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ORIGINAL ARTICLE

Incidence and risk factors for care-related pain in children with physical disabilities

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ABSTRACT

BACKGROUND: The daily life of children with a physical disability is organized around interventions and care, which is coordinated by a multidisciplinary team. Little is known about the incidence of care-related pain in pediatric rehabilitation centers and health facilities for children.
AIM: To determine the incidence and intensity of care-related pain in children with physical disabilities, identify risk factors for pain and practices used to prevent care-related pain in pediatric rehabilitation centers and health facilities for children in France.
DESIGN: Non-interventional observational study.
SETTING: Sixteen pediatric rehabilitation and special education centers in 4 departments of Brittany (France).
POPULATION: A number of 280 children with physical disabilities randomly selected (mean age: 12±4 years). Predominant medical diagnosis was nervous system diseases (68%; *e.g.*, cerebral palsy 33%).
METHODS: The FLACC-r scale was used to evaluate pain during each care activity or intervention that required physical contact with the child for five consecutive days and one night.
RESULTS: The recorded interventions were 7689. Pain was induced by 6% of physical acts, and 48% of children experienced at least one painful act during the study period. Acts that were more frequently associated with pain and had the highest pain intensity were standing frame use, feeding, gentle mobilizations and bladder catheterization. Age, level of dependency and type of act were all risk factors for care-related pain ($P<0.01$). Pain prevention was used for only 26.5% of acts.
CONCLUSIONS: Care-related pain is frequent and under-recognized in pediatric rehabilitation and health facilities for children. All acts that involve direct physical contact can cause pain. Young and severely dependent children are most at risk of pain.
CLINICAL REHABILITATION IMPACT: All professionals who are involved in the care of children with a physical disability and significant limitations in activity and participation must be aware of the issue of pain and that pain can be induced by even the most routine physical act. The management of care-related pain requires a benefit-risk analysis, a prevention and pain assessment, and a family-professional partnership. A multidimensional approach is needed for more individualized pain management and to evaluate the impact of pain on children's participation.

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KEY WORDS: Disabled children; Pain, procedural; Rehabilitation centers; Health facilities; Pain management.

Pediatric rehabilitation centers and health care facilities care for children with a wide variety of physical disabilities. These disabilities may be permanent or transient and result from many different etiologies. One common factor among children with physical disabilities is that they have significant limitations in activities and participation and have

greater care and rehabilitation needs than children who could receive home rehabilitation. Their daily life is therefore organized around medical and paramedical interventions that are coordinated by a multidisciplinary team (doctors, nurses, physiotherapists, occupational therapists, care assistants, etc.). Despite the professional and caring attitude of these professionals, some procedures have been reported as painful in children with cerebral palsy (CP), such as personal care (washing, dressing, toileting),[1] physiotherapy (stretching and mobilization),[1-4] and botulinum toxin injections.[4, 5]

Research on pain in children with physical disabilities has increased in recent years, but most studies have investigated chronic or physical therapy-induced pain, and other types of pain have been little considered.[6] For instance, little is known about acute pain induced by therapies and care interventions, including routine personal care performed in pediatric centers. Furthermore, most studies have been specifically conducted in children with cerebral palsy, which is the most frequent cause of physical disability.[7] In this population, pain is reported to be the most frequent comorbidity;[4, 8] reports describe both chronic (musculoskeletal and visceral) and acute pain experiences (procedural, post-surgical, rehabilitative or common types of pain such as stomach ache, headache, etc.).[6] Painful experiences reduce quality of life,[4] limit participation in social and educational activities,[9-12] are associated with behavioral problems and depression,[13] and have a negative impact on the wider family circle.[14, 15] The intensity and frequency of pain in CP vary according to the child's age (higher prevalence and intensity in adolescents than young children) and sex (higher prevalence in girls than boys), as well as the severity of the motor impairment (higher prevalence in higher than lower severities).[3, 4, 8, 9] Although pain is now well described in CP, studies are lacking on the acute pain experiences of children with other types of physical disability who require care and interventions in pediatric centers. These disabilities may be permanent (caused by nervous system diseases, congenital or chromosomal abnormalities, etc.) or transient (caused by fractures). The presence of motor and cognitive disabilities, limited communication skills, chronic pain, and frequent care interventions place such children at a high risk of experiencing induced pain.

An earlier pilot study[16] carried out in two pediatric rehabilitation centers on a small sample of children with physical disabilities (N.=32) determined the methodological feasibility (scale, organization, repetition of measurements, professional involvement, etc.) of assessing care-related pain in an exhaustive manner in pediatric centers. The first results showed that 3.6% of care interventions were painful and that personal care (mouth care, transfers, dressing) was the most frequently painful. They also showed that children with neurological, rather than orthopedic, disorders were the most at risk of care-induced pain. These results demonstrate the need to evaluate pain caused by all types of caring and therapeutic actions that involve direct physical contact with children with a physical disability. We will use the term 'physical act' in the present study to refer to these interventions. There is a need to evaluate pain induced by physical acts in all types of pediatric centers. This research was conducted in French pediatric rehabilitation and special education centers that provide coordinated medical and rehabilitation care for children with various physical disabilities. Few studies have investigated the management of pain in children with physical disabilities.[4, 10, 17, 18] It is also important to qualitatively and quantitatively identify the therapeutic and non-therapeutic preventative methods used by professionals in these centers.

The specific aims of the present study were: 1) to determine the incidence and intensity of care-related pain; 2) to identify risk factors for pain; and 3) to identify practices used to prevent care-related pain. Based on the pilot study[16] and previous data gathered on children with CP, we expected that: 1) any act that involved physical contact with the child with physical disabilities by a professional could induce pain, even the most routine physical act, and 2) risk factors for induced pain could include the nature of the physical act, the age, level of dependency and nature of the disability of the child, and finally the nature of the hospitalization (in-patient/day hospital care) and type of center.

Materials and methods

A non-interventional, observational, multicenter study was conducted between April 2016 and July 2017 in pediatric rehabilitation and special education centers in Brittany (France). The study was approved by a national ethics committee (reference 2015-S1; 25/01/2015). According to this reference, all children were informed of the study and all legal guardians were informed of the study and assented to their child's participation. The method and measurement scales used were based on the results of the earlier pilot study.[16]

Settings

Twenty-three rehabilitation and special education centers for children with physical disabilities were identified

in the four administrative divisions of Brittany (France). Only centers with at least 20 children with physical disabilities were considered for inclusion to ensure the methodological feasibility of the study and a diversity of physical disabilities. They were randomly drawn to avoid selection bias. Sixteen centers participated: five rehabilitation centers (Rehab-Centers), six special education centers for children with predominantly cognitive disabilities and physical disabilities (Sp-Ed-Centers), and five special education centers for children with predominantly physical disabilities (Phys-Centers) (Supplementary Digital Material 1: Supplementary Text File 1). The children in the rehabilitation centers could be in- or outpatients (day hospital), and those in the special education centers could be resident or attend daily.

Participants

Participants in the study were children aged between 0 and 18 years with a permanent or transient physical disability and present in the center for the duration of the data collection. To ensure the standardization and reliability of the data collection, children who received care at home and those who had chronic pain that was not related to physical acts were not included.

The sample size was set to ensure sufficient accuracy when estimating the mean FLACC-r score for painful acts in each of the three centers. Using data from our pilot study,[16] with an expected standard deviation that did not exceed 5 points, we calculated that 100 children would be sufficient to guarantee a margin of error below 1-point (95% confidence interval half-width) for the estimation of the mean pain intensity for each type center. Therefore a total of 300 participants was required. To account for the four administrative divisions and the three types of centers, we needed to recruit on average 25 participants from each type of center in each division. Sampling within each facility was proportional to the volume of activity in similar facilities. Each facility provided a computerized list of children eligible for participation. Participants were then randomly selected one by one until the expected number was reached. If a child or their legal guardian did not consent to participate, the next child on the list was asked to participate.

Data collection and measures

Staff at each participating center received training in the data collection methods and completion of the logbook. Data were collected by all professionals who performed physical acts on the child: nurses, physiotherapists, care assistants, etc. A logbook that always stayed with the child was used to record all physical acts performed with the child. Data collection was performed over five consecutive days and one night to obtain a list of the different physical acts that was as exhaustive as possible. For children in day hospital care, data collection began as soon as the child arrived at the center (*i.e.*, in the morning) and stopped when they left (*i.e.*, at the end of the afternoon), for each of the five days of the study. For inpatient children, data were collected by day staff for all five days and by night staff for one night during the study period. In all centers, the data collection always began on a Monday.

The primary outcome for measuring pain during physical acts was the French version of the FLACC-r (Face Legs Activity Cry and Consolability-revised) proxy-behavioral evaluation. This scale has been validated for pain rating in different pediatric populations (young children, children with and without communication disabilities, and children with CP).[19-22] It uses a three-point rating (from 0-2) in five categories: facial expression, leg movements, activities, cries and consolability. The maximum FLACC-r score is 10; a score ≥4 indicated a painful physical act. The professional performing the act rated the scale and calculated the total score. A 24h score for each physical act and each participant was obtained by calculating the mean score for the same physical act performed several times a day.

The professional also recorded the specific characteristics of each physical act, including the time (day or night), the type of physical act, its category, and pain prevention methods used from an exhaustive list of 15 methods, such as paracetamol, distraction, morphine-based medication, nitrous oxide, etc. The type of physical act was based on a list of 32 acts (subdivided into 8 categories) that were found to represent multidisciplinary care during the pilot study[16] and finalized after the data collection (Supplementary Digital Material 2: Supplementary Text File 2).

The following data were collected for each participant by the medical investigator of each center: age, sex, main medical diagnosis according to the ICD-10,[23] nature of the disability (transient or permanent), and level of dependency according to the Programme de Médicalisation des Systèmes d'Information (PMSI), which is the French national reference scale for assessing the dependency in children with physical disabilities. The scale is based on Diagnosis Related Groups[24, 25] and evaluates physical and cognitive dependency separately by rating six different activities of daily living: washing, dressing, feeding and continence compose the physical dependency domain,

and behaviour and communication compose the cognitive dependency domain. Each activity is rated from 1 to 4 (1: independent; 2: supervision; 3: needs partial assistance; and 4: needs total assistance). The final score ranges from 6 to 24 points.[26] A level of dependency (low, moderate or high) was attributed to the child according to the score for each dependency type (global, cognitive and physical) (the three levels of dependency are detailed in Supplementary Digital Material 3: Supplementary Text File 3).

The mode of hospitalization (inpatient or day hospital) and the type of center were also recorded.

Statistical analysis

Quantitative data are described by the mean, standard deviation, median and 1st and 3rd quartiles. Qualitative data are described by counts and percentages. For each physical act, the proportion (number of acts / total number of acts), the number of children who underwent each act, the pain characteristics (frequency of pain per act, mean and maximal pain intensity, and number of children who experienced pain), and any preventative measures used were analyzed.

Risk factors for care-related pain were sought using a stepwise linear regression model for repeated measures (since physical acts were performed over five days and one night) using backward elimination. The variables tested in the models were age, sex, main medical diagnosis, nature of the disability, level of dependency, physical act categories, mode of hospitalization, type of center, and time of day/night. We first tested these study variables using a univariate model and then used a stepwise multivariate model with backward elimination to determine the variables to include in the model at each step, with the threshold P value fixed at 10%. The scores for each physical act were compared with the baseline state of each child. The baseline state was obtained during a situation in which the children were relaxed and were not experiencing pain (play time, Snozelen room, etc.). This rating provided a FLACC-r score that could be different from 0 and was used as a reference to measure the change in score.

All statistical tests were performed with SAS, v.9.4® (SAS Institute, Cary, NC, USA), with a significance level of 0.05.

Data availability

The data associated with the paper are not publicly available but are available from the corresponding author on reasonable request.

Results

Participants

A total of 286 children with a physical disability were asked to participate; 6 were then excluded because their age was unknown or was >18 years (N.=3), or data were missing (N.=3) (Figure 1).

A total of 280 children (mean age: 12±4 years; 136 boys and 144 girls) were included in the final analysis. Of these, 97 were from Rehab-Centers, 82 were from Sp-Ed-Centers, and 101 were from Phys-Centers. In total, 87.9% had a permanent disability. The medical diagnoses mainly corresponded to three chapters of the ICD-10: diseases of the nervous system (67.9%; including 32.8% of cerebral palsy), congenital malformations, and deformities and chromosomal abnormalities (12.1%; *e.g.* trisomy, genetic syndromes); and diseases of the musculoskeletal system and connective tissue (14.6%; *e.g.* fracture, spinal arthrodesis surgery). A category termed 'other diseases' was created for the diseases that affected a small number of children (5.4%) (Supplementary Digital Material 4: Supplementary Text File 4). The mean level of dependency was moderate-to-severe (mean score PMSI:17/24).

During the study period, 47.5% of the children included were in-patients and 44.3% attended a day hospital (Table I).

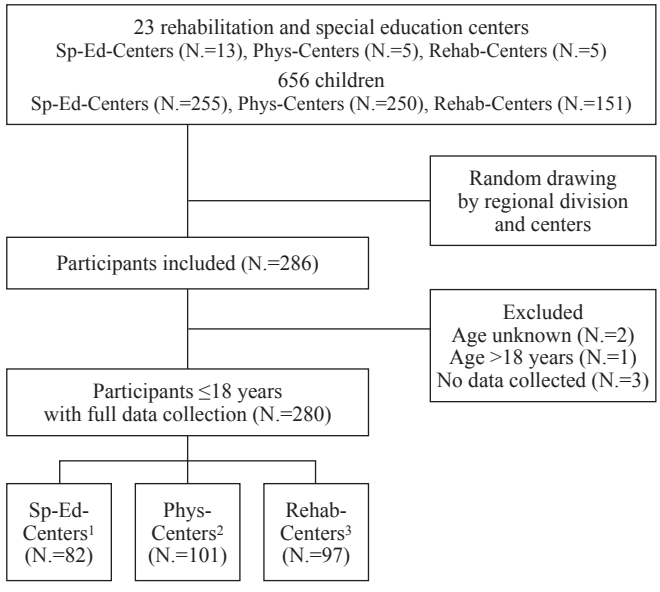

Figure 1.—Flow chart of inclusions.
[1]special education centers for children with physical and cognitive disabilities (Sp-Ed-Centers); [2]special education centers for children with physical disabilities (Phys-Centers); [3]rehabilitation centers (Rehab-Centers).

TABLE I.—*Demographic and clinical characteristics of participants.*

Age (years)	Mean age±SD	12±4
	Median age [Q1;Q3]	13 [19;15]
	Min-max	0-18
Sex	Male	136 (48.6%)
	Female	144 (51.4%)
Main medical diagnosis	Diseases of the nervous system	190 (67.9%)
	Cerebral palsy	92 (32.8%)
	Central neurological injury (*e.g.* stroke, encephalopathy, spinal cord injury)	82 (29.2%)
	Neuromuscular diseases (*e.g.* DMD, SMA, Steinert)	15 (5.4%)
	Peripheral neurological injury (*e.g.* CMT)	1 (0.4%)
	Congenital malformations, deformations and chromosomal abnormalities	41 (14.6%)
	Osteoarticular, muscle or connective tissue disorders	34 (12.1%)
	Other diseases	15 (5.4%)
Nature of the disability	Permanent	246 (87.9%)
	Transient	34 (12.1%)
Affected limb	4 limbs affected	152 (54.3%)
	2 lowers limbs affected	41 (14.6%)
	Half of the body	27 (9.6%)
	Other	60 (21.4%)
Level of dependency (PMSI)	Mean±SD	17.1±6
	Median [Q1;Q3]	18 [12-23]
	Min-max	6-24
Type of centers	Sp-Ed-centers	82 (29.3%)
	Phys-centers	101 (36.1%)
	Rehab-centers	97 (34.6%)
Mode of hospitalization	In-patient	133 (47.5%)
	Day hospital	124 (44.3%)
	Mixed	23 (8.2%)

CMT: Charcot Marie Tooth; DMD: Duchenne muscular dystrophy; SMA: spinal muscular atrophy; PMSI: Programme de Médicalisation des Systèmes d'Information (French national reference scale for assessing the dependency); mixed hospitalization: combination of day and in-patients during the inclusion period; SD: standard deviation; Q1;Q3: 1st and 3rd quartiles

General characteristics of the physical acts

All the physical acts were performed at least once for each child during the data collection period. A total of 7689 physical acts (N.=7510 daytime and N.=179 night-time) were recorded and categorized according to the list of the 32 types of physical acts. The number of physical acts reported in each logbook ranged from 1 to 26 (median: 5 [3;9]). Pain evaluation data were available for 7107 acts. Pain data were not available for 582 physical acts.

The most frequently performed physical acts were for personal care (transfers [30.5%], dressing/undressing [15%] and gentle bed mobilizations [7.1%]); physiotherapy (passive mobilizations and stretching [4.5%], walking [2.7%] and active mobilizations [2.2%]); and medical care (oral care [1.9%], invasive digestive care [1.9%] and bladder catheterization [1.4%]).

Pain characteristics and frequency of care-induced pain

Thirty of the 32 physical acts (not oral stimulation or hydrotherapy) were considered as painful (FLACC-r score ≥4/10) at least once during the data collection period, and 132/280 children (48%) experienced at least 1 painful physical act during the five-day and one-night data collection period. In total, the mean pain score on the FLACC-r was 0.6±1.5; 490/7689 physical acts (6.3%) were rated ≥4 on the FLACC-r with a mean pain score of 5.3±1.5.

To ensure reliability and representativity, the description below focuses on acts that were performed >100 times (frequency >100 in general characteristics; Table II). Those that were most often painful were standing frame use (14.1%, *i.e.* this was painful 14.1% of the times that it was performed), feeding (13.8%) and general mobilizations (13.2%). The physical acts that induced the highest pain scores (*i.e.* mean and median FLACC-r scores >5) were bladder catheterization, standing frame use and gentle bed mobilizations (means, SDs, medians and quartiles are provided in Table II). The physical acts which induced the highest pain intensity (*i.e.* FLACC-r =10/10) were transfers, dressing/undressing, gentle bed mobilizations, and standing frame use. When performed, feeding was painful for 30.3% of children, transfers for 25.2%, and standing frame use for 24.4% of children (Table II).

TABLE II.—*General and pain characteristics of the 32 types of physical acts.*

Type of physical act	General characteristics		Pain characteristics (acts with FLACC-r ≥4 only)				
	Freq. N. (%)	Nbr child N. (%)	Freq. N. (%)	Nbr child N. (%)	FLACC-r Mean±SD	FLACC-r Median [Q1;Q3]	FLACC-r intensity Min-max
Transfers	2345 (30.5%)^	202 (72.1%)^	103 (4.3%)	51 (25.2%)^	5.4±1.4	5 [4;6]	4-10^
Dressing/undressing	1154 (15%)^	197 (70%)^	62 (5.3%)	35 (17.7%)	5.6±1.7	5 [4;6]	4-10^
Gentle bed mobs	547 (7.1%)^	116 (41%)	23 (4.2%)	16 (13.7%)	5.8±1.9^	5 [4;7]	4-10^
Washing	532 (6.9%)	144 (51%)	38 (7.1%)	21 (14.5%)	5.4±1.5	5 [4;6]	4-9
Passive mobs/stretching	343 (4.5%)	156 (56%)ì	35 (10.2%)	30 (19.2%)	4.8±1.0	5 [4;5]	4-9
Donning/doffing orthosis	286 (3.7%)	99 (35%)	21 (7.3%)	12 (12.1%)	5.4±1.3	5 [5;6]	4-9
Feeding	239 (3.1%)	66 (24%)	33 (13.8%)^	20 (30.3%)^	5.7±1.9	5 [4;7]	4-9
Walking	208 (2.7%)	86 (31%)	12 (5.7%)	7 (8.1%)	4.8±0.6	5 [4.5;5]	4-6
Standing frame use	205 (2.7%)	86 (30.7%)	29 (14.1%)^	21 (24.4%)^	5.9±1.8^	5 [5;7]	4-10^
Active mobs	169 (2.2%)	79 (28%)	12 (7.1%)	11 (13.9%)	4.5±0.7	4 [4;5]	4-6
Oral care	148 (1.9%)	62 (22%)	13 (8.8%)	8 (12.9%)	4.8±1.3	4 [4;6]	4-8
Invasive digestive care	145 (1.9%)	23 (8%)	5 (3.4%)	4 (17.4%)	4.6±0.5	5 [4;5]	4-5
General mobs	136 (1.8%)	84 (30%)	18 (13.2%)^	17 (20.2%)	4.6±0.6	5 [4;5]	4-6
Sensory stimulation	110 (1.4%)	72 (26%)	4 (3.6%)	3 (4.1%)	5	5 [5;5]	5-5
Bladder catheterization	110 (1.4%)	18 (6%)	2 (1.8%)	2 (11.1%)	6±1.4^	6 [5;7]	5-7
Muscle strengthening	107 (1.4%)	51 (18%)	3 (2.8%)	3 (5.9%)	4.3±0.6	4 [4;5]	4-5
Eye care	86 (1.1%)	16 (6%)	12 (13.9%)	6 (37.5%)	5.1±1.5	5 [4;5]	4-9
Massage	81 (1.1%)	49 (18%)	5 (6.1%)	5 (10.2%)	5.2±0.4	5 [5;5]	5-6
Samples and injections	75 (1.0%)	29 (10%)	7 (9.3%)	7 (24.1%)	4.6±1.0	4 [4;6]	4-6
Sports sessions	69 (0.9%)	44 (16%)	7 (10.1%)	7 (15.9%)	5.9±2.2	6 [4;7]	4-10
Chest physiotherapy	61 (0.8%)	27 (10%)	2 (3.2%)	2 (7.4%)	5.5±0.7	5.5 [4;7]	5-6
Invasive bowel care	57 (0.7%)	30 (11%)	7 (12.2%)	4 (13.3%)	5±1.2	5 [4;6]	4-7
Invasive respiratory interventions	36 (0.5%)	14 (5%)	7 (19.4%)	6 (42.8%)	5.4±1.5	5 [4;7]	4-8
Rehabilitation of swallowing	23 (0.3%)	12 (4%)	1 (4.3%)	1 (8.3%)	5	5 [5;5]	5-5
Nebulizer administration	22 (0.3%)	10 (4%)	3 (13.6%)	2 (20%)	7.3±2.5	7 [5;10]	5-10
Oral stimulation	22 (0.3%)	14 (5%)	-	-	-	-	-
Complex dressings	20 (0.3%)	10 (4%)	4 (20%)	3 (30%)	5.3±1.0	5.5 [4.5;6]	4-6
Hydrotherapy	17 (0.2%)	13 (5%)	-	-	-	;	-
Orthosis molding and fitting	16 (0.2%)	14 (5%)	4 (25%)	4 (28.5%)	5.5±1.3	5.5 [4.5;6.5]	4-7
Tube feeding	13 (0.2%)	5 (2%)	1 (7.7%)	1 (20%)	6	6 [6;6]	6-6
Other	212 (2.8%)	88 (31%)	4 (1.8%)	3 (3.4%)	1	4.5 [5;5]	4-6
Total	7689 (100%)	280 (100%)	490 (6.3%)	*	5.3±1.5	5 [4;6]	4-10

The physical acts are classed by the number of procedures in descending frequency. In the descriptive analysis, to ensure reliability and representativity, the description focused on physical acts that were reported more than 100 times (frequency >100 in general characteristics; above the black line).
Mobs: mobilizations; SD: standard deviation; [Q1;Q3]: 1st and 3rd quartiles.
*A given child could experience pain during several different physical acts; ^the activities with the three highest pain scores (as a %) for each general and pain characteristic for the physical acts with a frequency >100.

Risk factors for induced pain

In the univariate model, five variables significantly influenced FLACC-r score: age (P<0.01), level of dependency (P<0.001), physical act category (P<0.001), mode of hospitalization (P=0.003), and type of center (P<0.001) (Table III).

The final multivariate model showed that three variables significantly influenced FLACC-r mean scores:

• age (P=0.03): FLACC-r mean scores were significantly higher for the younger children (continuous variable);

• overall dependency score (P=0.008): FLACC-r mean scores were significantly higher for children with a high level of dependency (continuous variable);

• physical act category (P<0.001): FLACC-r mean scores were significantly higher for nursing, personal and rehabilitation care compared with the baseline state (Table IV).

Pain preventative measures

Preventative measures were analyzed for each physical act. Fifty methods were identified (none, paracetamol, morphine, distraction, etc.). A pain prevention method was used for 26.5% of all physical acts. The main methods used were distraction (42.3%), morphine-based medication (21.5%), and paracetamol (19.6%). The physical act for which pain prevention methods were

TABLE III.—*Variables in the univariate model.*

Variable	Estimate (95% CI)	P value
Age (continuous variable)	-0.04 (-0.06; -0.02)	<0.001
Age (4 classes)		0.010
[0-6 yrs] *vs.* [15-18 yrs]	0.45 (0.15; 0.76)	0.003
[7-10 yrs] *vs.* [15-18 yrs]	0.26 (0.01; 0.50)	0.01
[11-14 yrs] *vs.* [15-18 yrs]	0.05 (-0.17; 0.27)	0.65
Sex		
Female *vs.* male	0.04 (-0.1; 0.22)	0.70
Main medical diagnosis		0.675
Osteoarticular, muscle or connective tissue disorders *vs.* diseases of the nervous system	-0.15 (-0.43; 0.13)	0.287
Congenital malfor., deform. and chromo. abnor. *vs.* diseases of the nervous system	-0.01 (-0.27; 0.25)	0.935
Others diseases *vs.* diseases of the nervous system	0.11 (-0.30; 0.51)	0.606
Nature of the disability		
Transient *vs.* permanent	-0.19 (-0.46; 0.08)	0.16
Level of dependency (PMSI) (continuous variable)	0.04 (0.02; 0.05)	<0.001
Physical dependence (PMSI) (4 classes)		<0.001
[1-4] *vs.* [13-16]	-0.46 (-0.78; -0.13)	0.006
[5-8] *vs.* [13-16]	-0.31 (-0.58; -0.04)	0.02
[9-12] *vs.* [13-16]	-0.41 (-0.65; -0.17)	0.001
Cognitive dependence (PMSI) (4 classes)		<0.001
[1-2] *vs.* [7-8]	-0.50 (-0.75; -0.25)	<0.001
[3-4] *vs.* [7-8]	-0.34 (-0.57; -0.10)	0.005
[5-6] *vs.* [7-8]	-0.31 (-0.55; -0.07)	0.01
Physical act categories		<0.001
Adapted sports *vs.* baseline state	0.71 (0.35; -1.08)	<0.001
Other *vs.* baseline state	0.22 (-0.03; -0.47)	0.08
Occupational therapy / psychomotricity *vs.* baseline state	0.32 (0.04; -0.6)	0.02
Speech and language therapy *vs.* baseline state	0.19 (-0.24; -0.63)	0.38
Medical care *vs.* baseline state	0.66 (0.48; -0.83)	<0.001
Personal care *vs.* baseline state	0.31 (0.16-0.46)	<0.001
Physiotherapy *vs.* baseline state	0.66 (0.49; -0.83)	<0.001
Mode of hospitalization		0.003
In-patient *vs.* day hospital	-0.32 (-0.50; -0.13)	<0.001
Mixed *vs.* day hospital	-0.08 (-0.42; 0.26)	0.65
Type of center		<0.001
Phys-centers *vs.* rehab-centers	-0.14 (-0.36; 0.07)	0.19
Sp-Ed-centers *vs.* rehab-centers	0.30 (-0.08; 0.51)	0.007
Time		
Night *vs.* day	-0.02 (-0.23; 0.19)	0.8526

PMSI: Programme de Médicalisation des Systèmes d'Information (French national reference scale for assessing the dependency); baseline state: FLACC-r Score obtained during a non-painful situation.

TABLE IV.—*Variables in the final multivariate model.*

Variable	Estimate (95% CI)	P value
Age (continuous variable)	-0.026 (-0.050; -0.003)	0.03
Level of dependency (PMSI) (continuous variable)	0.026 (0.007; 0.046)	0.008
Physical act categories		<0.001
Adapted sports *vs.* baseline state	0.72 (0.35; 1.09)	<0.001
Other *vs.* baseline state	0.20 (-0.05; 0.46)	0.12
Occupational therapy / psychomotricity *vs.* baseline state	0.30 (0.02; 0.59)	0.03
Speech and language therapy *vs.* baseline state	0.16 (-0.27; 0.59)	0.47
Medical care *vs.* baseline state	0.65 (0.47; 0.83)	<0.001
Personal care *vs.* baseline state	0.29 (0.13; 0.44)	<0.001
Physiotherapy *vs.* baseline state	0.67 (0.50; 0.84)	<0.001
Type of centers		0.07
Phys-centers *vs.* rehab-centers	-0.03 (-0.24; -0.19)	0.79
Sp-Ed-centers *vs.* rehab-centers	-0.24 (0.002; 0.49)	0.04

Baseline state: FLACC-r score obtained during a non-painful situation.

most often used was complex dressings: they were used for 80% of this act.

Pain prevention methods were hardly used for (I) eye care (88% with no pain prevention); (II) oral care (83%), (III) transfers (82%), and (IV) gentle bed mobilizations (67%).

Discussion

This study provided an exhaustive characterization of physical acts performed over five days and one night in 280 children with various physical disabilities in pediatric rehabilitation and special education centers in Brittany, France. The results confirmed and expanded those of the pilot study[16] by showing that all acts that involved direct physical contact with a child with a physical disability could cause pain. These physical acts included personal care (transfers, washing, dressing/undressing, feeding and use of standing frames), medical care (samples and injections, dressings, invasive interventions and eye care), and therapies (mobilization and stretching). Forty-eight percent of children experienced at least one painful physical act during the five-day and one-night study period.

The multivariate analysis showed that age and level of dependency were the main personal risk factors for care-related pain. With regards to age, in contrast with previous studies, our results showed that the risk of care-related pain was higher in younger than older children.[3, 4, 8, 9] This discrepancy could result from methodological differences; previous studies focused on CP whereas our study included children with a wide range of physical disabilities and medical diagnoses. The higher risk of pain in younger children may relate to child development; over the course of their development, children and adolescents become more able to manage and cope with their pain. They may also gain an understanding of the nature and origin of the pain, which can reduce the level of perceived pain.[27] If this hypothesis is confirmed, then it will be important to teach young children skills and strategies to cope with their pain. Our results confirm that children with high levels of dependency have a higher risk of experiencing care-related pain.[3, 4, 8, 9] This result was also reported in the pilot study[16] and is likely because of the fact that these children experience the highest number of care interventions and also frequently have a limited communication capacity, which makes pain management and assessment difficult.[9, 28, 29] Unexpectedly, the nature of the disability, the main medical diagnosis, and environmental factors, such as type of center and mode of hospitalization, were not determinants of care-related pain. These data did not confirm the finding of the pilot study[16] that children with neurological disorders had an increased risk of induced pain. In the present study, we found no disease-related profile for children-most-at-risk of induced pain, but we did find an association with age and level of dependency. The young and severely dependent children were the most at risk of pain. Although this study was only conducted in French pediatric centers, this finding, along with other findings in the literature, suggests that the results could be transferred to other pediatric rehabilitation and care systems and organizations. All professionals who are involved in the care of children with physical disabilities and significant limitations in activity and participation must be aware of the issue of pain and that pain can be induced by even the most routine physical act.

As already mentioned by Parkinson *et al.* in CP,[4] strategies to manage and reduce pain in children with physical disabilities are insufficient or inadequate. Indeed, the results indicated that pain prevention measures were used for only 26.5% of the physical acts. This finding is likely related to an underestimation of the painful nature of some acts by the professionals performing them and to a lack of knowledge about effective and existing prevention measures. A few pharmacological and non-pharmacological prevention methods have been shown to be effective during painful medical procedures (*e.g.* botulinum toxin injection),[18, 30, 31] but research investigating the efficacy of methods to manage pain induced by care and therapeutic interventions in children and adolescents with physical disabilities is lacking.[17, 18] Further studies are therefore needed to increase the number of methods available to professionals and to adapt them to the developmental and medical characteristics of each child. Our findings also suggest that the management of care-related pain could be improved through an analysis of the benefit-risk balance of all acts that require physical contact, for each child. As mentioned in a previous study,[4] individualized intervention information should be included in the child's care plan to ensure that only necessary acts are performed and that they deliver sufficient benefit to justify the pain and fear of pain that accompany them. If the act is necessary and pain is unavoidable, pain prevention measures should be used.

All care that requires physical contact could be painful and special attention should be paid to young children and children with a high level of dependency. This finding indicates that all professionals, even those not directly involved in the treatment of pain, need to have access to training and support to help them to identify potentially

painful physical acts and the children who are particularly at risk of experiencing care-related pain. It would also be valuable to include information about the use of standardized pain assessment tools in professional development training. Such knowledge would help professionals to recognize situations that risk causing pain and to accurately evaluate care-related pain. Several validated scales are currently available to rate pain in clinical practice: the PPP (Pediatric Pain Profile),[32] the DESS (Douleur Enfant San Salvadour),[33] and the NCCPC (Non-Communicating Children's Pain Checklist).[28] In addition to teaching professionals to recognize pain and use pain prevention techniques, collaboration between parents and professionals is also essential. The parents of non-communicating children are aware of idiosyncratic behaviors that indicate that the child is experiencing pain, such as moaning, agitation and increased spasticity or hypotonia.[29] Sharing of experiences would allow refinement of the care of the child within the care facility.

Finally, most children included in this study were hospitalized or attended a day hospital for several consecutive weeks or months, suggesting that they experienced repeated pain during their stay. This result is important because recurrent induced pain has negative long-term repercussions, such as developmental and psychological effects (fear of care, behavioral disorders, decrease of adaptive ability, etc.), that directly impact on the child's cognitive control and coping skills for the next painful experiences; this can lead to the avoidance of necessary medical and paramedical care during adolescence.[34, 35] Furthermore, repeated pain could contribute to a dysregulation of sensory processing and cause sensitization of pain pathways in the central nervous system. Central sensitization is a neurophysiological mechanism, defined as the amplification of neural signaling within the central nervous system. It causes pain hypersensitivity and is characterized by hyperalgesia or allodynia. This mechanism can cause chronic pain[36-38] and could contribute to the high prevalence of chronic pain in adults with CP.[9, 39, 40] The hypothesis of a sensory processing dysregulation in CP was also recently supported by a study that indicated altered spontaneous cortical activity in adults with CP compared with their neurotypical peers.[41] These findings suggest that pain perception is altered in some types of physical disability (*e.g.*, CP) and highlight the importance of a multidimensional approach to pain in this population. Indeed, pain has been defined as a sensory, emotional, cognitive, and social experience.[42] Understanding the experience of pain in people with physical disabilities requires consideration of these different components. The objectives of the present study were to describe the physical acts that induced pain in children with physical disabilities and to identify some personal risk factors (age, sex, disability, etc.). Now, further studies are needed to explore and identify the psychological, emotional and cognitive factors (anxiety, coping strategy, developmental level, etc.) that could influence painful experiences in the context of care and rehabilitation. Such a multidimensional approach would allow a more comprehensive, holistic and individualized pain management[14, 43] and an assessment of the impact of pain on participation, interference, and psychological functioning.[9]

Limitations of the study

This study has several limitations. First, the results may be subject to assessment bias because of the method of FLACC-r pain score rating; rating by the same professional who performed the physical act may have biased the subjective pain report. However, to ensure that the FLACC-r assessment was reliable, a double proxy evaluation was also performed for 2.1% of care acts. The analysis showed highly concordant results (ICC 0.90; 95% CI: 0.86-0.93), thus the risk of this bias was low. Furthermore, the pain assessments required time and organization to perform, and their repetition over a five-day and one-night period may have led professionals to become wearied, lose rigor in their ratings and to under-report the pain level (a posteriori recording with bias relating to memory, approximate ratings, incomplete data, etc.). Nevertheless, such assessment bias is frequent and inevitable in studies of pain and makes research on this topic difficult. Second, a proxy report was chosen as the primary outcome rather than a self-report of pain. This choice was made to include all children with physical disabilities (including younger children and those with cognitive disability) and to ensure standardized and reliable data collection. We chose not to evaluate the differences in pain scores according to the type of professional but according to the type of care, given that the same procedure may be performed by different types of professional. An analysis by type of professional could be interesting in a future study to question professional practices in a more precise and thorough manner.

Finally, the generalization of results to all children with physical disabilities may be limited since children followed in outpatient clinics or by home-services were not included in the present study. The purpose of this study was to provide an insight into care-related pain in French pediatric rehabilitation centers and health facilities for children who have a high level of dependency and whose

care and rehabilitation needs may be greater than those of children whose rehabilitation could be performed at home. We targeted this population for methodological reasons and to have a standardized protocol. Another study should be carried out on children with physical disabilities whose care is provided at home. Studies in other countries will also be needed to describe care-related pain in other pediatric care settings and to allow generalization of the incidence of pain induced by care and therapeutic interventions to all contexts.

Conclusions

In pediatric rehabilitation centers and health facilities for children, health professionals provide rehabilitation and care for children with a wide variety of physical disabilities and medical conditions. It is therefore important to provide these professionals with objective and accurate indicators to guide their practice. This study revealed that care-related pain is frequent and under-recognized in pediatric centers in France. All acts that involve direct physical contact with a child with a physical disability (personal care, medical and therapy interventions) could cause pain.

All professionals (medical and non-medical) involved in the care of children with physical disabilities need to be aware of this fact, especially those who care for young children and severely dependent children. The nature of the disability, the main medical diagnosis and some environmental factors, such as type of center and mode of hospitalization, were not determinants of care-related pain. The results of this study demonstrate that the management of care-related pain in children with physical disabilities could be improved by systematizing the use of pain prevention measures, assessing pain with validated scales, and enhancing the family-professional partnership.

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Conflicts of interest
The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

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Authors' contributions
Amandine Dubois conceived and designed the study, analyzed and interpreted the data, and reviewed and revised the manuscript for important intellectual content; Caroline Hall contributed to data interpretation, drafted the initial manuscript, and reviewed and revised the manuscript for important intellectual content; Emmanuelle Courtois-Communier carried out the data analysis and data interpretation and reviewed and revised the manuscript; Arnaud Brasseur coordinated and supervised data collection, contributed to data interpretation and critically reviewed the manuscript for important intellectual content; Marine Cacioppo contributed to data interpretation and critically reviewed the manuscript for important intellectual content; Sylvain Brochard conceived and designed the study and reviewed and revised the manuscript for important intellectual content. All authors read and approved the final version of the manuscript.

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SUPPLEMENTARY DIGITAL MATERIAL 1

Definition of the French paediatric centres that participated in the study (rehabilitation and special education centres)

PAEDIATRIC REHABILITATION CENTRES (Rehab-Centres):

The aim of these facilities is to provide medical and rehabilitation care and to prevent or reduce the functional, physical, cognitive, psychological and social consequences of impairments and capacity limitations, and to promote integration.

SPECIAL EDUCATION CENTRES:

The aim of these facilities is to provide medical and rehabilitation care and specialized education.

Sp-Ed-Centres: ***Centres for children and adolescents with predominantly cognitive disability with or without physical disorders*** (in French: Instituts Médico-Educatif [IME]). Only children with cognitive and physical disabilities were included in the study.

Phys-Centres: ***Centres for children and adolescents with predominantly physical disability with or without cognitive disorders*** (in French: Instituts d'Education Motrice [IEM]).

SUPPLEMENTARY DIGITAL MATERIAL 2

List of the physical acts (N.=32) within each of the 8 categories

MEDICAL CARE
Samples and injections
Simple dressings
Complex dressings
Nebulizer administration
Eye care and eye drops
Oral care
Invasive respiratory interventions
Invasive digestive care (changing gastrostomy button)
Bladder Catheterization
Invasive bowel care
Tube feeding

PERSONAL CARE
Gentle bed mobilizations
Washing
Dressing/undressing, including shoes
Transfers (toilet, bed, chair)
Donning/doffing orthosis
Standing frame use: positioning and standing in a standing frame
Feeding

PHYSIOTHERAPY
General mobilization on a plinth
Massage
Passive mobilization / stretching
Active mobilization
Walking: weight-bearing, gait rehabilitation
Muscle strengthening
Chest physiotherapy
Hydrotherapy

OCCUPATIONAL THERAPY / PSYCHOMOTRICITY
Orthosis molding and fitting
Sensory stimulation

SPEECH AND LANGUAGE THERAPY
Rehabilitation of swallowing
Oral stimulation

ADAPTED SPORTS
Sports session

OTHER
Other

SUPPLEMENTARY DIGITAL MATERIAL 3

Scores and levels of dependency measured by the French national reference scale for assessing dependency (PMSI; Programme de Médicalisation des Systèmes d'Information)

PMSI	Low dependency	Moderate dependency	High dependency
Physical dependency	5-8	9-12	13-16
Cognitive dependency	3-4	5-6	7-8
Global score	**7-12**	**13-18**	**19-24**

SUPPLEMENTARY DIGITAL MATERIAL 4

List of the main medical diagnoses of the children included according to the ICD-10. The reason for inclusion in the study was a transient or permanent physical disability.

Validated by doctors experienced in paediatric rehabilitation.

The authors are aware that some diseases are not exclusive and may overlap, but for methodological and statistical reasons and in accordance with ICD-10, children were classified by the main medical diagnosis reported by a medical investigator.

DISEASES OF THE NERVOUS SYSTEM (N.=190) (Chapter VI; ICD-10). For the reader's information and for clinical relevance, diseases are classified in four subcategories:

Cerebral palsy

Central neurological injury

- Ischemic or hemorrhagic stroke
- Epileptic encephalopathy (West's syndrome, Lennox Gastaut, other)
- Encephalopathy (post-infectious, anoxo-ischemic, other)
- Cerebral malformation (agenesis of the corpus callosum, schizencephaly, lissencephaly, cerebellar atrophy)
- Cerebral tumour (astrocytoma)
- Post-traumatic subdural or extradural hematoma
- Subarachnoid hemorrhage
- Adrenoleukodystrophy (Aicardi Gouttières syndrome), leucodystrophy
- Neurodegenerative disease
- Spinal cord injury C1C2 / C5C6, acute transverse myelitis
- Benign familial chorea
- Dystonia
- Diffuse cerebral angiopathy
- Atrophy cortical
- Hereditary ataxia

Peripheral neurological injury

- Charcot Marie Tooth disease

Neuromuscular disease

- Duchenne muscular dystrophy
- Steinert myotonic dystrophy syndrome
- Spinal muscular atrophy

CONGENITAL MALFORMATIONS, DEFORMATIONS AND CHROMOSOMAL ABNORMALITIES (N.=41) (Chapter XVII; ICD-10)

- Trisomy (21,13,8,9Q34,4P)
- Genetic syndromes (Gorlin, Angelman, Kabuki, Sturge Weber Krabbe, Joubert, leucodystrophy 4H, Adams Olivier, Curry Jones, Prader Willi, Pallister Killian, Rubinstein Taybi, Sotos)
- Primitive ciliary dyskinesia
- Incontinentia pigmenti
- Bourneville tuberous sclerosis
- Arthrogryposis
- Spina bifida

DISEASES OF THE MUSCULOSKELETAL SYSTEM AND CONNECTIVE TISSUE (N.=34) (Chapter XIII; ICD-10)

- Fracture (upper and lower limbs)
- Amputation
- Blount's disease
- External longitudinal ectromelia
- Severe spondylolisthesis
- Spinal arthrodesis surgery
- Spinal fusion
- Primitive hip osteochondritis
- Femoral deformities
- Foot deformities
- Burns

OTHER DISEASES (N.=15) (Diseases with small numbers of participants; chapter non specified in ICD-10)

- Autism
- Menkes disease
- Respiratory disorder due to pathology of the surfactant system
- Mucopolysaccharidosis type
- Mitochondrial cytopathy
- CMV embryopathy
- Carbamoyl-phosphate synthetase deficiency
- Hirshprung's disease
- Meningococcal purpura fulminans
- Carbamoyl phosphate synthetase deficiency