Assessing Pain in Patients With Severe Cerebral Palsy: Development, Reliability, and Validity of a Pain Assessment Instrument for Cerebral Palsy

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ABSTRACT. Boldingh, EJ, Jacobs-van der Bruggen MA, Lankhorst GJ, Bouter LM. Assessing pain in patients with severe cerebral palsy: development, reliability, and validity of a pain assessment instrument for cerebral palsy. Arch Phys Med Rehabil 2004;85:758-66.

Objectives: To develop the Pain Assessment Instrument for Cerebral Palsy (PAICP) and to study its test-retest reproducibility and construct validity.

Design: Cross-sectional validation study.

Setting: Homes for severely handicapped.

Participants: A total of 164 adults with severe cerebral palsy (CP), caregivers, and physiotherapists, and 9 healthy children.

Interventions: The PAICP contains drawings of situations, some situations of which usually produce pain. Patients rate the pain associated with each activity using a Faces Pain Scale. Reproducibility and construct validity was assessed in a pilot study with CP patients and healthy children. Construct validity and agreement between the pain scores of the patients and proxies was assessed in 160 patients with severe CP.

Main Outcome Measure: Pain score on the PAICP.

Results: The measure showed adequate test-retest reproducibility. A significant difference was found between the mean scores for "painful" and "not painful" situations. We also found moderate agreement between the scores of the patients and proxies for daily activities but only for those activities in which the proxies were personally involved.

Conclusions: The PAICP has adequate test-retest reproducibility and construct validity. It provides an indication of the pain experienced by patients in situations in which proxies are not personally involved and may also be more valid than proxy measures for other situations.

Key Words: Cerebral palsy; Pain; Rehabilitation; Reliability and validity.

IT IS VERY DIFFICULT to assess the severity of pain experienced by people with cerebral palsy (CP). The fact that many patients cannot express their pain verbally,[1] due to motor impairment, makes the use of nonverbal scales necessary. Some patients with CP also have visual impairments.[2,3] Another complicating factor in the assessment of pain is mental retardation, which frequently occurs in people with severe CP; approximately 40% of the CP population has an intelligence quotient below 70.[4] Although measuring pain in cognitively impaired patients is difficult,[5] recent studies have demonstrated that it is possible.[6,7] However, the common practice in the case of severely disabled persons is still to interview the caregivers to assess the amount of pain suffered by the patient.[8-11] Unfortunately, the pain scored by the patient often differs from the pain scored by the caregivers,[12-16] although 1 study[17] has reported a strong correlation.

To measure the relation between hip disorders and pain in patients with severe CP, an assessment instrument was developed and the present study was undertaken to investigate its test-retest reproducibility and construct validity.

METHODS

The Assessment Instrument

A literature search (PubMed and MEDLINE using key words *cerebral palsy* and *pain* from 1993 to 2002) was performed to identify scales for the self-rating of pain by people with severe CP. No available scales have been specifically developed for this group of patients. The scale that is needed should be appropriate for use with nonverbal patients with a low mental age, some of whom can only communicate by scanning symbols. Because mental retardation is not associated with a disturbance of face recognition[18] and CP is not associated with disturbances in body image,[19] researchers[20] suggest that a pain scale expressed in facial expressions be used for people with low levels of mental development. Recently, a high correlation between a visual analog scale and a Faces Pain Scale (FPS) was demonstrated.[21] It is known that children from the age of 4 can recognize and interpret symbols such as a drawn face.[22] Such a scale should range from a neutral to a painful face, instead of starting from a happy face, which suggests a different mood.[23] The FPS developed by Bieri et al[24] (fig 1) might be suitable for this purpose. The scale, which consists of 7 faces with expressions ranging from neutral to very painful, was designed and validated for use with children from the age of 4 years.[24] The intervals between the faces are almost equal.[25] The use of this scale with cognitively impaired people has recently been assessed, and its reliability and construct validity was acceptable in people with moderate cognitive impairment.[6] The original scale has recently been revised.[26]

Basing our design on the FPS, we developed the Pain Assessment Instrument for Cerebral Palsy (PAICP) to assess pain in patients with hip problems. The instrument consists of 6 drawings of daily situations that are usually not painful and 6 that usually are painful. To be able to relate pain in the hip

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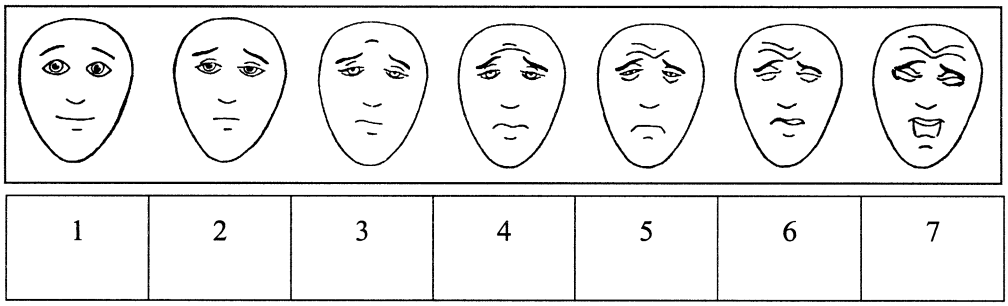


Fig 1. The score options assigned to items of the FPS. Numbers were not shown to patients. From Hicks CL, von Baeyer CL, Spafford P, van Korlaar I, and Goodenough B (2001). Adapted from Bieri D, Reeve RA, Champion GD, Addicoat L, and Ziegler JB. The Faces Pain Scale for self-assessment of the severity of pain experienced by children: development, initial validation, preliminary investigation for ratio scale properties. Pain 1990;41:139-50. Reprinted with permission.[24,26]

region to other types of pain, 5 drawings of situations that may be painful for those with hip problems were added (fig 2). There are 4 preliminary drawings with obvious answers introducing the method. The drawings are shown in random order (table 1). The patient scores the amount of pain experienced in these situations according to the FPS.

Participants

We studied the instrument in 2 groups of subjects. First, we conducted a reliability study of the PAICP in a group of 9 healthy children in their own homes and 4 adults with severe CP in a home for severely handicapped persons. The adults were included if they had CP, were unable to walk independently, had a mental age of 4 or above, and were able to use an FPS. The ability to use an FPS (vision, ability to recognize and select) and the mental level was assessed beforehand using the Columbia Mental Maturity Scale[27] (CMMS), a nonverbal mental development test that has been validated for adults and young children with CP.[28,29] To use the FPS, a minimum score of 25 points on the CMMS is needed, which indicates a minimal mental age of 4 years. The healthy children were 3 to 7 years of age, and the adults with CP were 24 to 31 years of age.

Second, we conducted a construct validity study in 160 patients with severe CP. These subjects met the same criteria as those in the reliability study, and they all resided in the Netherlands. The patients were recruited in nursing homes for severely handicapped persons and through rehabilitation centers in the Netherlands. Physicians and physiotherapists were asked to select patients according to the inclusion criteria and to predict whether they would meet the CMMS criteria for selection. Of the 160 patients, 87 (54%) were men and 73 (46%) were women. Their ages ranged between 16 and 84 years (mean age, 36y). Nineteen patients (12%) could not speak, and 11 used scanning symbols for communication.

Reliability Study

The children and patients were asked to indicate the level of pain they usually had in situations shown in the drawings, and they rated the amount of pain they experienced in these situations using the FPS. They indicated the location of the pain experienced on a female or male drawing of the human body according to their gender (fig 3). A standard list of instructions and questions was applied (appendix 1). The researcher recorded the number of the face, which ranged from 1 to 7. The test-retest reproducibility of the PAICP was assessed by applying the instrument twice with an interval of 2 weeks, and the test-retest analysis was performed with a modified κ.[30] The percentage of observed agreement between scores (OBS) was defined as the percentage of patients with the same score, ± 1, on test and retest. Expected agreement (EXP) was defined as the expected percentage of patients with the same score, ± 1, on test and retest just by chance, which is 3 out of 7. Modified κ was calculated as (OBS$-$EXP)/(1$-$EXP). The results were classified according to the Altman method.[31] Response to a question was considered reproducible if a modified κ of 0.4 or higher was reached.

Construct Validity Study

A total of 160 patients who met the inclusion criteria were asked to score the pain they experienced in the 21 situations. Subsequently, 1 main caregiver and 1 physiotherapist associ-

Table 1: PAICP Items

Item		Painful	Not Painful	Possibly Painful
Preliminary questions	1. Squeezing a hand in the door	X		
	2. Dirt in an eye	X		
	3. Removing adhesive strip from the skin	X		
	4. Injection by a dentist	X		
5. Putting on trousers				X
6. Drinking hot tea		X		
7. Cleaning teeth			X	
8. Eating bread			X	
9. Burning hand			X	
10. Doctor using a stethoscope			X	
11. Combing hair			X	
12. Biting own tongue			X	
13. Being lifted from bed				X
14. Putting on sweater			X	
15. Listening to music			X	
16. Lying in bed				X
17. Physiotherapy for legs				X
18. Stubbing a toe		X		
19. Having a blood sample taken		X		
20. Sitting in a wheelchair				X
21. Wasp sting		X		

Legend: Painful, situations usually painful in daily life; Not painful, situations usually not painful.

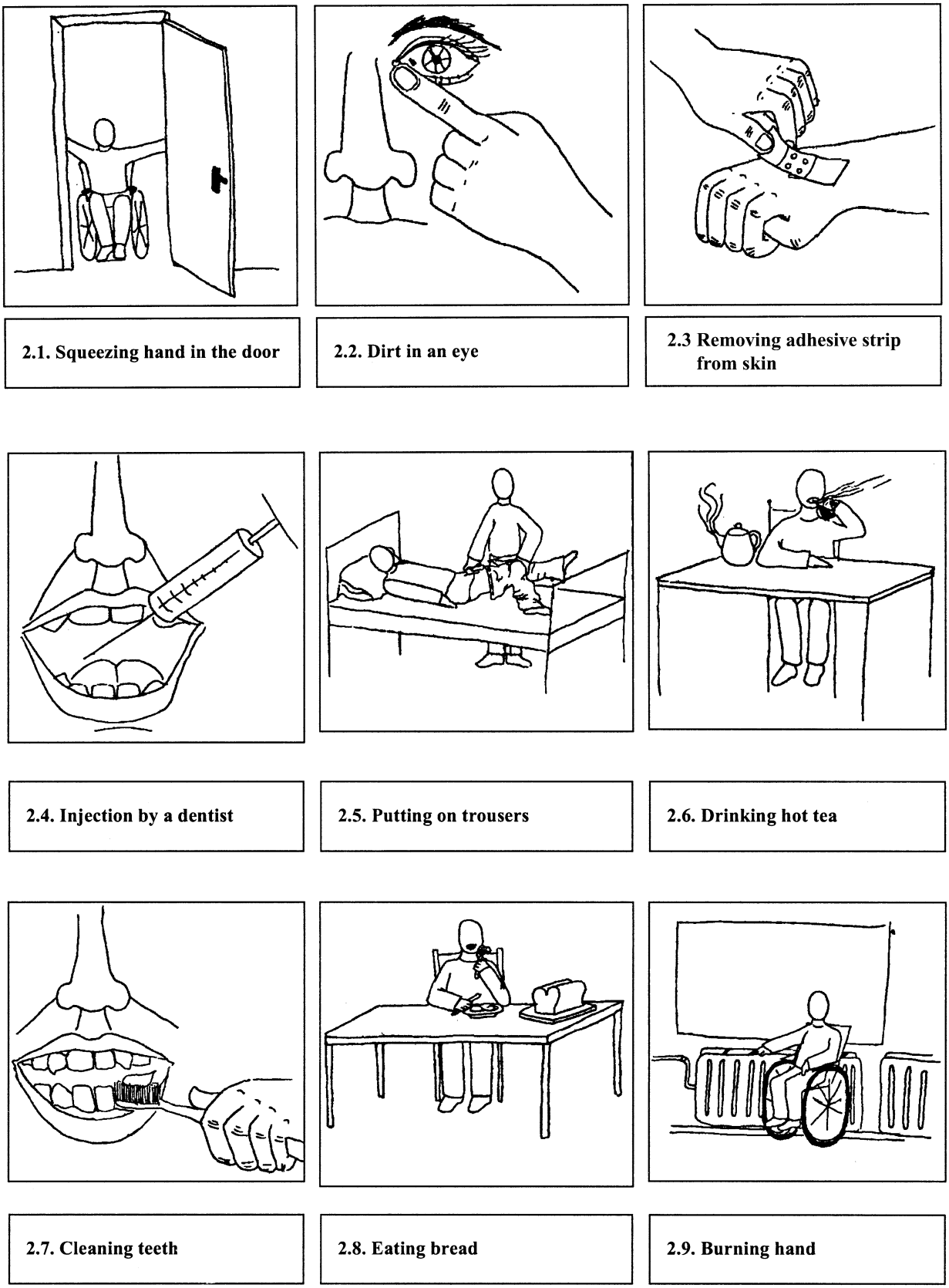
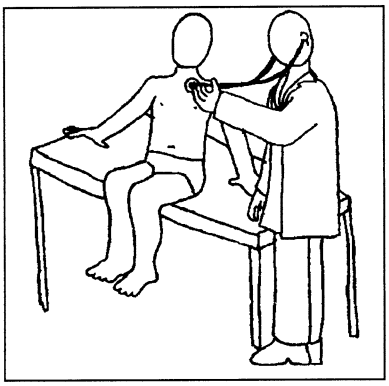
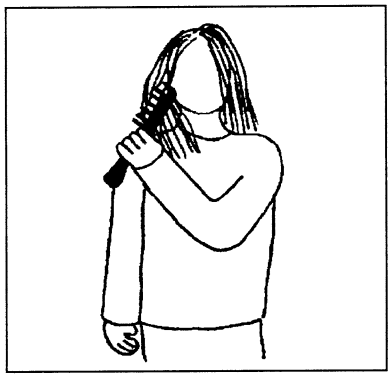


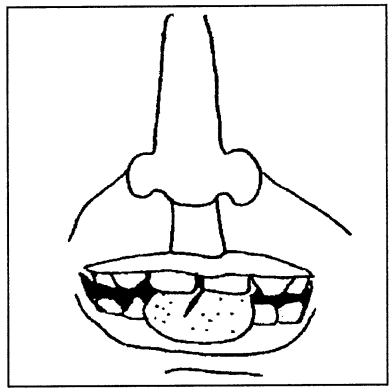
Fig 2. Drawings of daily situations that may or may not be painful.



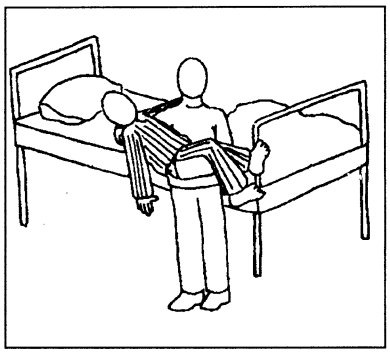
2.10. Doctor using stethoscope



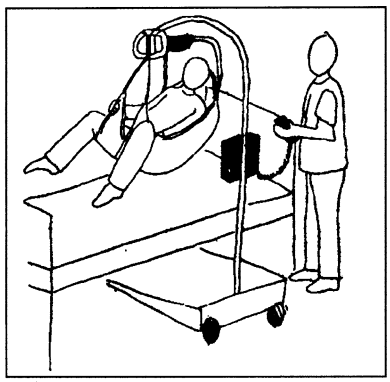
2.11. Combing hair



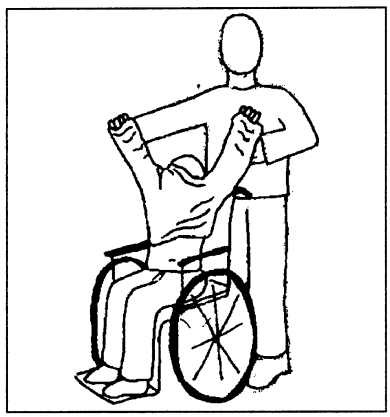
2.12. Biting own tongue



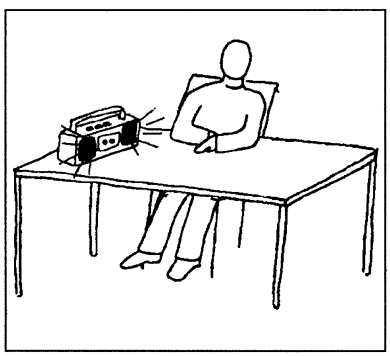
2.13A. Being lifted from bed



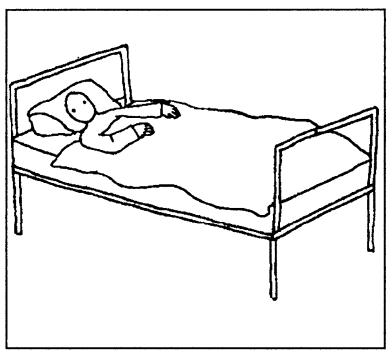
2.13B. Being lifted from bed



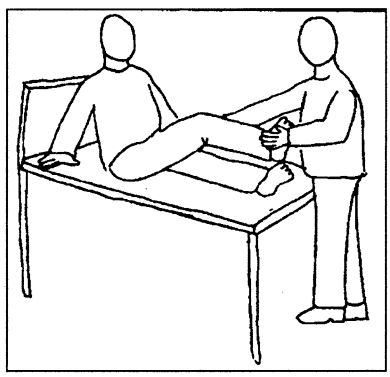
2.14. Putting on sweater



2.15. Listening to music

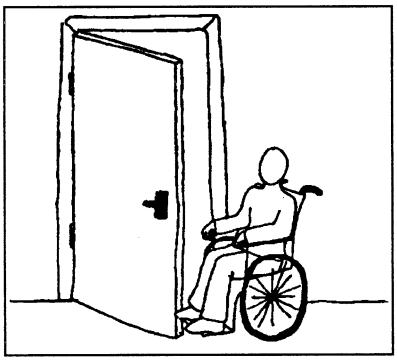


2.16. Lying in bed

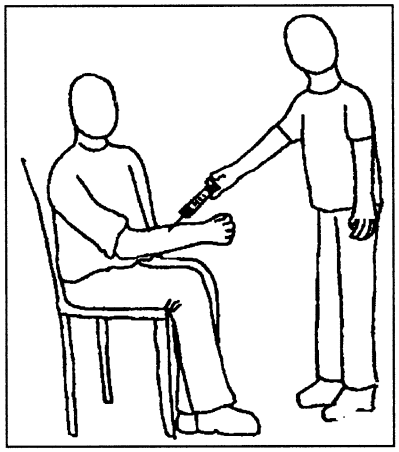


2.17. Physiotherapy for legs

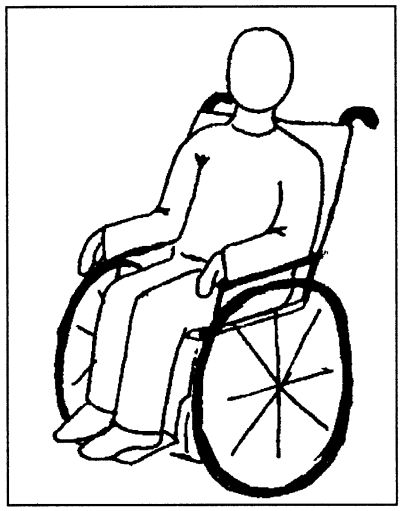
Fig 2. (*Continued*)



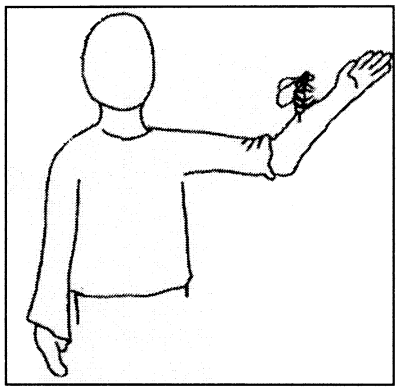
2.18. Stubbing a toe



2.19. Having blood sample taken



2.20. Sitting in a wheelchair



2.21. Wasp sting

Fig 2. (*Continued*)

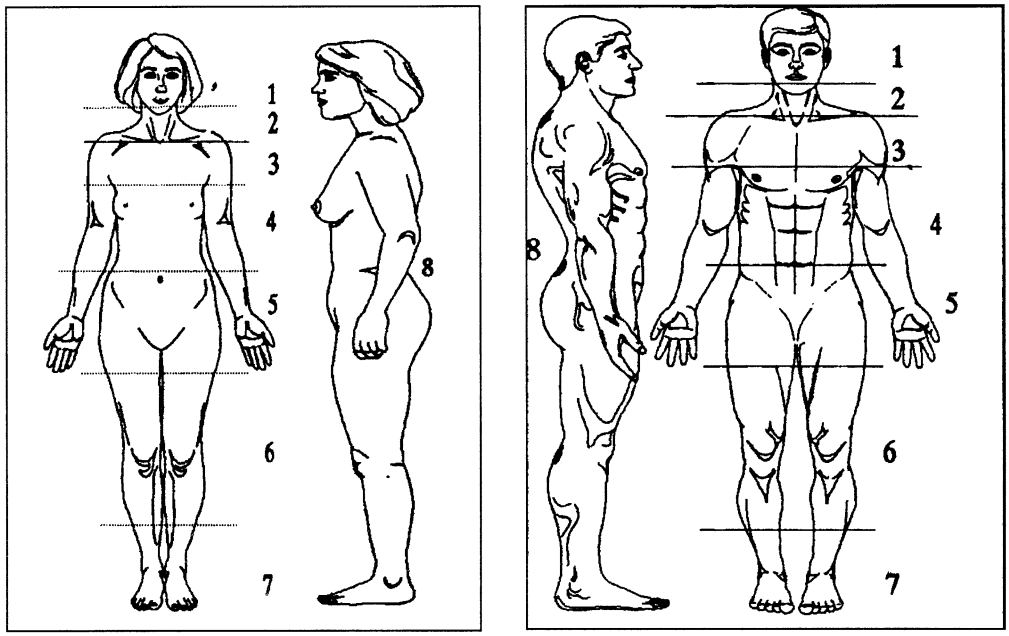


Fig 3. Drawings of human body.

ated with the patients were asked to predict the scores of the patients in all situations on the PAICP, without being aware of the patients' scores. The construct validity was considered adequate if the drawings of situations that were usually painful produced a mean score of 3 or higher, and the situations that were usually nonpainful produced a mean score below 3 on the 7-point scale. Further, the mean score of all painful situations should exceed the mean score of all situations that were not nonpainful. Nonparametric correlations between the PAICP scores of patients and caregivers were calculated using the Spearman ρ,[a] because the answers were not normally distributed. Internal consistency of the PAICP was analyzed by calculating the Cronbach α.

RESULTS

The Assessment Instrument

The characteristics of the PAICP are shown in figure 1 and table 1.

Table 2: Test-Retest Reproducibility of the Assessment Instrument Based on the FPS

Category	Paired Samples	QBS	κ*	Classification
Situations usually painful	Hot tea	70	0.48	Moderate
	Burn hand	75	0.56	Moderate
	Bite tongue	82	0.69	Good
	Injection dentist	100	1.00	Very good
	Blood sample	75	0.56	Moderate
	Wasp sting	91	0.84	Very good
Situations usually not painful	Clean teeth	100	1.00	Very good
	Eat bread	92	0.86	Very good
	Stethoscope	100	1.00	Very good
	Combing hair	100	1.00	Very good
	Putting on sweater	100	1.00	Very good
	Listening to music	92	0.86	Very good
Situations possibly painful	Putting on trousers	100	1.00	Very good
	Being lifted from bed	100	1.00	Very good
	Lying in bed	100	1.00	Very good
	Physiotherapy for legs	92	0.86	Very good
	Sitting	100	1.00	Very good

NOTE. Modified κ; reliability study; n=13.
Abbreviations: OBS, observed percentage of patients with same score ($\pm$1) in test and retest; EXP, expected percentage of patients with the same score ($\pm$1) in test and retest just by chance, which is 3 out of 7$\times$100%=43%.
*Modified κ=(OBS$-$EXP)/(1$-$EXP).

Table 3: Mean Score Items for Painful and Not Painful (n=160)

Category	Item	Mean ± SD
Situations usually painful	Hot tea	4.3±1.9
	Burn hand	4.7±1.9
	Bite tongue	4.0±1.9
	Injection dentist	4.1±2.0
	Blood sample	3.1±2.0
	Wasp sting	4.8±2.0
Situations usually not painful	Clean teeth	1.4±1.0
	Eat bread	1.1±0.5
	Stethoscope	1.2±0.6
	Combing hair	1.3±0.8
	Putting on sweater	1.4±1.1
	Listening to music	1.0±0.3
Situations possibly painful	Putting on trousers	1.6±1.4
	Being lifted from bed	1.8±1.6
	Lying in bed	1.6±1.4
	Physiotherapy leg	2.7±2.0
	Sitting	1.5±1.3

Abbreviation: SD, standard deviation.

Reliability Study

Adequate test-retest reproducibility was found for all items, for both the healthy children and the patients. The modified κ was .48 or greater, with the exception of the question about "stubbing a toe" (κ=.37). In subsequent analyses, this question was replaced by the question "injection by a dentist" (table 2).

Construct Validity Study

The mean scores met the predetermined criteria, with all mean scores of painful drawings being 4.1 or higher, and all mean scores of nonpainful drawings being 1.1 or lower (table 3). The difference between the mean scores for painful and nonpainful drawings was statistically significant. A significant difference also existed between the drawings for situations that were possibly painful and situations that were usually not painful (table 4). The Cronbach α analysis revealed good internal consistency (table 5).

Caregivers were able to predict that the patients would meet the CMMS criteria for selection: 179 of the 219 caregivers (82%) made a correct prediction.

There was a statistically significant, but only modest, agreement between the patients' pain scores and the pain scores given by the caregivers and physiotherapists for the situations that could be painful for patients with hip problems. Two other situations showed significant correlations as well, but they were limited to situations in which caregivers applied direct care to the patients (ie, cleaning teeth and combing hair; table 6).

Table 4: Difference in Mean Scores Between Situations on the PAICP (n=160)

Group	Mean ± SD		Difference of the Mean	95% CI*	
	Situations Usually Painful	Situations Usually Not Painful		Lower	Upper
Usually Painful and Not Painful					
CP patients	4.11±1.46	1.25±0.45	2.86	2.63	3.08
Possibly Painful and Not Painful					
CP patients	2.21±1.29	1.21±0.45	0.96	0.78	1.14

Abbreviation: CI, confidence interval.
*Analysis paired samples *t* test.

Table 5: Internal Consistency of Questions Posed

Category	Cronbach α	95% CI
Situations usually painful	.83	.77–.87
Situations usually not painful	.65	.55–.73
Situations possibly painful	.81	.75–.86

DISCUSSION

Measuring the pain experienced by people with severe CP has always been difficult. The PAICP showed adequate test-retest reproducibility and construct validity and appears to be suitable for use with patients with severe CP, several of whom were unable to speak and/or had the mental age of a toddler. The usefulness of the FPS has recently been demonstrated for elderly people as well.[25] Chibnall and Tait[6] found the FPS is valid for assessing the most severe pain in the past and retrospective levels of pain, which was also the focus of the present study. Their study population consisted of people with moderate mental retardation; the participants in the present study had severe mental impairments. Preassessment with the CMMS worked well: every patient (n=160) who scored 25 or higher on the CMMS used the FPS easily.

The PAICP is an important improvement in scientific research among this group of patients. In the present study, we added drawings of situations affecting the hip, but the instrument can easily be amended to suit other specific situations that are the focus of research by changing the drawings accordingly.

Table 6: Construct Validity: Correlations Between Scores of Patients, Physiotherapists, and Caregivers on the PAICP (scale range, 1–7)

Category	Question	Physiotherapist vs Patient Correlation*	Caregiver vs Patient Correlation
Situations usually painful	Hot tea	.13	.13
	Burn hand	.02	.14
	Bite tongue	−.03	.06
	Injection dentist	.15	.14
	Blood sample	−.03	.20
	Wasp sting	.11	.08
Situations usually not painful	Clean teeth	−.03	.35†
	Eat bread	.05	−.08
	Stethoscope	.01	−.10
	Combing hair	.03	.28†
	Putting on sweater	.20	.11
	Listening to music	−.01	−.01
Situations possibly painful	Putting on trousers	.32†	.26†
	Being lifted from bed	.52†	.23†
	Lying in bed	.29†	.37†
	Physiotherapy for legs	.34†	.48†
	Sitting	.36†	.28†

*Spearman ρ; †significance at the .01 level (2-tailed).

One limitation of the instrument is that it can only be used in persons with a mental age of at least 4 years, which excludes patients with very severe CP. Another prerequisite is sufficient visual ability to see the drawings. It may therefore be necessary to increase the size of the pictures in some cases. People must also be able to indicate their choice. In the present study, some patients indicated their choice by just looking at a drawing or by sticking out their tongue a number of times corresponding to the number of the drawing. Preassessment with the CMMS worked well for assessing patients' ability, not only with regard to their level of mental development, but also with regard to their ability to see the drawings and to indicate their choice.

Caregivers in the study were able to estimate well the level of intelligence of the patients they cared for and consequently their ability to use an FPS (82%), which makes the use of a pretest such as the CMMS unnecessary when caregivers are closely involved with their patients. The instrument was developed in the Netherlands, based on a scale of drawings created in Australia. Almost all the drawings illustrate situations that have been experienced by most people with CP. Thus, the scale may have international applicability, apart from translation of the verbal instructions to the native language of the patient. However, 2 of the drawings may have to be altered or replaced in some cases: the "burning hand" and, perhaps, the "wasp sting." The former may not have been experienced by respondents who do not have radiators in their houses and the latter by respondents who have never been stung by a bee or a wasp. Future versions may need to use a hand in a fire or on a stove to illustrate burning a hand and perhaps to omit the wasp sting (or use it only for respondents who have experienced it).

The findings also indicate that caregivers and physiotherapists do not necessarily provide accurate estimates of the amount of pain experienced by patients with CP. The associations between self-reports and proxy reports were only modest at best in the current study. The estimate of proxies is better, but not optimal, in situations in which they perform an act for the patient that directly causes discomfort or pain, such as cleaning teeth or lifting the patient out of bed.

CONCLUSIONS

The amount of pain and discomfort rated by the patient using this instrument was quite different from the estimates made by the proxy. This finding emphasizes the usefulness of the instrument. The PAICP enables the patient to rate the amount of pain he/she experiences in certain common situations that others would find clearly painful or clearly not painful. The instrument gives the caregiver a way to assess the pains impact and to select the treatment needed because of the pain. Without an instrument such as the PAICP pain experienced by a person with CP may otherwise not be signalled or treated.

Caregivers should not rely on their own estimate of the pain experienced by their patient but should make use of an instrument like the PAICP more often. The measure also gives people who are unable to explain their problems verbally or patients with a mental disability a new chance to express their needs.

APPENDIX 1: INSTRUCTIONS AND QUESTIONS CONCERNING THE PAICP

I would like to know whether you experience pain from time to time.
I will show you a couple of drawings.
On the drawings you can see various situations; some of them are painful and some are not.
Look, this is an example (show drawing of squeezing hand).
Here you see seven faces; they are all different.
This one has a lot of pain (indicate face no. 7).
This one has no pain at all (indicate face no. 1).
These faces show that the pain increases in severity (indicate faces no. 2–6).
Now, which face do you think will match the situation in the drawing?
Here is another example (show drawing no. 2: dirt in eye).
Did you ever experience that?
Did that hurt?
Can you indicate how much it hurt, which face is the best match?
Can you indicate on this drawing where you felt the pain?
OK: next . . . et cetera.

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