17 years. Seventy percent of this sample expressed having one or more areas of 'bothersome' pain in the previous 3 months, with the pain persisting for at least 3 months. Each pain episode was reported to last 1 to 6 hours. In a larger sample of 230 adolescents with CP across Ontario, Doralp and Bartlett<sup>11</sup> found that 63% of girls and 49% expressed experiencing physical pain in the previous month.

## Does the prevalence vary according to gender or severity of CP?

Some authors described their sample according to the Gross Motor Function Classification System (GMFCS); a valid and reliable classification tool for children with CP based on age-specific functional motor abilities.<sup>12</sup> This tool features five levels with children classified in level V having more 'severe' motor impairment than children in preceding levels (i.e., levels I to IV).

In that sample studied by Doralp and Bartlett<sup>11</sup>, females were found to report more pain than males in all GMFCS levels except level I; no statistically significant effect between genders was found however. Similarly, males in levels III to V have been perceived to have less pain than females in the same levels, according to caregivers,<sup>2</sup> consistent with typically developing children.<sup>3</sup>

Additionally, Houlihan and colleagues<sup>2</sup> found that the frequency of reported pain was related to the severity of motor impairment (i.e., GMFCS level) and the presence of gastrostomy tube ( $p=0.05$ ). Children with more severe motor impairment were perceived to experience more frequent pain. However, other studies have found no statistically significant differences between GMFCS levels and pain<sup>9,10</sup> or between distribution of CP (i.e., hemiplegia, diplegia, quadriplegia) and pain.<sup>8,13</sup>

The discrepancy in study results is confusing; however, it is important to note that there were several differences between studies, including: sample sizes, means of reporting pain differed (self- vs. proxy-report), outcome measures used, time-frame considered, and aspect of pain reported (i.e., 'frequency' vs. 'experience' vs. 'level of pain').

In the largest study, Doralp and Bartlett<sup>11</sup> found that self-reported pain prevalence was highest in GMFCS level II for males and level IV for females, but no *statistically significant* trend for increasing GMFCS level. The most common sites of pain reported by adolescents in this study in each GMFCS level were:

**Table 1: Pain Location by GMFCS Level**

GMFCS Level	Pain Location
I	Ankle/foot, knee, calf, lower back
II	Ankle/foot, knee, lower back
III	Ankle/foot, knee, lower back, hip, neck
IV	Ankle/foot, thigh, hip, knee, shoulder, lower back
V	Ankle/foot, knee, upper back, lower back

## What are the risk factors and causes of pain in children and adolescents with CP?

It is well established that pain, whether acute or chronic, is a common experience for children and adolescents with CP. There are many potential causes for this pain as a diagnosis of CP is associated with numerous secondary impairments. The causes and risk factors as identified in the literature are reviewed and categorized according to the International Classification of Functioning, Disability and Health (ICF).<sup>14</sup> This classification system is used extensively in pediatric rehabilitation practice and research, providing a common framework for communication and evaluation of children with CP.<sup>15</sup>

### Body Structures and Functions

Breau and colleagues<sup>16</sup> examined risk factors for pain in children with severe cognitive impairments, including 44 children with CP and 59 children with a seizure disorder. Parents were surveyed every three months over one year and asked to report on their child's pain in the previous week. The models generated from this research were found to "differentiate well between children with and without pain, distinguishing the child with pain in 74 to 89% of pairs in which one child had pain and one did not".<sup>(p367)</sup> These results provide good evidence to suggest that there are specific characteristics associated with pain in this population and that unique combinations of factors increase a child's risk for specific types of pain. The models were found to be more specific than sensitive, indicating that they are better able to identify children who did not have pain due to that specific factor. The authors cautioned that further research is needed to confirm the findings of the models in larger samples.

**Table 2: Pain Demographics**

Type of Pain (% of sample affected)	Risk Factors Identified for the Specified Type of Pain
Gastrointestinal (22%) <ul style="list-style-type: none"> <li>• Digestive or gas issues (22%)</li> <li>• Reflux (2%)</li> <li>• Bowel issues (10%)</li> <li>• Constipation (5%)</li> </ul>	Females Children who are gastrostomy tube (G-tube) fed Children with upper extremity impairments
Musculoskeletal (19%) <ul style="list-style-type: none"> <li>• Spasticity (6%)</li> <li>• Orthopedic pain (13%)</li> </ul>	Children who are G-tube fed Males
Recurrent (13%) <ul style="list-style-type: none"> <li>• Ear pain (not infection) (9%)</li> <li>• Seizures (3%)</li> <li>• Diaper rash (1%)</li> </ul>	
Common Childhood (11%) <ul style="list-style-type: none"> <li>• Teething (5%)</li> <li>• Menstruation (4%)</li> <li>• Headache (1%)</li> </ul>	Children who are G-tube fed Children who took fewer medications
Infection (20%) <ul style="list-style-type: none"> <li>• Throat (3%)</li> <li>• Chest (3%)</li> <li>• Other (15%)</li> </ul>	Children <b>without</b> a diagnosis of CP (i.e., those children in the sample who had a seizure disorder and not CP) → the authors suggested that perhaps children with CP are followed more routinely by medical professional; thus, infections are detected and treated sooner
Accidental (30%) <ul style="list-style-type: none"> <li>• Injury (30%)</li> </ul>	Children who <b>lack</b> visual or leg impairments (perhaps these children are more mobile and participate more frequently in gross motor activities?)

### Activity and Participation Factors

Several activities are thought to cause pain in children and adolescents with CP. Not surprisingly, parents reported that assisted stretching was the daily living activity that most frequently caused pain for children with CP.<sup>8</sup> These authors reported significant correlations between assisted stretching, independent standing ( $p < 0.01$ ) and assisted walking ( $p < 0.05$ ) with pain. Also, parents in this study rated toileting and putting on splints as painful experiences for their children. Similarly, another group of parents of children with CP reported that ambulation, prolonged sitting, static positioning and donning orthotics or splints caused their children pain.<sup>5</sup>

Although there is insufficient evidence to discontinue these activities, it is important for clinicians to be aware of the potential for pain during these tasks, as they are routinely recommended as part of treatment programs. Alternative treatment options need to be considered to avoid causing pain in children and adolescents with CP, while still providing therapeutic benefits.

### Environmental Factors

In a sample of typically developing children, it was suggested that the child's experience of pain is influenced by reactions to pain from parents, siblings and friends.<sup>17</sup> The family history and the presence of pain or attention from pain in others in the home can influence how a child reacts to pain.<sup>17</sup> Also,

painful events experienced at an early age affect the experience and expression of pain at older ages, even if they are not consciously remembered.<sup>17</sup> Although these suggestions stem from literature on children with typical development, they are important considerations for children with CP. Houlihan and colleagues<sup>2</sup> questioned the influence of the parents' own pain and medical experience on the perception of their child's pain. This remains unknown. However, these factors may be modifiable when treating pain in children with CP.

### **What are the implications of pain in children and adolescents with CP?**

The literature describes serious sequelae of pain in children and adolescents with CP, ranging from impairments in body functions and structures, to limitations in activities and restrictions in participation.

#### Body Structures and Functions

There is a lack of strong statistical evidence of associations between pain and resulting impairments in body structures and functions in children and adolescents with CP. However, in a descriptive paper on spasticity-related pain in children with CP, Roscigno<sup>18</sup> suggested that unrelieved pain can cause cortical reorganization and can become chronic. Also, chronic pain can lead to cardiac, respiratory, gastrointestinal, immunological, neurologic and musculoskeletal complications.<sup>18</sup> It is unclear if these complications are a direct result of pain or occur indirectly through decreased physical activity as a result of pain, or through both mechanisms. Houlihan and colleagues<sup>2</sup> suggested that chronic or recurrent pain might have lifelong physiological and psychological consequences, based on literature on typically developing children. Still other literature on typically developing children indicated that repeated pain might have long-term consequences on a child's behaviour.<sup>10</sup>

#### Activity Limitations and Participation Restrictions

With higher-level evidence, several studies have demonstrated associations between pain and decreased activities of daily living and school functioning.<sup>19,2</sup>

Berrin and colleagues<sup>19</sup> measured the health-related quality of life in children with spastic CP. One hundred and eighty-nine parents of children with CP and 73 children with CP completed the PedsQL Generic Core Scale and the PedsQL CP Module to test a model of pain, fatigue and school functioning in children with CP. The results indicated that pain and school functioning were significantly associated ( $p < 0.001$ ,  $r^2 = 0.163$ ). Although the findings were statistically significant, the magnitudes of correlation are weak. With a moderate to good correlation; however, pain was significantly associated with fatigue ( $p < 0.001$ ,  $r^2 = 0.387$ ). Children with more pain tended to experience more fatigue, which in turn was associated with lower school functioning, but children with greater pain also experienced lower school functioning independent of the fatigue they experienced.

More specifically, Houlihan and colleagues<sup>2</sup> found that the frequency of reported pain had a significant and independent effect on school days missed ( $p = 0.03$ ), days in bed ( $p = 0.01$ ) and suggestive trends towards days unable to do usual activities ( $p = 0.17$ ) and family activities ( $p = 0.17$ ) in their sample of children classified in GMFCS levels III-V. Pain frequency was assessed by parent proxy-report using the CHQ.

To consider the perception of children and adolescents exclusively, Dickinson et al<sup>20</sup> completed a large cross-sectional study. They visited 818 children with CP in Europe, aged eight to twelve years. Of this total sample, 500 children could report their own quality of life and experience of pain. There was a trend for children who reported pain in the previous week to report a lower quality of life on all domains of the KIDSCREEN. Pain was significantly associated with poorer scores in the domains of relationships with parents ( $p = 0.007$ ), school ( $p < 0.0001$ ), moods and emotions ( $p = 0.0003$ ), self-perception ( $p = 0.005$ ), autonomy ( $p < 0.0001$ ) and physical wellbeing ( $p < 0.0001$ ). Although the authors do not provide definitions of these domains or further explanations of the items within each domain, the ICF classifies most of these domains under activity and participation.<sup>14</sup>

## Environmental Factors

Finally, through their qualitative study parental assessment of pain in children with CP, Carter and colleagues<sup>21</sup> commented on the impact of the child's pain experience on the parent. Some parents reported feeling unprepared for the painful problems their children developed. A common theme extracted from the data was that parents were upset by having to watch their children decline over the years and deal with ongoing pain issues. These findings were echoed in a sample of 198 parents of children with CP who were interviewed using the CHQ.<sup>2</sup> Although the association is weak, parents who perceived that their children were in pain were emotionally affected by the child's health and emotional wellbeing ( $r=0.38$ ).

## **How is pain assessed in children and adolescents with CP?**

As pain is multifaceted, there are many attributes of pain to assess in children and adolescents with CP. First, clinicians must determine exactly what information is desired from assessment or measurement: pain presence, intensity, frequency, or interference on function. Health outcome measures can serve one or more purposes; a measure can provide discriminative, predictive, or evaluative information.<sup>22,23</sup> A discriminative measure "distinguishes between individuals with and without a particular characteristic or function"; does the child have pain or not?<sup>22(p126)</sup> A predictive measure is designed to "estimate future outcome or prognosis"; will the child develop pain based on the presence of specific risk factors?<sup>24(p184)</sup> Finally, an evaluative measure quantifies the amount of change in a function or characteristic over time; has the child's pain changed as a result of a given intervention?<sup>22,24</sup> Some health outcome measures may be designed to serve more than one of these purposes.

Regardless of the purpose of the measure, self-report is considered the gold standard for pain assessment due to pain's subjective and individual nature.<sup>5</sup> Varni et al<sup>25</sup> suggested that clinicians and researchers should seek self-report from children regarding their pain experience whenever possible. This is particularly challenging with children who are non-verbal; thus, there are times when parent proxy-report is necessary. Research supports this alternate approach to data collection or clinical assessment, as Engel and colleagues<sup>5</sup> found the agreement between parent and child report of pain occurrence was 93%. Additionally, Carter and colleagues<sup>21</sup> recommended that pain assessment scales *should* involve the parents' perception and observation of their child. Consistent with family-centred services, Carter and colleagues<sup>21</sup> contended that parents are experts regarding their child. These authors found that parents follow a systematic process when assessing their child's pain: recognizing subtle cues, systematically identifying the presence and potential causes of pain based on context, and instinctively knowing. One parent explained: "I don't know any short cuts...it's just they're so subtle...But I can get up of a morning and go 'There's something wrong. He's not well'".<sup>21(p452)</sup>

Aside from parent observation, there have been numerous outcome measures developed to measure aspects of pain in children and adolescents with CP. For the purpose of this paper, only a few of the most commonly used measures will be reviewed, both those using parent proxy- and child self-report.

**Table 3: Pain Measures**

<b>Name of Measure</b>	<b>Evaluative Scale for Pain in CP<sup>26</sup></b>	<b>Non-Communication Children's Pain Checklist-Revised<sup>27,28</sup></b>	<b>Child Health Questionnaire<sup>29,30</sup></b>	<b>Pediatric Outcomes Data Collection Instrument<sup>30,31</sup></b>
<b>Type of Measure</b>	Evaluative & Discriminative	Discriminative	Discriminative	Evaluative
<b>Target Population</b>	Children and adolescents with CP with severe cognitive and communication impairments	Children with CP with severe cognitive impairment	Children 5 years and older	Children
<b>Child or Proxy Report</b>	Proxy (via observation)	Proxy (via observation)	Child or Parent	Child or Parent
<b>Administration</b>	Behavioural observation Rapid (10-15 min)	Behavioural observation	Questionnaire 20-30 min for all 10 domains	Questionnaire 15 min
<b>Scoring</b>	Ordinal Based on how behaviour differs from typical for that child (with parent input)	Not specified	Not specified	Not specified
<b>Aspect of Pain Measured</b>	Presence or absence of pain	Presence or absence of pain	General well-being with one domain on pain	General health with pain and discomfort domain
<b>Psychometric Info</b>	High internal consistency (Cronbach's alpha coefficient of 0.93); Moderate to substantial levels of agreement (Cohen's kappa coefficients ranging from 0.47 to 0.74); Good sensitivity and specificity (0.73 to 0.88), when compared to expert consensus; No test of responsiveness (thus no idea if it works as evaluative tool)	Good internal consistency (Cronbach's alpha coefficient of 0.79); Good specificity (0.77 to 0.84)	High internal consistency for pain scale (Cronbach's alpha coefficient of 0.92)	High internal consistency for pain scale (Cronbach's alpha coefficient of 0.83); Responsive to change over time (but questionable methods for testing this <sup>24</sup> )

## What are management options for pain in children and adolescents with CP?

Just as pain assessment has proven to be challenging in children and adolescents with CP, management of pain can be equally difficult. Parents of children with CP have reported difficulty in accessing adequate pain management from health care providers.<sup>8</sup> Other parents described that once they do access services, the health care providers “can’t seem to figure out” how to manage their child’s pain.<sup>21(p454)</sup> Additionally, the process of seeking services and undergoing medical investigations related to pain is stressful and upsetting, parents “feel isolated and that they don’t have options” but they want professional support.<sup>21(p454)</sup> Health care professionals face challenges in helping parents manage their child’s pain; clear mechanisms of pain remain unknown and numerous organizational barriers exist.<sup>18,32</sup> Despite these challenges, the literature provides suggestions related to pain management in children and adolescents with CP. This literature is discussed and categorized according to the ICF.

### *Body Structures and Functions*

In their survey-based study with twenty children with CP, Engel and colleagues<sup>5</sup> found that use of analgesic medications was one factor identified in relieving pain. Larger pharmacological studies have demonstrated the efficacy of medications for spasticity-related pain in children and adolescents with CP, as outlined by Roscigno<sup>18</sup> in her descriptive review. However, a number of these medications may cause serious adverse reactions as well. Roscigno<sup>18</sup> reported on the literature related to dorsal rhizotomy for pain management in CP; although this procedure was thought to eliminate pain in this population, neuropathic pain and spinal deformity are also documented outcomes of this procedure.<sup>33,34</sup> From her review, Roscigno<sup>18</sup> concluded that intrathecal baclofen and botox have shown the “most promising results in reducing pain related to spasticity in children with CP with the fewest side effects”.<sup>p131</sup>

Additional therapeutic options have been described elsewhere.<sup>35</sup> In a descriptive study, 207 children with a range of diagnoses (22 with CP) were followed through a tertiary pain clinic.<sup>35</sup> Various treatment options were provided to the children, the most common of which was medication. Adjunct treatment options provided included: acupuncture, psychology, iontophoresis, and nerve blocks. The author reported that most children with CP were able to sleep through the night once they received treatment for their pain. This is a descriptive study lacking rigorous statistical analysis or systematic documentation; thus, clinical decisions cannot be drawn from these findings. However, it may be beneficial to evaluate the efficacy of each treatment option in children with CP.

### *Activity and Participation and Environmental Factors*

Several studies have suggested the use of coping and relaxation exercises in the management of pain in children and adolescents with CP.<sup>5,21,36</sup> Although the efficacy of these interventions was not tested experimentally, the twenty children and adolescents with CP interviewed by Engel and colleagues<sup>5</sup> identified that resting or lying down helped to relieve pain. These authors suggested that relaxation training and instruction in coping strategies might be helpful in reducing pain as well. Specific coping strategies for the management of chronic pain include task persistence, diverting attention, self-statements and increasing activity.<sup>36</sup> Parents of children and adolescents with CP use various strategies to help their child cope with pain.<sup>21</sup> These parents reported performing activities such as rocking, stroking, massaging and positioning to attempt to reduce their child’s pain. Also, some parents identified that each child has a preferred environment; one child may prefer music or videos, another may want a quiet, dark surrounding. Consequently, it is important to manage the environment to decrease negative stimuli.<sup>21</sup>

Although several treatment options are described in the literature, there is a lack of strong evidence to inform evidence-based practice in the management of pain in children and adolescents with CP. Again, further research is required to improve treatment for this population.

## Summary

It is evident that most children and adolescents with CP experience pain, resulting in serious consequences to their health and daily life activities and participation. Furthermore, these issues negatively impact their caregivers. The literature offers several outcome measures to identify pain in this population; however, better clinical tools are needed to evaluate change in these symptoms with intervention. Most importantly, further research (including clinical case studies) is required to evaluate effective intervention options in the management of pain in children and adolescents with CP. It is believed that a pain intensity of 3 (on a 0-10 scale) is clinically significant;<sup>10</sup> we need more treatment options to successfully minimize pain in this population before it reaches and exceeds that point.

### Want to know more? Contact:

**Tanja Mayson, Physiotherapist**

Sunny Hill Health Centre for Children

tmayson@cw.bc.ca

604-453-8300

A copy of this document is available at: [www.childdevelopmentandrehab.ca](http://www.childdevelopmentandrehab.ca)

## References

1. McKearnan, KA, Kieckhefer, GM, Engel, JM, et al. Pain in children with cerebral palsy: A review. *Journal of Neuroscience Nursing*. 2004;36:252-259.
2. Houlihan, CM, O'Donnell, M, Conaway, M, et al. Bodily pain and health-related quality of life in children with cerebral palsy. *Dev Med Child Neurol*. 2004;46:305-310.
3. Howard, RF. Current status of pain management in children. *JAMA*. 2003;290:2464-2469.
4. American Pain Society. Quality improvement guidelines for the treatment of acute pain and cancer pain. American Pain Society Quality of Care Committee. *JAMA*. 1995;274:1874-1880.
5. Engel, JM, Petrina, TM, Dudgeon, BJ, et al. Cerebral palsy and chronic pain: A descriptive study of children and adolescents. *Physical & Occupational Therapy in Pediatrics*. 2005;25:73-84.
6. Rosenbaum, PL, Paneth, N, Leviton, A, et al. A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology*. 2006;49:8-14.
7. Lauder, GR & White, MC. Neuropathic pain following multilevel surgery in children with cerebral palsy: A case series and review. *Pediatric Anesthesia*. 2005;15:412-420.
8. Hadden, KL & von Baeyer, CL. Pain in children with cerebral palsy: Common triggers and expressive behaviors. *Pain*. 2002;99:281-288.
9. Kennes, J, Rosenbaum, P, Hanna, SE et al. Health status of school-aged children with cerebral palsy: Information from a population-based sample. *Dev Med Child Neurol*. 2002;44:240-247.
10. Breau, LM, Camfield, CS, McGrath, PJ et al. The incidence of pain in children with severe cognitive impairments. *Arch Pediatr Adolesc Med*. 2003;157:1219-1226.
11. Dorralp, S & Bartlett, DJ. The prevalence, distribution, and effect of pain among adolescents with cerebral palsy. *Pediatric Physical Therapy*. 2010;22:26-33.
12. Palisano, RJ, Rosenbaum, PL, Walter, SD et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology*. 1997;39:214-223.
13. Tervo, RC, Symons, F, Stout, J et al. Parental report of pain and associated limitations in ambulatory children with cerebral palsy. *Arch Phys Med Rehabil*. 2007;87:928-934.
14. World Health Organization (WHO). *International Classification of Functioning, Disability, and Health: Children & Youth Version*. 2007. Geneva: author.
15. Wright, VF, Rosenbaum, PL, Goldsmith, CH et al. How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? *Developmental Medicine & Child Neurology*. 2008;50:283-289.
16. Breau, LM, Camfield, CS, McGrath, PJ et al. Risk factors for pain in children with severe cognitive impairments. *Dev Med Child Neurol*. 2004;46:364-371.

17. Craig, K, Lilley, C, Gilbert, C. Barriers to optimal pain management in infants, children and adolescents: Social barriers to optimal pain management in infants and children. *The Clinical Journal of Pain*. 1996;12:232-242.
18. Roscigno, CI. Addressing spasticity-related pain in children with spastic cerebral palsy. *Journal for Neuroscience Nurses*. 2002;123-133.
19. Berrin, SJ, Malcarne, VL, Varni, JW et al. Pain, fatigue, and school functioning in children with cerebral palsy: A path-analytic model. *Journal of Pediatric Psychology*. 2007;32:330-337.
20. Dickinson, HO, Parkinson, KN, Ravens-Sieberer, U et al. Self-reported quality of life of 8-12-year-old children with cerebral palsy: A cross-sectional European study. *Lancet*. 2007;369:2171-2178.
21. Carter, B, McArthur, E, Cunliffe, M. Dealing with uncertainty: Parental assessment of pain in their children with profound special needs. *Journal of Advanced Nursing*. 2002;38:449-457.
22. Rosenbaum, PL, Russell, DJ, Cadman, DT et al. Issues in measuring change in motor function in children with cerebral palsy: A special communication. *Phys Ther*. 1990;70:125-131.
23. Portney, LG & Watkins, MP. *Foundations of clinical research: Applications to practice (2<sup>nd</sup> Ed)*. Upper Saddle River, NJ: Prentice-Hall, Inc; 2000.
24. Bjornson, KF & McLaughlin, JF. The measurement of health-related quality of life (HRQL) in children with cerebral palsy. *European Journal of Neurology*. 2001;8:183-193.
25. Varni, JW, Burwinkle, TM, Sherman, SA, et al. Health-related quality of life of children and adolescents with cerebral palsy: Hearing the voices of children. *Dev Med Child Neurol*. 2005;47:592-597.
26. Collignon, P & Giuisiano, B. Validation of a pain evaluation scale for patients with severe cerebral palsy. *European Journal of Pain*. 2005;5:433-442.
27. McGrath, PJ, Rosmus, C, Camfield, C, et al. Behaviors caregivers use to determine pain in non-verbal, cognitively impaired children. *Dev Med Child Neurol*. 1998;40:340-343.
28. Breau, LM, McGrath, PJ, Camfield, C, et al. Psychometric properties of the Non-Communicating Children's Pain Checklist-Revised. *Pain*. 2002;99:349-357.
29. Landgraf, J, Abetz, L, Ware, JE. *The CHQ User's Manual*, 1<sup>st</sup> edn. The Health Institute, New England Medical Center, Boston; 1996.
30. McCarthy, ML, Silberstein, CE, Atkins, EA, et al. Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Dev Med Child Neurol*. 2002;44:468-476.
31. Daltroy, LH, Liang, MH, Fossel, AH, et al. The POSNA pediatric musculoskeletal functional health questionnaire: Report on reliability, validity, and sensitivity to change. Pediatric outcomes instrument development group. Pediatric orthopaedic society of north america. *J Pediatr Orthoped*. 1998;18:561-571.
32. Hester, NO, Miller, KL, Foster, RL, et al. Symptom management outcomes: Do they reflect variations in care delivery systems? *Medical Care*. 1997;35:NS69-NS83.
33. Abbott, R. Sensory rhizotomy for the treatment of childhood spasticity. *Journal of Child Neurology*. 1996;11:36-42.
34. Mooney, JF & Millis, MB. Spinal deformity after selective dorsal rhizotomy in patients with cerebral palsy. *Clinical Orthopedics*. 1999;364:48-52.
35. Chalkiadis, GA. Management of chronic pain in children. *MJA*. 2001;175:476-479.
36. Ehde, DM, Jensen, MP, Engel, JM, et al. Chronic pain secondary to disability: A review. *The Clinical Journal of Pain*. 2002;19:3-17.