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Laetitia Houx, Christelle Pons, Helene Saudreau, Amandine Dubois, Mathilde Creusat, Philippe Le Moine, Olivier Rémy-Néris, Juliette Ropars, Jean-Yves Lereste, Sylvain Brochard

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## **No pain, no gain? Children with cerebral palsy and their experience with physiotherapy**

L. Houx, MD<sup>1,2,3</sup>; C. Pons, MD, PhD<sup>2,3</sup>; H. Saudreau, MD<sup>4</sup>; A. Dubois, PhD<sup>5,6</sup>; M. Creusat, MD<sup>4</sup>; P. Le Moine, MD<sup>7</sup>; O. Rémy-Néris, MD, PhD<sup>1,3</sup>; J. Ropars, MD<sup>3,8,9</sup>; J.Y. LeReste, MD, PhD<sup>10</sup>; S. Brochard, MD, PhD<sup>1,2,3</sup>

1. Physical and Medical Rehabilitation Department, CHRU de Brest, Brest, Bretagne, France
2. Paediatric Physical and Medical Rehabilitation Department, FONDATION ILDYS, Brest, France
3. Laboratory of Medical Information Processing, INSERM U1101, Brest, France
4. Paediatric Physical and Medical Rehabilitation Department, Centre de Kerpape, Ploemeur, France
5. Department of Psychology, University of Western Brittany Brest, Brest, Bretagne, France
6. CRPCC, EA 1285, Rennes 2, France
7. Centre for the Evaluation and Treatment of Pain, CHRU Brest, Brest, France
8. Department of pediatry, CHRU de Brest, Brest, France
9. University of Western Brittany, Brest, France
10. University of Western Brittany ERCR SPURBO and Department de Generale Médecine, Brest, France

**Corresponding author:** Laetitia Houx, MD

Service de Médecine Physique et Réadaptation

CHRU de Brest - Hôpital MORVAN

2 avenue Foch 29609 Brest Cedex 2, France

Sec: +33 (0)2 98 22 31 52

Fax: +33 (0)298 22 39 33

email: [laetitia.houx@chu-brest.fr](mailto:laetitia.houx@chu-brest.fr)

# 1 **No pain, no gain? Children with cerebral palsy and their experience with physiotherapy**

2

## 3 **Abstract**

4 **Objectives.** Recent studies have shown that physiotherapy can induce pain in children and  
5 young adults with cerebral palsy (CP). There is a lack of knowledge of children's pain  
6 experiences during therapy sessions and the specific causes of pain. The main objective of this  
7 study was to better understand the experience of children and young adults with CP during  
8 physiotherapy sessions and to analyse the coping strategies used by children and therapists.

9 **Methods.** Qualitative study with focus groups. Eighteen children/young adults with CP who  
10 experienced pain during physiotherapy were interviewed, using focus groups as a source of  
11 data collection in a phenomenological perspective. Data collection and analysis were  
12 consecutive to ensure that the data saturation point was reached. The transcripts were coded  
13 manually using thematic analysis. First, interesting features of the verbatim were coded, then  
14 codes were collated into potential themes and then the themes were checked to ensure they  
15 worked in relation to the coded extracts. Multiple coding was performed by 3 different  
16 researchers, and results were merged at each step.

17 **Results.** This study confirmed that among the 18 children interviewed (mean [SD] age 13.17  
18 [4.02] years, 10 girls), physiotherapy, particularly stretching, induced pain. Participants  
19 reported that the experience of pain led to a dislike of physiotherapy, although some believed  
20 that the pain was necessary to show that the treatment was effective. The use of distraction  
21 techniques and the relationship with the physiotherapist were key elements associated with  
22 the perception and experience of pain.

1 **Conclusions.** This study confirmed that patients with CP experience pain during  
2 physiotherapy. Stretching seems to be the main source of pain. Beliefs and practices regarding  
3 the concept of pain show that physiotherapists need training in this field.

4  
5 **Keywords.** cerebral palsy, physiotherapy, therapy-induced pain, coping, qualitative research,  
6 focus groups

## 7 8 9 **Introduction**

10 Physiotherapy plays an important role in the lives of children with cerebral palsy (CP)  
11 because of the motor impairments associated with the condition. Routine physiotherapy may  
12 cause pain in these children [1–3]. The current definition of pain by the International  
13 Association for the Study of Pain is “an unpleasant sensory and emotional experience  
14 associated with actual or potential tissue damage, or described in terms of such damage” [4].  
15 The European Sparcle 2 study reported that almost half of children with CP experienced pain  
16 during physiotherapy sessions [5]. Another study of pain during hamstring stretching in 50  
17 individuals with CP 6 to 30 years old, found that on a numerical scale, the mean (SD) reported  
18 level of pain was 3.5 (3.2)/10 [2]. Furthermore, a survey of 43 parents whose children had CP  
19 revealed that 93% of those who reported pain said that the most painful activity of daily living  
20 was assisted stretching [3]. In France, children with CP undergo physiotherapy twice a week  
21 on average[6], and sessions can continue throughout the patient’s lifetime. Therefore, the fact  
22 that physiotherapy can cause pain is an extremely important issue.  
23 Despite these findings, pain induced by exercise and mobilization has received little attention  
24 in the literature, especially in children. A previous study of adults with various conditions  
25 suggest that pain worsens clinical conditions and may cause a refusal to undergo

1 physiotherapy [7]. Moreover, repeated procedural pain may have long-term negative effects  
2 on behavioural responses to pain and reduce the willingness to accept and participate in future  
3 treatment [8].

4 The main objective of this study was to improve our understanding of the experience of  
5 children and young adults with CP during physiotherapy sessions by identifying 1)  
6 physiotherapy procedures that induced pain; 2) where pain occurred; 3) strategies used by  
7 both physiotherapists and participants to cope with pain and 4) solutions suggested by the  
8 children and young adults to alleviate or relieve pain.

9

## 10 **Method**

### 11 Design

12 This was a qualitative study with focus groups used as the data collection method [9] and  
13 thematic analysis [10].

14

### 15 Participants

16 Criterion sampling [11,12] was used to ensure different ages, sexes, type of CP, level of Gross  
17 Motor Function Classification System (GMFCS), number of physiotherapy sessions, use of  
18 analgesics, and numerical rating scale (NRS, 0-10) score. In- or outpatients of the Brest and  
19 Lorient paediatric physical, medical and rehabilitation centres (Brittany, France) were asked  
20 to participate during routine medical consultations if they fulfilled the eligibility criteria.

21 We included participants if they were 1) between 8 and 20 years old (to ensure that they were  
22 able to participate in a group discussion and to correspond with the ages of the children and  
23 young people followed in participating centres), 2) had a diagnosis of CP (GMFCS levels I to  
24 IV) and 3) underwent regular physiotherapy and experienced pain during physiotherapy  
25 sessions. During routine consultations, physicians asked all potentially eligible children if

1 they sometimes experienced pain during physiotherapy and could they rate the pain on the  
2 NRS [13]; those with an NRS score >1 were invited to participate in a focus group. Exclusion  
3 criteria were 1) an inability to communicate and actively participate in a group conversation  
4 lasting at least 20 min and 2) having undergone musculoskeletal surgery in the previous 6  
5 months (to avoid including children with residual pain induced by the surgery).

6

### 7 Focus groups

8 Each focus group was conducted by the same facilitator (HS), a 27-year-old female medical  
9 resident, who was not directly involved in any of the participants' care. The facilitator was  
10 alone with the focus group during the session and interviews were recorded by 2 audio-  
11 recording devices. The sessions were carried out in a quiet, comfortable room that was not  
12 used for medical or rehabilitation purposes. The session with each group lasted 30 to 45 min.

13 A guide, developed for the study by an expert in qualitative research (JYLR) and 2 content  
14 experts (SB and LH) [14,15] was used to focus the discussion around predefined themes.

15 Each session began with a snack, then everybody introduced themselves to the group,  
16 including the facilitator who also presented the reason for the study and the information hoped  
17 to be gained. Once the facilitator felt that the children were at ease, she began the questioning.

18 The questions were semi-structured and open-ended to allow participants to express their  
19 feelings. The discussion opened with a general question regarding physiotherapy sessions and  
20 continued with more specific questions about the children's own experiences of pain during  
21 physiotherapy, how they managed the pain and what their physiotherapists did to help.  
22 Finally, the children were asked if they had any ideas about how their pain could be reduced  
23 during the sessions.

24

### 25 Determination of sample size

1 The sample size was determined according to the principle of saturation [12]. On the basis of  
2 this principle, we estimated that at least 3 groups of 3 to 5 children were needed to saturate the  
3 emergent data categories; therefore, we planned to include 15 to 20 children. The groups were  
4 formed with children of similar ages to facilitate cohesion and discussion. As each focus  
5 group transcript was analysed, key ideas and comments emerged from the participants'  
6 comments and responses and were organised into themes and subthemes. The focus groups  
7 were stopped when analysis of new transcripts no longer yielded additional themes or ideas  
8 and instead the extracted comments only served to further support the already-existing  
9 themes[12].

10

#### 11 Data analysis

12 Recorded conversations were transcribed by HS and verified by LH. The verbatim was  
13 anonymised by using focus group and participant codes before being analysed. Data analysis  
14 was undertaken during the data collection process, to determine when saturation was reached.  
15 The transcripts were coded manually by using thematic analysis [10] and an inductive  
16 analysis was performed [16]. First, interesting features of the verbatim transcript were coded  
17 by using a spreadsheet (Microsoft Excel). The codes were then collated into potential themes  
18 that were checked to ensure they worked in relation to the coded extracts. Multiple coding  
19 was performed; all data were independently analysed by 3 different researchers (HS: medical  
20 resident, SB: MD, PhD, LH: MD) and the results were merged at each step to ensure that data  
21 extraction was a consensus decision and thus as credible as possible [9].

22

#### 23 **Results**

1 The sample characteristics are presented in the Table. Eighteen individuals with CP (mean  
2 [SD] age 13.17 [4.02] years) consented to participate in the focus groups. Mean NRS score  
3 was 4.56 (2.33). The median number of physiotherapy sessions per week was 3 (0.79).  
4 Four focus groups were developed, with 3 to 5 children of similar ages in each group. Each  
5 lasted between 30 and 45 min.  
6 Four main themes, each with subthemes, emerged from the focus groups: perception of  
7 physiotherapy, pain associated with physiotherapy, pain management, and suggestions for  
8 improvement. The sub-themes are presented as a conceptual map in the Figure. Verbatim  
9 quotations are presented in the text in italics with a reference that indicates the participant's  
10 number. The interviews were conducted in French and the verbatim was translated for this  
11 article by a native English translator, bilingual in French, who is also a physiotherapist.

12

### 13 **Theme 1: Perception of physiotherapy**

14 A few participants were positive about attending physiotherapy but most did not enjoy their  
15 sessions. Despite this, most participants believed that physiotherapy was important, as it  
16 provided clinical benefits in terms of range of motion and functional ability, and therefore  
17 they felt had no choice but to attend. However, a few participants expressed doubts regarding  
18 the effectiveness and necessity of physiotherapy sessions. Physiotherapy sessions were  
19 described as boring as well as tiring.

20 *"[Physio is important] to keep up my transfers because I do them on my own. If I wasn't*  
21 *forced to, or if I didn't need to, I wouldn't make myself go" (p2).*

22 *"It's not nice to feel pain.... but without physio we wouldn't do anything.... if you stay like that*  
23 *you will just get worse" (p16).*

24

### 25 **Theme 2: Pain associated with physiotherapy**

1           Sub-theme 2.1: Description of pain

2   By far the commonest cause of reported pain was from stretches, which seemed to make up a  
3   large proportion of the sessions according to the participants. Some complained that they felt  
4   pain during the sessions, which persisted after the session for some, and others experienced  
5   pain the following day. The most reported locations of pain were in the lower limbs,  
6   specifically the calves and adductors, although pain could be experienced in the arms and  
7   back as well.

8   *“Sometimes the pain stays after the sessions, I know that at the moment, my leg hurts because*  
9   *[the physio] must have pulled too much and so I have pain after the session” (p17).*

10

11           Sub-theme 2.2: Significance of pain

12   The participants agreed that the pain was due to the therapist trying to lengthen their  
13   shortened tendons. Therefore, most perceived that stretching was something to be endured for  
14   their own good. Many participants equated pain with efficacy, and some suggested that pain  
15   was used by therapists to know they were being effective. One participant thought that pain  
16   informed of the limits (i.e., when to stop). Many also believed that without stretching they  
17   would regress, although a few found that despite painful stretches, their range of motion did  
18   not improve. Several children acknowledged that pain could be different for each individual  
19   and could also depend on their disability.

20   *“If it hurts it is because it is doing something, so it’s normal.... in my opinion [if it isn’t*  
21   *painful] it’s not as effective because we are not going far enough into the ranges that we*  
22   *need” (p15).*

23   *“It’s because we are going against the laws of nature....my tendons are too short...so they*  
24   *want to lengthen them.... It’s normal that it’s painful” (p9).*

1 *“Sometimes it pulls and it hurts but when you are assessed... you see that nothing has*  
2 *changed” (p17).*

3

#### 4 **Theme 3: Pain management**

##### 5 Subtheme 3.1: Impact of therapeutic relationship on pain

6 Some participants discussed the impact of their relationship with their therapist on pain during  
7 sessions. Most agreed that it was important to have a good relationship with the therapist. A  
8 good relationship meant easy discussions which distracted from pain; however, 2 participants  
9 felt that having a good relationship did not affect the pain. Conversely, one participant also  
10 stated that the pain affected their relationship with their therapist. A sense of betrayal was  
11 sometimes apparent: a few children felt that their therapist took advantage when they relaxed  
12 to “pull harder” and a few felt that if they complained, their therapist made them work even  
13 harder.

14 *“The therapist was not great so I didn’t talk much and it was harder” (p9).*

15 *“Sometimes you are talking and you get the impression that she pulls even more when she’s*  
16 *talking because you’re relaxed” (p5).*

17

##### 18 Subtheme 3.2 Physiotherapist-led strategies (as perceived by the children)

19 It was clear from the interviews that the participants perceived that physiotherapy practices  
20 were not universal and that therapists did not all have the same understanding of pain. About  
21 one-third of the participants felt their therapists continued the exercise regardless of the pain  
22 and did not listen to them. Some understood that the therapists had to continue stretching,  
23 despite the pain, for their own good. Others said their therapist pulled less strongly if they said  
24 it hurt.

1 *“...I say [that it hurt] but it doesn’t change anything.... Anyway the more you complain, the*  
2 *more you will get exercises [to do]” (p1).*

3 *“I have asked several times [to stop] during the stretching, but, as she has to do it, she just*  
4 *carries on” (p15).*

5 *“Sometimes you get the impression they [therapists] are sadistic” (p2).*

6

7 **According to the children,** their physiotherapists most frequently used distraction through  
8 chatting or telling jokes to help them endure the pain. Other forms of distraction, such as  
9 music, were not used. Less frequently used techniques included non-prescription medication  
10 and massage, and some therapists pulled more gently or changed the exercise if the child said  
11 it was too painful. The children were split as to the effectiveness of these techniques: some  
12 found they helped and others felt they made no difference.

13

#### 14 Subtheme 3.3 Child-led coping strategies

15 The participants described using various strategies to help them to cope with the pain. Some  
16 used internal methods such as focusing on their breathing or thinking about other things, and  
17 others conversed with the therapist to try to distract themselves. Some participants would ask  
18 the therapist to stop if the stretching was too painful. A few participants did not seem to try to  
19 use coping strategies; instead they simply endured the pain and waited until it was over, and  
20 some actually tried to hide from their therapist. Unfortunately, sometimes coping strategies  
21 failed and a few participants reported having cried.

22 *“She [the therapist] does her job, you talk at the same time and it feels a bit better after that”*  
23 *(p9).*

24 *“You have to grit your teeth” (p3)*

25 *“I’ve already cried because it was painful” (p15).*

1

## 2 **Theme 4: Suggestions for improvement**

3 The participants suggested numerous ways to improve the physiotherapy sessions, including  
4 antalgic techniques such as massage or hypnosis. Several participants suggested that  
5 therapists should give paracetamol or nitrous oxide during the session; however, not everyone  
6 agreed with the regular use of medication in this way. Three participants felt there was no  
7 solution. A few participants were keen on pain-free treatment, but most did not necessarily  
8 want a solution to remove the pain: they expressed concern that it would be less effective.  
9 However, 2 participants felt that milder stretches, that were less painful, could still be  
10 effective even if it took longer.

11 *“If one day I’m offered that [stretching without pain], I would ask them to do tests first to see*  
12 *if it really pulls [lengthens] and if it’s effective. And if I see that it doesn’t pull much, I prefer*  
13 *to have the pain” (p14).*

14 A few participants suggested that session lengths should be reduced; however, the others  
15 disagreed. Despite the pain associated with treatment, they believed it was important for them.  
16 Some already felt that they rarely had full sessions due to the time taken to get in and out of  
17 their wheelchair.

18 *“[If sessions were shorter], you would spend the whole session getting in and out of the*  
19 *wheelchair; it’s pointless” (p4).*

20

## 21 **Discussion**

22 The results of this study confirmed that physiotherapy, particularly stretching, induced pain.  
23 Participants reported that the experience of pain led them to dislike physiotherapy, although  
24 some believed that the pain was necessary to show that the treatment was effective. The use of

1 distraction techniques and the relationship with the physiotherapist were reported as key  
2 elements associated with the perception and experience of pain.

3

#### 4 *Main cause of pain during physiotherapy sessions: stretching*

5 Stretching was identified as a major source of pain, in agreement with another recent study  
6 [2]. Participants predominantly expressed pain in the lower limbs; in particular the triceps  
7 surae and adductor muscles. Stretching is often performed in the belief that it will help to  
8 prevent or reduce muscle contractures and joint deformities. Although a small amount of  
9 research has suggested that daily stretching over a period of 1 year may alter muscle structure  
10 [17], most published meta-analyses and systematic reviews have shown that regular stretching  
11 has no clinically significant long-term effect on joint range of motion [18–22].

12 These results question whether stretching, as it is currently carried out, actually fulfills its  
13 intended purpose of improving or maintaining muscle length. We propose considering  
14 alternative methods that integrate flexibility and fitness. They may be more effective and may  
15 also facilitate participation [18,23,24]. Research is needed to evaluate different groups of  
16 patients with CP to determine which, if any, would benefit from stretching to maintain or  
17 improve their range of motion or to improve activity and participation according to the  
18 International Classification of Functioning model. Further studies that more deeply probe  
19 children’s perceptions of the causes and locations of pain during physiotherapy would be of  
20 interest; such data would help in developing more appropriate methods for managing therapy-  
21 induced pain.

22

#### 23 *Children- and physiotherapist-led coping strategies*

24 To our knowledge, no study has investigated the coping strategies used by children  
25 experiencing physiotherapy-induced pain. Many children in this study used cognitive self-

1 instruction (i.e., “be brave, it’s OK”), which is considered a maladaptive strategy in terms of  
2 emotional adjustment outcomes [25], although some used more effective, active strategies  
3 such as talking. Likely, a considerable proportion of the children also had chronic pain [26],  
4 for which they had probably also developed coping strategies, although children with CP have  
5 been shown to use fewer pain-coping strategies than typically developing children,  
6 particularly those with high GMFCS level [27]. Two-thirds of the sample in the present study  
7 had high GMFCS level (i.e., more severe CP).

8 The children’s pain experience and their coping strategies were also likely affected by their  
9 perception of the significance of physiotherapy-induced pain: some considered the pain as a  
10 marker of effectiveness and others remained sceptical about its benefits. These beliefs were  
11 themselves likely influenced by the therapist’s own beliefs and attitudes [28]. Previous studies  
12 of children and adults with chronic pain have shown an interrelationship between types of  
13 coping strategies used, beliefs regarding pain and pain perception [29,30].

14 With regard to therapist-led strategies, some participants reported that they felt their  
15 physiotherapist did not understand their pain sufficiently. Previous work has also shown that  
16 patients feel that procedural pain is generally insufficiently considered by therapists [7,31].  
17 This finding is particularly important given that painful treatment, which is long lasting and/or  
18 repetitive, can create a vicious circle of pain, anticipatory anxiety and emotional distress  
19 [32,33]. Other participants indicated that their therapist was aware of pain caused by  
20 treatments and that the most frequently used technique by the physiotherapists was  
21 distraction, mostly conversation. These techniques are known to reduce the stress response  
22 and so help the child to deal with a painful intervention [34]. A good relationship with the  
23 therapist was found a key component of the child’s perception of pain in this study. Previous  
24 study showed that even the simple act of acknowledging the pain of a treatment by the  
25 therapist can increase the child’s resilience to pain [35]. The vocabulary used by the children

1 suggested that they submitted to their therapists, but the concept of collaboration was never  
2 mentioned. Further research into therapist attitudes and beliefs towards pain would be useful  
3 to guide information and training programs for therapists on such issues.

4

#### 5 *Suggestions for improvement by children*

6 The responses to the question of how sessions could be improved highlighted the dependency  
7 on physiotherapy and the importance given to physiotherapy sessions by a proportion of the  
8 children. Some wanted proof that non-painful techniques were effective, and if not, they  
9 preferred to continue to experience pain. This was also the reason some felt there was no  
10 solution regarding pain, since they believed that pain was a marker of effectiveness. Other  
11 children suggested that analgesia would help them tolerate the painful exercises or that that  
12 the techniques could be adapted so that they caused less pain.

#### 13 *Clinical implications*

14 Because stretching is considered an important component of physiotherapy for preventing  
15 contractures and deformities in children with CP, therapists may have to choose between  
16 providing effective therapy and beneficial care. There is a need for specific training programs  
17 to teach therapists to recognise and measure therapy-induced pain [36] as well as appropriate  
18 methods to use with children to alleviate it [37]. Therapists must also be able to adapt these  
19 methods to the individual child and his/her changing circumstances. Family- and patient-  
20 centred care has been discussed in terms of optimising outcomes in CP [38] but not  
21 specifically in terms of pain management. However, it seems intuitive that integrating  
22 children and their families in the therapy program and collaborating with them in its goals and  
23 design could help children feel in control of the situation, which could reduce their perception  
24 of pain [39].

1 *Limitations*

2 The study has several limitations. All participants had a high level of disability (67% GMFCS  
3 levels III-IV), and previous studies have found that GMFCS level is a significant predictor of  
4 musculoskeletal pain [26]; thus the results may only be applicable to this population. The use  
5 of a pre-determined guide for the focus groups ensured the research questions were answered  
6 but may have prevented the emergence of other relevant issues. However, attempts were made  
7 to ensure sampling adequacy by the process of saturation and by the collection of data in 2  
8 separate centres [40]. Multiple coding was also used, and the researchers discussed their  
9 coding strategies and data interpretation to ensure credibility [41].

10 **Conclusion**

11 This qualitative study revealed that stretching, particularly of the lower limb muscles, induced  
12 the most pain in children and young adults with CP. In view of the lack of evidence  
13 supporting stretching as it is currently carried out, we suggest this practice should be  
14 reviewed. The children expressed the perception that many physiotherapists did not  
15 understand or did not fully consider their pain. Further research into physiotherapists'  
16 attitudes and beliefs regarding pain is urgently required as is the development of specific  
17 training programs for managing physiotherapy-induced pain. If pain is unavoidable,  
18 physiotherapists must be able to help children use effective coping strategies.

19

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22

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24

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**Legend**

**Figure 1.** Mind-map of themes and subthemes that emerged from focus group discussions.

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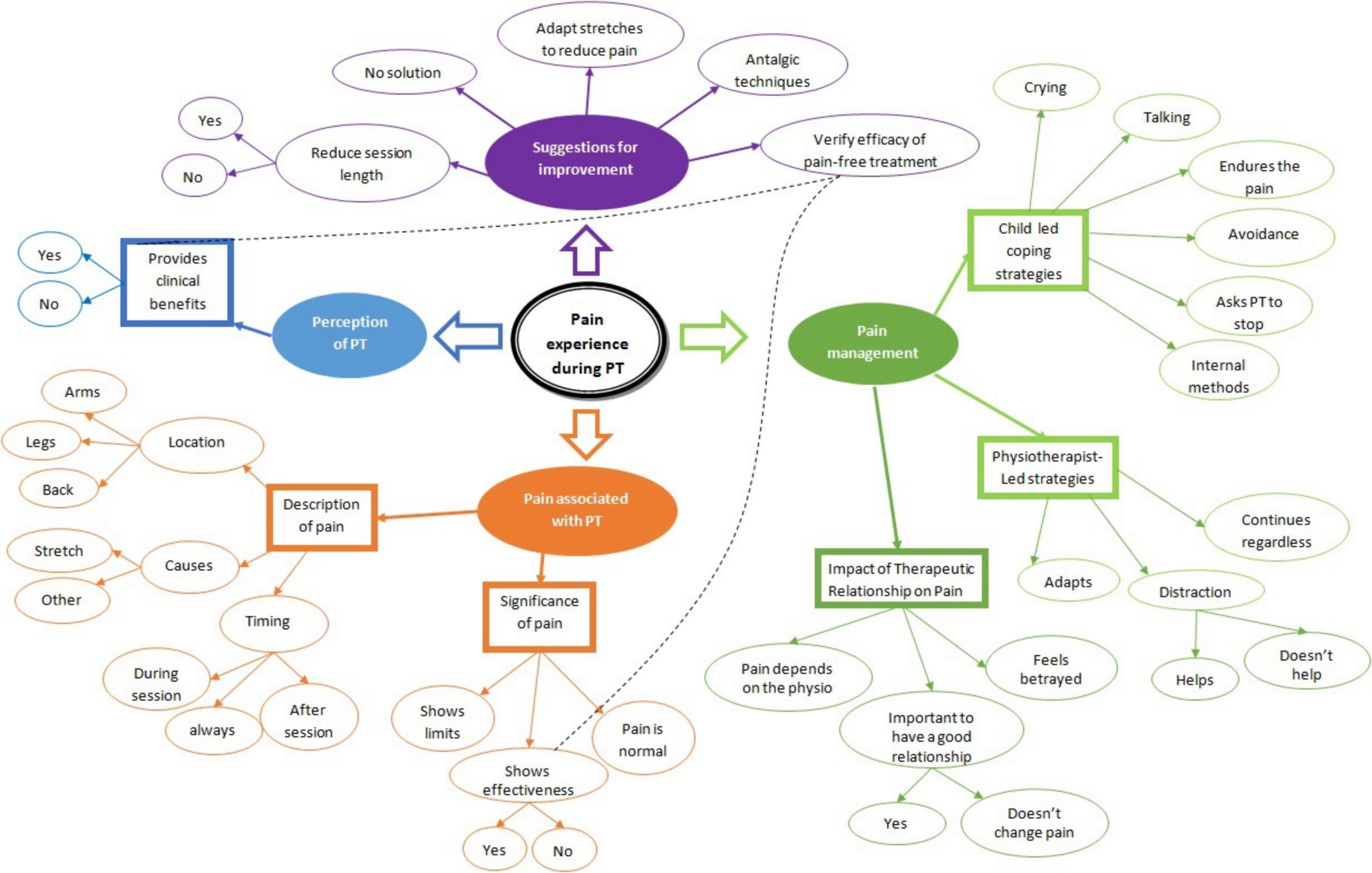
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**Table.** Description of the children and young adults with cerebral palsy (CP) undergoing physiotherapy (PT).

Focus group	Participants	Sex	Age, years	Type of CP	GMFCS level	PT sessions/ week	Analgesics	NRS pain, 0-10	Toxin (< 6 months)	Orthopaedic deformity	Orthosis (day/night)
<b>2</b>	<b>1</b>	F	19	bilateral	IV	4	Y	5	N	Y	N
	<b>2</b>	M	19	bilateral	IV	4	N	7	N	Y	N
	<b>3</b>	M	19	bilateral	III	4	N	3	N	Y	Y
	<b>4</b>	F	20	bilateral	III	3	N	7	N	Y	N
	<b>5</b>	M	15	bilateral	III	3	N	2	N	N	Y
<b>3</b>	<b>6</b>	F	10	unilateral	II	2	N	3	Y	N	Y
	<b>7</b>	M	9	unilateral	III	3	N	2	Y	Y	Y
	<b>8</b>	M	9	unilateral	I	2	N	2	N	N	Y
<b>1</b>	<b>9</b>	M	13	bilateral	IV	2	N	3	N	Y	Y
	<b>10</b>	F	8	bilateral	IV	3	Y	4	Y	N	Y
	<b>11</b>	M	8	unilateral	II	2	N	4	Y	N	Y
	<b>12</b>	F	11	unilateral	I	2	N	9	N	N	Y

	<b>13</b>	F	11	unilateral	I	2	N	9	N	N	Y
<b>4</b>	<b>14</b>	F	12	bilateral	IV	4	Y	5	N	Y	Y
	<b>15</b>	F	14	unilateral	III	3	Y	6	N	N	Y
	<b>16</b>	M	11	unilateral	III	2	N	2	N	Y	Y
	<b>17</b>	F	16	bilateral	IV	3	Y	6	N	N	Y
	<b>18</b>	F	13	unilateral	I	3	Y	3	Y	Y	N
	<b>Mean (SD)</b>	10F/8M	13.17 (4.02)	9 B/9 U	6-IV/6-III 2-II/ 4-I	2.83 (0.79)	12N/6Y	4.56 (2.33)	13N/5Y	9N/9Y	4N/14Y

GMFCS, Gross Motor Function Classification System; NRS, numerical rating scale for pain; Y, yes; N, no; U, unilateral; B, bilateral; F, female; M, male.