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#### Research Paper

### Are physiotherapists reliable proxies for the recognition of pain in individuals with cerebral palsy? A cross sectional study

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#### Abstract

**Background:** Pain is an important problem for individuals with cerebral palsy (CP). In addition to pain associated to the pathology, individuals with CP are often exposed to physiotherapy procedures which may cause or relieve pain.

**Objective:** The major aim of this study was to compare pain ratings self-reported by individuals with cerebral palsy and ratings about pain in others provided by their physiotherapists.

**Method:** Cross-sectional study. Children and young adults with cerebral palsy (n = 50) and their physiotherapists (n = 18) completed semi-structured interviews about clinical pain, as well as about procedural pain and pain relief elicited by standardized health procedures. Moreover, pain ratings were obtained during the application of hamstring stretching and passive joint mobilization.

**Results:** Moderate-to-high agreement was observed between individuals with cerebral palsy and their physiotherapists on presence and intensity of pain, pain interference with physical activities and current and retrospective pain ratings elicited by physiotherapy procedures. By contrast, agreement regarding pain relief elicited by physiotherapy techniques was low.

Conclusions: Our data suggest that although physiotherapists may be reliable proxies for the recognition of pain in individuals with cerebral palsy, further research should be done to improve the communication between health professionals and individuals with cerebral palsy around pain. © 2015 Elsevier Inc. All rights reserved.

Keywords: Pain; Cerebral palsy; Physical therapy; Agreement

Pain is frequently underestimated and, therefore, poorly treated in most neurological patients.<sup>1</sup> In the case of individuals with cerebral palsy (CP), they often experience ongoing pain from a variety of disabilities such as dislocated hips, muscle spam, gastro-oesophageal reflux or musculoskeletal pain.<sup>2–5</sup> It is also known that these individuals may require surgical interventions from early childhood, and that they have to cope with pain caused by handling, immobility and poorly fitting aids and equipment.<sup>6,7</sup> Finally, it has been observed that some physiotherapy procedures performed to increase range of movement almost on a daily basis, such as stretching or manipulation, are often considered as very painful by individuals with CP.<sup>8,9</sup>

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Optimal pain management depends on accurate behavioral assessment. In the case of individuals with CP, it has been observed that they can express discernible pain behaviors regardless of cognitive or language ability, 10 and that attention to these behavioral responses could optimize pain management. 11 Nevertheless, there are some idiosyncratic pain behaviors in CP, such as laughing or grinding teeth, which would not be adequately recognized by health professionals. The correct understanding of pain expressions by physiotherapists is relevant in CP, since physiotherapeutic interventions may have an important impact on pain in this population,<sup>8,9</sup> and pain management during physiotherapy procedures depends on the accurate recognition of these pain behaviors. 11 Although several studies have already examined the agreement between patients' and health professionals' pain reports in general health settings or during hospitalization stays, 12,13 there is no information about the agreement in the case of individuals with CP. The present study was guided by the following research questions:

1. Is there any agreement between self-reports of pain provided by individuals with CP and their physiotherapists?

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2. How accurate are ratings of pain intensity and pain relief elicited by physiotherapist procedures in these individuals?

#### Methods

#### **Participants**

Fifty individuals with CP (21 females) (age range: 6-30 yrs, mean = 16.9 yrs, SD = 13.9), and their 18 attending physiotherapists (PT) were recruited from several educational and occupational centers in Majorca (Spain). Physiotherapists were attending individuals with CP on a regular basis for at least the previous 6 months. Inclusion criteria for individuals with CP were: (1) aged from 4 to 30 years and (2) basic cognitive level for understanding questions about medical and psychological health status. Minimum age for participating in the study was set to 4 years according to previous findings showing that these children can accurately provide pain self-reports. 12 Individuals with CP were not excluded based on specific communication difficulties. Augmentative communication devices were used if needed to facilitate data collection. Type of cerebral palsy and cognitive level was obtained from medical reports. An experienced physiotherapist (IR) assessed the level of motor impairment by using the Gross Motor Function Classification Scale (GMFCS). 14 Table 1 displays clinical characteristics of individuals with CP.

Physiotherapists and legal guardians of individuals with CP gave written informed consent according with the Declaration of Helsinki. In addition, individuals with CP corroborated verbally the decision to participate in the study. The study was approved by the Ethics Committee of the Regional Government of the Balearic Islands (reference number IB 768/07).

#### Outcome measures

All participants completed a protocol-based interview consisting of questions about demographic data and clinical characteristics of pain experienced in the past and current pain. The interview was specifically designed for this study taking into account previous findings about pain expression<sup>8,10</sup> and pain treatment<sup>15</sup> in individuals with CP. Questions about pain were grouped into following main categories:

- Clinical pain. This category was included to measure general aspects of pain experience, such as the presence of chronic pain (pain with more than 3 months of duration; yes/no answer), pain intensity experienced in the previous week, and how much did pain interfere with daily physical activities (walking, running, climbing stairs, doing physical exercise or sport).
- Retrospective procedural pain. Participants were asked to rate how much pain did they feel when several physiotherapy techniques (surgery, stretching, botulinum

Table 1 Clinical characteristics of individuals with cerebral palsy

Variable	Individuals with cerebral palsy $(n = 50)$
Sex (n)	21 females
Age (mean, SD)	16.9 (13.9)
Type of cerebral palsy (n)	
Bilateral spastic	35
Unilateral spastic	7
Diskinetic	4
Ataxic	4
Mixed	0
Motor impairment (GMFCS) (n)	
Level 1	13
Level 2	17
Level 3	7
Level 4	10
Level 5	3
Cognitive impairment (n)	
None	35
Mild	7
Moderate	8
Severe	0

toxin A injections, assistive standing, assistive walking, use of splints, passive joint mobilization, clinical assessment, assistive sitting, and massage) were applied in the recent past.

- Retrospective pain relief. Participants were asked to rate how much and for how long did they experience pain relief when specific (heat, stretching, massage, ice, ultrasounds, passive mobilization, hydrotherapy, transcutaneous electrical nerve stimulation) and nonspecific physiotherapy treatments (medication, splints, active exercise, exercise in the swimming-pool, biofeedback, relaxation techniques, psychological treatment) were applied in the recent past.
- Current procedural pain. Subjective pain ratings were obtained immediately after the application of two standardized physiotherapy techniques in individuals with CP: hamstring stretching and passive joint mobilization of lower extremities.

For all categories, individuals with CP were asked to rate their own pain, whereas physiotherapists were asked to rate pain felt by individuals with CP. Subjective ratings were obtained from individuals with CP by using the Wong-Baker FACES pain scale, <sup>16</sup> and from PTs by using a 11-point numerical scale (0 = no pain; 10 = unbearable pain). The Wong-Baker pain scale consists of six faces ranging from a very smiling face (no hurt) to a crying face (hurts worst). An even number from 0 to 10 was assigned to each face for allowing comparison between pain intensity rated by individuals with CP and pain estimations obtained from PTs.

Data from individuals with CP were collected in face-toface interviews at educational centers. In addition, PTs completed the same questionnaires at home in a written way. PTs completed one questionnaire for each CP patient

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